

DOCTOR OF PHILOSOPHY

Illness perceptions, beliefs and prevention
of Type 2 Diabetes among British
Pakistani mothers and young British
Pakistani women

Fozia Ikram

2013

Aston University

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**Illness perceptions, beliefs and prevention of Type 2
Diabetes among British Pakistani mothers and young
British Pakistani women**

Volume 1

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Doctor of Philosophy

Aston University

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Aston University

Thesis Summary

Illness perceptions, beliefs and prevention of Type 2 Diabetes among British Pakistani mothers and young British Pakistani women

Fozia Ikram

Doctor of Philosophy, January, 2013

The prevalence rates of type2 diabetes mellitus (T2DM) continues to rise among British Pakistanis. The aim of this project was to explore T2DM perceptions and any preventative intentions among British Pakistani women and to discover whether they are doing anything to prevent the onset in themselves and their families. Initially a systematic review was conducted to investigate 20 existing prevention interventions and to assess their effectiveness (n=12,419). Mixed methods approach was adopted and three studies were conducted.

The first study consisted of two focus groups with T2DM mothers (n=8) and three focus groups with non-T2DM mothers (n=17). The second study consisted of four focus groups young British Pakistani females (n=11). All focus groups were transcribed verbatim and analysed using thematic analysis. Following these a quantitative study was undertaken comprising of a questionnaire survey; 12 prevention-perception items (derived from the qualitative data) and the Illness-Perception Questionnaire Revised (IPQ-R) using participants from the same populations: T2DM mothers (n=41), non-T2DM mother (n=47) and young women (n=42). Results were analysed using multiple/hierarchical regression.

The systematic review highlighted that the most effective prevention programmes focussed on behaviour and lifestyle with a combination of support and education to participants. The research studies demonstrated that T2DM was seen as an older person's disease to be dealt with if/when it happens. T2DM mothers demonstrated knowledge and prevention understanding. There were non-significant relationships between prevention perceptions and T2DM illness perceptions across all three groups.

The finding of this thesis emphasised that lifestyle interventions are crucial to aiding T2DM preventions as a good healthy diet and regular physical activity are the key components to T2DM prevention, and the importance of personal experience in perceived severity and lay-beliefs regarding T2DM and on family/cultural influences in British-Pakistanis. The findings of this project can be used to design culturally specific interventions towards preventing T2DM in the British Pakistani community.

Keywords: type 2 diabetes, British Pakistanis, prevention, lifestyle, mixed methods

Dedication

This thesis is dedicated to my parents, Muhammad Ikram UI-Haq and Nagina Ikram, for their unwavering support and for encouraging me to learn, understand and seek knowledge as well as instilling in me my cultural, religious and traditional values to embrace my identity and to be proud of who I am.

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'In the name of Allah, the most merciful the most compassionate'

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List of Abbreviations

BEN	Birmingham East & North
CSM	Common-Sense Model
GD	Gestational Diabetes
HEFT	Heart of England Foundation Trust
IFG	Impaired Fasting Glucose
IGT	Impaired Glucose Tolerance
IPQ	Illness Perception Questionnaire
IPQ-R	Illness Perception Questionnaire Revised
PMT	Protection Motivation Theory
OGTT	Oral Glucose Tolerant Test
R and D	Research and Development
RCT	Randomised Control Trial
T2DM	Type 2 Diabetes Mellitus
TPB	Theory of Planned Behaviour

List of Notation Symbols

CAPITALS	louder voice
◦	softer/quieter voice - degree symbol
<u>Underline</u>	emphasised speech
<slow>	slowed down speech
>fast<	quicker up speech
?	questioning tone (rising intonation)
(.)	pause
(...)	long pause
=	no gap between words
...	quotation taken from part of transcript speech not whole
::	stutter

Chapter 1

Thesis Introduction

1.1 Background

1.1.1 Type 2 Diabetes Mellitus

Type 2 diabetes mellitus (T2DM) is a very serious health problem. Chowdhury and King (2007) estimated that there are 171million people worldwide with the condition and by 2030 this will rise to 336million. With regards to South-Asian people the World Health Organisation (WHO, 2007) have stated that by 2030 one-third of all individuals with diabetes will reside in the sub-continent. This is a very significant statement as many individuals residing in the sub-continent travel and migrate for a significant period of their life to the UK. In the UK 2.2 million people have T2DM and it is estimated that a further one million are not aware that they have it because they do not experience any symptoms (Chowdhury & King, 2007). The risk of T2DM is about 4-5 times higher in South-Asians than in white Europeans, about 1 in 4 South-Asian adults over the age of 25 have diabetes and 1 in 3 South-Asians develop it (Chowdhury & King, 2007). Compared to white Europeans the condition tends to develop sooner in South-Asians, about 10 years earlier, and the complications of the disease develop more frequently such as kidney disease and heart disease (Hawthorne & Tomlinson, 1999). Therefore an individual is at high risk of T2DM if they are of South-Asian descent and over the age of 25. Hence it is crucial to explore the perceptions and health behaviours of individuals especially South-Asians in order to learn, understand and develop sufficient and efficient strategies to combat the onset of T2DM and preventing it in the future generations.

King, Aubert and Herman (1998) conducted a study to estimate the prevalence of diabetes in all countries of the world, the number of people aged 20 years or more with diabetes in 1995 and to project the prevalence of the disease in 2000 and 2025. Gender ratio, urban rural ratio, and the age structure of the diabetic population were calculated. Their research

supports previous predictions of an T2DM epidemic around the world during the first quarter of the 21st century and provides an indication of its characteristics e.g. that the population of people with diabetes in the developing world is growing faster and developing diabetes younger than that in the developed world. King and colleagues believe that continual worldwide scrutiny of diabetes is a necessary first step towards prevention and control. T2DM is now recognised as an urgent priority as it is one of the two non-communicable diseases which has been discussed and formed a UN resolution: '*United Nations World Diabetes Day Resolution*' back in December 2006.

There are three forms of T2DM prevention: primary secondary and tertiary. Primary prevention focuses on those who are at high risk of developing diabetes and secondary prevention targets individuals who have diabetes in the early stages (Jones, 2010). The International Diabetes Federation (2010) stated that controlling blood sugar levels will reduce the need for more serious treatment in the future. Tertiary prevention focuses on preventing serious complications in people with diabetes who have had the disease for a long time. This thesis concentrates and explores primary prevention of T2DM in British Pakistani women and subsequent generations.

The UK is a multicultural society and ethnic minorities make up 7.9% of the population, with the Black population being the largest at 2.0%, Indian population at 1.8% and Pakistani population being the third largest ethnic group at 1.3% (Office for National Statistics, 2001) and these numbers continue to rise. The latest figures were due in the Office for National Statistics 2011 report, which had not been published at the time of originally writing this chapter. The size of the non-white population in Birmingham is a third of the total population of Birmingham with a reported figure of over 200,000 people of Pakistani origin residing there out of a total population of over 977,000 (Office for National Statistics, 2001). Although London has twice as many Pakistanis, Birmingham is viewed as the 'main location' of all Pakistanis in Britain (Neighbourhood statistics, 2010). Most British-Pakistanis speak English, and those who are born in the UK consider English to be their first language. Urdu is

understood and spoken by many British-Pakistanis and it is the main language spoken in Pakistan. British-Pakistanis with literacy problems are often those who have migrated from Pakistan and therefore experience language barriers. At present most British-Pakistanis are literate in English and those who are not tend to be of the older generation or from the migrant group (Linguistic and Ethnic Groups, 2010).

Modood (2007) stated that multiculturalism has different meanings but in the UK it has a restricted meaning. In the UK a multicultural society represents a fundamental movement of people focusing on the consequences of immigration, on the struggles of a range of marginalised populations and on differences between groups. Therefore previous western research conducted with white western participants is not applicable for the multicultural western society we live in today and there is a significant need to develop culturally sensitive resources and strategies. By understanding and studying other groups and cultures we can develop appropriate resources and interventions to tackle and prevent many illnesses such as T2DM. This project aims to research British-Pakistani perceptions and beliefs of T2DM as this population group has a high prevalence rate in the UK of T2DM (Pieroni, Sheikh, Wajid & Torry, 2008; Hawthorne & Tomlinson 1999).

1.1.2 Physiology of T2DM

Diabetes is a condition caused by high levels of glucose in the blood (Chowdhury & King, 2007). Glucose provides the human body with energy and is the main source of fuel needed to be able to live, eat, breathe and move. Glucose is found in many foods including fruits, bread, rice and potatoes. When glucose is consumed it is broken down in the stomach and small intestine and then absorbed into the bloodstream. From there it travels to the cells where it is needed and then insulin enables glucose to get into the cells. Insulin is released by the pancreas which has two roles. Firstly to produce enzymes to breakdown food in the stomach and small intestine, and secondly to release insulin into the bloodstream in response to increasing glucose levels. The cells that produce insulin are called pancreatic beta cells. In diabetes there are two main problems. The first is insulin resistance which is

when the body does not respond to insulin as it should and much greater levels of insulin are needed to allow glucose to enter cells. South-Asian people are more insulin resistant than white Europeans and this is why T2DM is much more common among South-Asian people compared to their white counterparts (Chowdhury & King, 2007). No-one knows why this happens but it is linked with being overweight especially around the waist (Diabetes UK, 2006). Another explanation is that South-Asian ancestors were able to survive on lower carbohydrate intakes so in the presence of excess carbohydrates they develop diabetes (Chowdhury & King, 2007). The second problem is insulin deficiency which is when there are reduced levels of insulin released from the pancreas either due to beta cells being destroyed (as in type 1) or the beta cells cannot produce enough insulin to overcome the insulin resistance (as in type 2) (Diabetes UK, 2006).

T2DM has been known as non-insulin-dependent diabetes as insulin resistance occurs with different levels of insulin deficiency. It commonly affects older people although there are increasing rates of T2DM in children and young adults due to the increasing problem of obesity (Ehtisham, Hattersley, Dunger & Barrett, 2004). Increased risk of T2DM is associated with increasing age, being overweight/obese, lack of physical activity, being South-Asian as well as a strong family history, however it can be treated, with lifestyle change e.g. healthier diet and more physical activity, tablets e.g. Metformin, or insulin (Diabetes UK, 2006). Less common causes include medication such as steroids or psychiatric medication, pregnancy, pancreatic disease or hormonal problems (Chowdhury & King, 2007).

1.1.3 Genetics

Genetics plays a crucial role in that diabetes is more prevalent in certain families and groups than others. Recently a variant gene (TCF7L2) has been discovered that increases the risk of T2DM and is carried by more than a third of the American population (Grant, Gudmar & Inga, 2005). However Kleinfield (2006b) suggested that social behaviours (e.g. dietary behaviours) are more implicated in the development of T2DM in particular populations than

genetics as they are linked to race, through ethnic and cultural differences, and income. Groop and Tuomi (1997) demonstrated that T2DM is a result of the collision between thrifty genes and an affluent society. Thrifty genes are referred to as survival genes helping to store energy during long periods of starvation therefore Groop and Tuomi propose that when these genes are exposed to sedentary lifestyles and high calorie intake the individual becomes predisposed to obesity and T2DM. However previous research has demonstrated that genetics still plays a significant role especially among British-Pakistanis, as South-Asian people are more insulin resistant than Europeans (Chowdhury & King, 2007). Additionally South-Asians develop diabetes at lower body weights than people of other races (Landrine & Klonoff, 2002).

Genetic research has implicated the PCK1 gene as a candidate for T2DM susceptibility (Zouali, Hani, Philippi, Vionnet, Beckmann, et al. 1997; 1996;). Fewer studies have reported on this genetic susceptibility to T2DM in South-Asian groups. PCK1 gene is an enzyme involved in gluconeogenesis, glyceroneogenesis and cataplerosis and is under hormonal control. Rees and colleagues (2009) investigated the association between variants of the PCK1 gene and T2DM in South-Asians and suggested that the -232C/G promoter polymorphism produces susceptibility to T2DM in this ethnic group. Beale, Hammer, Antoine and Forest (2004) reported that T2DM could be caused by either excessive PEPC-C production in the liver or reduced levels of PEPC-C in adipose tissue. Although there is a universal agreement among researchers that T2DM has a genetic link, no specific gene has been discovered as of yet that triggers the onset of the disease.

Children are at high-risk of developing T2DM if their parents have it (Chowdhury & King, 2007; Groop & Tuomi, 1997). Family studies illustrate that the risk of an individual developing T2DM is estimated to increase to fourfold when one or both parents have T2DM diagnosis (Klein, Klein, Moss & Cruikshanks, 1996; Mitchell, Valdez, Hazuda, et al., 1993). Meigs, Cupples and Wilson (2000) found that the risk of T2DM in children is the same whether both parents are affected or if either parent is affected. Viswanathan, Mohan,

Snehalatha and Ramachandran (1985) reported high prevalence rates of T2DM among the children of Indian parent(s) with diabetes. They found that although none of the parents were diagnosed with T2DM younger than 20 years, a few children of the recruited sample were, supporting a strong T2DM genetic link.

1.1.4 Gestational diabetes

Gestational diabetes (GD) is becoming a common disease in the UK (Diabetes UK, 2006). Research from around the globe estimates that between 1-5% of pregnancies involve GD (Bertowitz, Lapinski, Wein & Lee, 1992). The prevalence of GD is increasing along with increasing obesity and T2DM rates (Korpi-Hyovalti, Laaksonen, Schwab, Vanhapiha, Vihla, et al., 2011; Dabelea, Snell-Bergeon, Hartsfield, et al., 2005). There are many known risk factors of GD the main ones being obesity, advanced maternal age, family history of diabetes, ethnicity, increased weight gain in early adulthood and smoking (Scott, Loveman, McIntyre & Waugh, 2002; King, 2009). Ethnicity is one of the predominant risk factors of GD supported by a UK study which demonstrated that South-Asian women were eleven times more likely to develop it than British-white women (Dornhorst, Paterson, Nicholls et al, 1992). Dornhorst and colleagues (1992) highlighted increased prevalence rates in ethnic minorities versus white population groups. GD in South-Asians also occurs at a lower BMI (Gunton, Hitchman & McElduff, 2001). A history of GD increases the risk of developing T2DM (Nicklas, Zera, Seely, et al., 2011; Kim, Newton & Knapp, 2002). A study in Leicester found that four years after diagnosis South-Asian women with GD were twice as likely to develop T2DM compared to British-white women (Oldfield, Donley, Walwyn, Schudamore & Gregory, 2007).

There is limited GD data among Pakistani women. An analysis of birth records in New York between 1995-2003 showed high GD prevalence rates among South-Asian women, the highest among Bangladeshi (21.2 percent) and Pakistani (16.2 percent) women (Savitz, Janevic, Engel, Kaufman & Herring, 2008). Akhter and colleagues (1996) conducted a five year study exploring GD among pregnant women in Pakistan. They found that complication

rates were higher due to poorer glycaemic control. This is supported by previous studies which report that GD results in higher maternal and foetal complications (Sepe, Connell, Geiss & Teutsch, 1985; Heckbert, Stephens & Daling, 1988). Akhter et al. also stated that the prevalence rates of GD in women from Pakistan were similar to Western population rates although the complications were higher.

1.1.5 T2DM and pharmacology

Pharmacological therapy is used to provide needed physiological support for insulin deficiency or insulin resistance (Odegard & Capoccia, 2007). It is used when diet and physical activity modifications have either failed or are not producing adequate results in lowering HbA1c levels (Siminerio, 2006). Red blood cells are made of haemoglobin which combines with glucose producing HbA1c, thus the more glucose in the blood the more HbA1C will be present in the blood. The American Diabetes Association (2006) recommended metformin for all T2DM patients at diagnosis (as long as there are no contradictions to the use of metformin) along with appropriate lifestyle modifications. The rationale for the use of metformin is largely based on its 40year long-term safety record (Knowler, Barrett-Connor & Fowler et al., 2002). A systematic review conducted by Wulffele, Kooy, de Zeeuw, Stehouwer and Gansevoort (2004) explored how intensive T2DM treatments with metformin reduce physiological factors and mortality in individuals with newly diagnosed T2DM compared with intensive treatment with insulin or sulphonylurea derivatives. They predicted that metformin may have a glucose-lowering independent effect on blood pressure and lipid profile and in order to test this they systematically reviewed the literature and pooled the data obtained in a meta-analysis. From the forty-one RCTs used in their analysis, the data suggested that metformin has no intrinsic effect on blood pressure, HDL cholesterol and triglycerides in T2DM patients however it does reduce total and LDL cholesterol significantly (relatively small reductions). In addition to metformin there are a number of alternative pharmacological options including oral agents, injected insulin, incretin mimetic agents, amylin analogs and inhaled insulin. Prior to commencing pharmacological therapy a patient's needs, adherence challenges and physiological benefit of the drug must

be assessed and careful follow-up conducted to achieve and maintain diabetes control (Odegard & Capoccia, 2007). Effective use of pharmacological therapy has clearly been documented and several studies have also illustrated the benefit of pharmacological therapy in improving microvascular and macrovascular outcomes (Turner, Cull, Frighi & Holman, 1999).

1.1.6 Main symptoms and diagnosis of T2DM

The main symptoms of T2DM include feeling thirsty and drinking water frequently, passing a lot of urine, rapid weight loss, severe tiredness, frequent skin infections, excessive hunger and blurred vision (Diabetes UK, 2006). By having an oral glucose tolerance test (OGTT) by a health professional, a person can find out if they have diabetes, whether they are at risk of developing it in the future (known as impaired fasting glucose (IFG)) or if they have impaired glucose tolerance (IGT) (Chowdhury & King, 2007). IGT indicates that after consuming food glucose goes higher than it should due to insulin resistance, which means an individual is at the highest risk of developing diabetes this state is known as pre-diabetes.

1.1.7 Health complications

Diabetes can have very serious effects on health and complications can arise 5-10 years after diagnosis (Chowdhury & King, 2007; Wens, Vermeire & Hearnshaw, 2007; Ogden, 2004). Therefore, if undetected, an individual can develop the complications before being diagnosed. The complications of diabetes can be divided into acute and chronic. Acute complications include hyperglycaemia and hypoglycaemia. Hyperglycaemia is when blood glucose levels become very high, i.e. above 20mmol/l, causing severe dehydration leading to kidney failure or stroke. Patients have rapid breathing and may have a sweet smell on the breath. Hypoglycaemia is when the blood glucose drops below 4mmol/l. This mainly affects those treated with insulin and can be due to missed or delayed food, taking too much insulin or diabetes medication, vigorous physical activity and drinking alcohol. Hypoglycaemia can have a damaging effect on health however the treatment is very simple i.e. by taking carbohydrates such as three-four ounces (100-120ml) of fruit juice, about four-five ounces

(120-150ml) of fizzy drinks containing sugar, one slice of white bread or one serving of most starchy foods.

Chronic complications can be divided into microvascular and macrovascular. Microvascular complications include effects on the eyes, kidneys and nerves, and macrovascular include heart problems, stroke and circulatory problems in the legs. The most serious complication of T2DM is the effect on the heart. Three out of four people with diabetes will suffer heart disease, the major problem being heart attacks. South-Asians with diabetes are up to three times more likely to have a heart attack than white people with T2DM (Chowdhury & King, 2007). T2DM is also associated with ischemic stroke, which is when the blood supply to an area of the brain is interrupted usually due to a clot in a brain artery. A person with diabetes is at a higher risk of suffering from a stroke due to risk factors such as high blood pressure and abnormal blood cholesterol levels (American Diabetes Association, 2010).

Complications can be prevented. The key steps include educating people with diabetes and their families to empower them to self-manage their condition which involves monitoring diabetes and attending regular screening for complications, improving diet, increasing physical activity, smoking cessation, treating high blood glucose levels with lifestyle changes or tablets or insulin, treating high blood pressure, treating high blood cholesterol and taking anticoagulation medication e.g. aspirin (American Diabetes Association, 2010; Chowdhury & King, 2007; Diabetes UK, 2006; Lawton, Ahmad, Hanna, Douglas & Hallowell, 2006).

Previous research indicates that British-Pakistanis diagnosed with T2DM or at high-risk are known for having one or more recorded diabetic complication, diagnosed for longer, on tablets rather than just diet controlled and are older compared to British-whites (Hawthorne & Tomlinson 1999; Simmons, Meadows & Williams, 1991). There are documented differences of T2DM diagnosis and treatment between ethnic minority groups and the British-white population group, with Pakistanis having one of the highest T2DM rates compared with other South-Asian groups (Chowdhury & King, 2007). Finucane and McMullen (2008) conducted a

study in Hawaii and reported that Filipino-Americans have 2-3 times the age-adjusted prevalence of T2DM compared with white-Americans and 45% of Filipino-Americans in Hawaii are overweight or obese. They are less likely to engage in significant self-care behaviours which may also be the reason for the poorer outcome in British-Pakistanis.

1.1.8 Educational programmes

T2DM education programmes try to enable people to discuss their diabetes with other patients as well as health professionals and to develop a problem-solving approach. DESMOND is a UK theoretically-based diabetes education and self-management programme and aims to deliver high quality patient education to people with T2DM or who are at risk of it (DESMOND, 2008). DESMOND encompasses a range of patient education programmes and training developed by a collaboration of NHS organisations and a co-ordination centre hosted by University Hospitals of Leicester NHS Trust. It is a well-established and successful initiative improving the care for people with T2DM (Davies, Heller, Campbell, Carey, Dallosso, et al., 2008). It is also a research organisation as it draws on the expertise of many researchers, academics and health professionals to test and provide evidence of the effectiveness of the psychological theory-based education programmes and training DESMOND develops. An example of a DESMOND programme based study is a randomised controlled study (RCT) for the prevention of diabetes using an educational intervention and continuous support programme for those with pre-diabetes in a multi ethnic population titled 'Let's Prevent' (DESMOND, 2008). Let's Prevent explores whether diet and exercise can prevent those with pre-diabetes developing T2DM. The three year trial is currently running and findings are expected in 2014.

There is a lot of burden on the NHS to help people with diabetes and its complications as well as the financial implications. As a result many programmes have been implemented to deal with this. A popular example of a T2DM education programme is X-PERT Health (Deakin, 2006). This is a six-week group education programme for people with T2DM, aimed to help them learn to self-manage their condition and reduce the need for medication. It is

clinically effective as participants have demonstrated improved diabetes control, increased self-management skills, improved lifestyle and quality of life, and a reduction in medication use (X-PERT Health, 2009). The X-PERT Health programme is based upon the theories of patient empowerment, discovery learning and patient-centred care (Deakin, 2001). The success of the programme is believed to be due to developing knowledge, skills and confidence for diabetes self-management through a process of discovery learning and is in accordance with NICE guidance criteria. This educational programme is also committed to providing X-PERT Educator courses to healthcare professionals to develop their competencies in evidence-based diabetes care and enable them to deliver structured T2DM patient education (X-PERT Health, 2009).

Fischbacher, Bhopal, Steiner, Morris and Chalmers (2009) examined the processes and outcomes among South-Asians with diabetes and reviewed UK literature as there are doubts to whether diabetes care is equitable across UK ethnic groups. Impressively they found evidence of equity in many aspects of diabetes care for South-Asians. During the 1990s the NHS encouraged and pushed for diabetes care to be transferred towards primary care (Primary Care: Delivering the future 1996, 1996) freeing hospital teams to concentrate on complication management and provide support for GPs. Vyas, Haidery, Wiles et al. (2003) conducted a randomized controlled trial in Manchester to investigate a secondary–primary care partnership education package to demonstrate whether or not it would improve understanding of diabetes care among South-Asians. Participants were invited to four or more rotating visits per year by a diabetes specialist nurse, dietician or chiropodist. Participants and practice scores were taken at baseline and 1year follow-up using an interview and questionnaire on knowledge, awareness and self-management of diabetes. Vyas et al. found that the intervention had no impact on scores for diabetes knowledge, or awareness between baseline and 1year. They reported that this form of secondary-primary care support did not transfer information and knowledge effectively in South-Asians therefore different methods of information exchange need to be developed for diabetes. This needs to be considered for prevention programmes.

There are many good examples of effective educational programmes especially as they have started to encompass British ethnic minorities, however there is still a gap between delivering these programmes to relevant populations especially British-Pakistanis and preventing the onset of T2DM in this group. Finucane and McMullen (2008) highlighted some of the main barriers to current diabetes interventions such as the teaching style of the class leader, the design of resources, strategies used to recruit participants, the frequency, length, time of day/week, and locations of classes as well as mobility barriers. There are many other factors that may influence diabetes care such as psychological dysfunction including feelings of depression (Polonsky & Welch, 1996; Peyrot & Rubin, 1997), and theoretical constructs such as locus of control (Peyrot & Rubin, 1994), self-efficacy (Peyrot & Rubin, 1990; Robiner & Keel, 1997) and optimism bias (Weinstein & Nicolich, 1993). An individual's understanding including literacy competence (Baker, Parker, Williams et al., 1996) and diabetes care knowledge (Abourizk, O'Connor, Crabtree & Schnatz, 1994), as well as other health problems (Wang, Abbott, Goodbody et al., 1999), and socioeconomic status/poverty/unemployment (Auslander, Bubb, Rogge & Santiago, 1993) are also significant factors. Therefore this project explores this gap by tackling perceptions, knowledge and health behaviours of British-Pakistanis.

1.1.9 Diet

Healthy eating is what everybody should do whether or not they have diabetes. Most newly diagnosed people are encouraged to control their T2DM via diet alone though medication may be recommended depending on the severity of the disease (Diabetes UK, 2006). Around 80% of people with diabetes are overweight thus weight-loss is recommended (Chowdhury & King, 2007). Their diet should be low in sugar, saturated fat, salt, based around starchy carbohydrates but portions need to be controlled, and high in fruit and vegetables (Tuomilehto, Lindstrom & Qiao, 2005; Sevak, McKeigue & Marmot, 1994). Some recommendations specific to South-Asian cuisine include cutting down on rice as it is a popular over-eaten dish and to use Basmati rice as it has a lower glycaemia index compared

to standard long grain rice. It is also recommended to make chapattis without oil or ghee and to avoid using it in cooking in general (Chowdhury & King, 2007). South-Asian sweets are not good for individuals with diabetes as they contain large amounts fat and sugar (Diabetes UK, 2006). Diabetes UK also recommend South-Asians with T2DM to avoid sugar in hot drinks, drink only one pure fruit juice a day, drink plenty of water, avoid biscuits, and increase their vegetable intake and salad. Lentils like dahl, chick peas, peas and kidney beans are an excellent source of fibre which helps to reduce glucose and cholesterol levels (Chowdhury & King, 2007; Sevak, McKeigue & Marmot, 1994). They are also encouraged to reduce pickles, red meat, and to consume more lean meat, chicken and oily fish, use semi-skimmed dairy products and low-fat dairy products (Chowdhury & King, 2007; Sevak, McKeigue & Marmot, 1994). There are many significant changes British-Pakistanis can make to their diet in order to aid their diabetes control and this project aims to explore what other factors are perceived to contribute and help.

The glycemic index was constructed to measure the effect of different foods on postprandial glycemic reactions. Energy which is slowly absorbed has low glycemic indexes and leads to better short-term glycemic control (Wolever, 1990). Some studies have emphasised a positive relationship between the glycemic index and diabetes risk (Salmerón, Manson, Stampfer, et al., 1997). Previous studies have also found that high-fat low-fibre diets increase the risk of developing T2DM as an individual is at an increased risk of becoming insulin resistant (Lovejoy & DiGirolamo, 1992). Fibre decreases postprandial glucose and insulin concentrations in individuals with and without diabetes (Meyer, Kushi, Jacobs et al., 2000). Salmerón, Ascherio, Rimm, et al. (1997) reported that cereal fibre is related to T2DM risk whereas fruit and vegetable fibre is not associated with T2DM risk. Also whole-grain products are digested and absorbed slowly compared to refined-grain products, and refined-grain products have more than double the glycaemia and insulinemic responses than whole-grain products (Jenkins, Wesson & Wolever, 1988; Heaton, Marcus, Emmett & Bolton, 1988). Liu, Manson, Stampfer et al. (2000) investigated the link between whole and refined grain intake and the risk on T2DM among US women without a previous diagnosis of either

T2DM or cardiovascular disease. A food frequency questionnaire was used to evaluate the relationship. They reported that substituting refined grain products with whole grains may decrease the risk of T2DM. Meyer et al. (2000) also support this as they found protective properties of grains, cereal fibre and dietary magnesium for the development of diabetes in older Iowa women. They suggested that dietary carbohydrates may influence the onset and risk of T2DM.

1.1.10 Physical Activity

Physical activity can help to control weight, blood glucose and blood pressure. Diabetes UK (2006) recommend thirty minutes of aerobic exercise a day which can be in the form of swimming, walking, jogging, cycling and/or dancing to help control and prevent T2DM symptoms/complications.. Walking is particularly good and effective as it improves the body's responsiveness to insulin, reduces weight, reduces cholesterol and blood pressure and reduces the risk of blood vessel complications related to diabetes (Chowdhury & King, 2007).

Drew (2002) conducted a qualitative study aimed to explore participants' own accounts of their experiences of physical activity and the perceptions of barriers to being active. Two main themes emerged. The first theme was self-perception where they viewed themselves as inappropriate for exercise as they were unskilled and believed that physical activity was not for them. They had negative attitudes, feelings and self-esteem. Lack of time was the second theme as women prioritised others over themselves. Family, work and caring duties were constraints on time and they felt guilty leaving others to do things whilst they spent time on themselves. Learning about an individual's personal understandings of T2DM and life priorities are important shared sources of information for planning meaningful care and resources (Hornsten, Sandstrom & Lundman, 2004).

Lawton and colleagues (2006) found that Pakistanis as well as Indians have a higher risk of diabetic complications due to low levels of physical activity. They reported that Pakistanis

and Indians are aware of the need to undertake physical activity and a minority do practise this, however most give excuses of practical barriers such as lack of time interlinked with cultural norms and social expectations. Some report health problems which could make physical activity difficult for them and these are reinforced by their perceptions and understandings of T2DM. Lawton et al. expressed that education may play a role in physical activity promotion however health promoters need to work with cultural norms and individual perceptions. They recommend a realistic and culturally sensitive approach which is based on the activities they already do in their everyday lives. Hayes and colleagues (2002) reported similar findings among British South-Asians in Newcastle. They found that Pakistanis and Bangladeshis in particular were less active compared to the white population group. They found that cultural values and attitudes held by South-Asians do not encourage sport or physical activity participation. A previous study reported that Bangladeshis living in London view a large body size as healthy compared to thinness, and that in the Sylheti language no phrase exists to describe physical activity as it is understood in English (Erens, Primatesta & Prior, 2001).

In Pakistan Iqbal, Rafique, Badruddin, et al. (2006) reported that it is necessary to record precise measurements of activity at a population level for monitoring trends and evaluating health promotion strategies. Hence they used the Monica Optional Study of Physical Activity (MOSPA) questionnaire which assesses energy expenditure (EE) related to physical activity (employment, household work, transportation, and leisure time) over 1 year. Many studies conducted in South-Asia suggest that the main contributors to EE are everyday tasks and walking to work/school rather than the leisure time activity which is common in the West (Tudor-Locke, Ainsworth, Adair & Popkin, 2003). Fischbacher, Hunt and Alexander (2004) found that levels of physical activity were lower in all South-Asian groups than the general population in the UK and the patterns of activity also differed. There is a lack of attention to issues of cross-cultural equivalence in previous research.

There is a great deal of evidence that diabetes is preventable in people who are at high-risk of developing it. The best way to prevent it is to lead a healthy lifestyle and not to gain weight as one grows older. Regular exercise is a very important factor. Currently there is no cure for diabetes and it is a condition which is chronic and lifelong. Treatments only control it not cure it. Albarran, Ballesteros, Morales and Ortega (2006) illustrated that there is a lack of responsibility recognised by patients, families, healthcare professionals, and local/national agencies regarding T2DM risk factors. Diabetes control and prevention consists of lifestyle modifications and social support. Knowledge is a very important entity for diabetic patients and family members to have in order to understand this disease. A socio-cultural environment is closely linked to lifestyle, thus complicating the change process (Skinner, Anderson & Marshall, 1993). Alternative interventions need research on socially and culturally sensitive methodology focusing on environmental and personal factors (Valadez, Aldrete & Alfaro, 1993).

1.1.11 British-Pakistanis women

British-Pakistanis women were selected for the purpose of the present project as they are an accessible and relevant population group to research. They are at the forefront of familial responsibilities and child rearing. Vyas, Greenhalgh, Cade et al. (2003) reported that out of adult Pakistanis, Europeans and African-Caribbeans in Britain, risk factors for long-term chronic disease are the highest in Pakistani women. As a population group South-Asians in the UK have the highest rates of CHD and T2DM (Sevak, McKeigue & Marmot, 1994; Landman & Cruickshank, 2001) hence the reason why it is crucial to tackle the T2DM problem. Pollard, Unwin, Fischbacher and Chamley (2008) explored whether the risk factors for T2DM changed from migrants to subsequent generations born in the west. They examined 30 Pakistani migrants living in the UK, 30 British-born Pakistani women and 25 British-born women of European origin. British-Pakistani women were taller, had a lower waist to hip ratio, lower mean fasting glucose levels, lower mean triglyceride levels, and higher mean HDL levels compared to migrant British-Pakistani women. Healthier levels of heart disease and T2DM risk factors were found in British-Pakistani women than in migrant

British-Pakistani women. They suggested that this may be due to the effects of early environment or to differences in health behaviours. Pollard et al. reported that British-Pakistani women also differed from British-born European women as they had more adverse body composition, but healthier levels of HDL cholesterol and blood pressure. Providing support to these British-Pakistani women regarding T2DM prevention may lead to better preventative care in their homes.

Drummond's (2005) research highlights that many people with diabetes do not exercise regularly nor maintain healthy diets to lose the weight necessary for diabetes control, especially overweight, middle-aged women. Psychosocial factors such as patient knowledge, previous levels of adherence, perceived confidence in one's ability to perform specific behaviour, and level of satisfaction with healthcare influence attempts to manage diabetes (Burke & Dunbar-Jacob, 1995). One of the most significant and influential factors is the availability of social support (Pham, Fortin, & Thibaudeau, 1996). Drummond found that women with diabetes encountered avoidance, indifference, encouragement and temptation to weight-loss when they experienced social support. There are many different factors which may impact on British-Pakistani women's perceptions about the T2DM illness and management, thus these are likely to influence their prevention behaviours and perceptions towards T2DM. This research opens a gateway to understanding women's emotional and cognitive states and therefore can provide a basis for mothers to support their children's eating habits and lifestyles in a positive and healthy way. Hence an aim of the current project is to tackle the perceptions and preventative behaviours of British-Pakistani mothers to learn about strategies they use and/or identify the ones they should be using. It is also an opportunity to explore the behaviours of the younger females and learn about the influences of their mothers.

1.2 Psychosocial Health Constructs

1.2.1 Beliefs

In contrast to knowledge which is considered as true, beliefs are defined as acceptable principles or groups of principles (Purnell & Paulanka, 1998). Beliefs are built on knowledge held by a person and an attitude towards a particular behaviour represents an outline of beliefs about that behaviour and determines the behaviour (Hjelm, Bard, Nyberg & Apelqvist, 2003). Beliefs are culturally determined, learned via society and transmitted through language (Berger and Luckmann, 1991). They form the basis of an individual's explanation of disease, strategies for self-care measures, treatment of disease and health-care seeking decisions (Berger and Luckmann, 1991).

1.2.2 Perceptions

Perceptions are interpretations of events that unfold before an individual's senses. They occur as a result of subjective interpretations, many influenced by cultural upbringing (Laungani, 2007). The personal understanding of illness helps an individual make sense of an illness experience (Hornsten, Sandstrom & Lundman, 2004). The understanding of illness is not created consciously, changes over time and is influenced by a person's social environment, ethnicity (Cockerham, 2007; Aspinall 2002;), culture (Laungani, 2007, Sontag 1991) and gender (Vyas, Greenhalgh, Cade et al., 2003) as well as past experiences and knowledge (Fagerli, Lien & Wandel, 2004; McSweeney, Allan & Mayo, 1997). The common-sense model (Leventhal et al., 1984; 1998; 2008) is an influential model used to assess illness perceptions, which is discussed in more detail later on in this chapter. According to McSweeney et al. (1997) the illness experiences are integrated into the beliefs and value systems of an individual in the form of common-sense understanding of bodily sensations. The different perspectives on disease and illness between patients and professionals have been discussed in several studies (Toombs 1993, Atkinson 1995, Loewe & Freeman 2000). These often lead to conflicting expectations about treatment, outcome of care and priorities, resulting in dissatisfaction, inappropriate treatment and unsatisfactory care (Cohen, Tripp-

Reimer, Smith, Sorofman & Lively, 1994; Toombs, 1993). Exploring perceptions of British-Pakistani women is a plausible place to start learning about this group's behaviours, knowledge and culture towards T2DM.

1.2.3 Social factors

There are recognisable social factors believed to make people ill (Blaxter 2004). Poverty, low socioeconomic status, unhealthy lifestyles, and unpleasant living and work conditions are social variables that cause ill health (Cockerham, 2007). Usually social variables are perceived as secondary influences on health and illness, not as direct causes (Phelan, Link, Diez-Roux, Kawachi & Levin, 2004). Social context can shape the risk of exposure, the susceptibility of the host, and the disease's course and outcome such as CHD and T2DM (Holtz, Holmes, Stonington & Eisenberg, 2006). However social factors do more than just influence health and the experience of illness for individuals. They have a direct causal effect on physical health and illness. Social factors can initiate the onset of the pathology and in this way serve as a direct cause for a number of diseases (Cockerham, 2007).

The behavioural/cultural explanation describes the differences between social groups in various types of activities and aspects of life relating to health such as smoking, exercise and diet (Bartley, 2004) (see figure 1.1). It states the lower the income/status of a person the less likely they will engage in health-promoting behaviours such as jogging or eating five portions of fruit and vegetables a day. Another explanation for exploring the relationship between social position and health behaviours centre around self-regulation, which is the fulfilment of central social roles (Siegrists, 1998; 2000). Also giving positive feedback to an individual about their acceptance and esteem within their immediate social context and in society, thereby creating a stable contact between the individual and society gives signals about desirable behaviour by rewarding actions that are valued. Therefore there are many factors to consider when dealing with British-Pakistani women in the project, and they need to be thoroughly explored.



Figure 1.1 The behavioural/cultural explanation model (Bartley, 2004)

1.2.4 Culture

Culture is a system of meanings that exists in the minds of people within a community. It is composed of behaviour which occurs regularly in institutional domains within a community such as religious, familial or political institutions. Shared culture or lifestyle may be an influence on social differences in health (Sacker, Bartley, Firth & Fitzpatrick, 2000; Chandola, 1998). Even if differences in expressed attitudes to health do not seem to have much effect on health risk behaviours, it may still be that other forms of cultural differences between people of different social status are important. Social differences in the adoption of a healthy lifestyle do not have to be a result of explicit beliefs about health itself. Therefore culture may influence health behaviours. This kind of social influence would also be less amenable to change as a result of health information. Cultural shift focuses on the differences between countries in the overall prevalence of certain kinds of health risk behaviours (Kunst, 1997).

Culture is often misunderstood as it is used to explain away differences between groups of people, noticeable differences in attitudes, values and behaviours (Laungani, 2007). We are each born into a particular family which has a genetic and social history of its own. The

family is an integral part of a wider section of our community which is part of the society we live and grow in. Society provides us with a structure including rules and norms of behaviour regulating our beliefs and practices. As an integral part of society we are able to make sense of ourselves, our own lives, of others, and of the world around us.

There are different psychological perspectives on culture. From a behaviourist view point culture is only an abstraction based on common characteristics displayed in behaviour of a particular group of people (Barnlund & Araki, 1985). On the other hand Valsiner (2000) sees culture in terms of organised psychological function which is intrapersonal as well as interpersonal. Some focus on value systems and the networks of communication as being essential ingredients comprising a culture. The general consensus of culture is that it includes core and secondary features. Core features include a past history which regulates political, legal, and social systems and communication networks, a dominant organised religion, a set of core values and traditions, and artefacts unique to the society. The secondary features include freedom from linguistic, religious, political and social persecution, shared common language(s), commonly recognised physical and geographical boundaries, housing and other living arrangements and socially accepted dietary, health and medical practices. Studying culture or at least acknowledging it is an important construct of future research in the UK, and this project tackles the issue of culture and the effect of culture on the perceptions and behaviours of British-Pakistani women.

A significant part of exploring Pakistani culture involves understanding traditional medicines and herbal remedies (Pieroni et al., 2008) that are believed to help improve health and prevention behaviours of British-Pakistani people especially the older generation. Pieroni et al. report that herbal medicines are commonly used for self-treatment purposes worldwide, and that the use of these is found in established health systems. Learning about traditional knowledge related to health beliefs and practices and about traditional pharmaceutical knowledge originating from developing countries can aid the T2DM educational process

among ethnic minorities living in the UK today, however very little research has been conducted regarding this in Western Europe (Pieroni, M"unz, Akbulut, et al., 2005).

The majority of the traditional medicines and herbal remedies are represented as food medicines (Pieroni et al., 2008). These are plant foods and spices that are eaten for their medicinal purpose. Karela (bitter melon) is an example of one of the most quoted remedies and is believed to control and even cure T2DM. This was supported by some research using Pakistani migrants living in Oslo, Norway (Fagerli, Lien & Wandel, 2004). Some ethno-scientific studies carried out previously have indicated the inextricable connection between food and ethno-medical practices (Pieroni & Price, 2006; Ekin, 2006). Pieroni and colleagues (2008) conducted focus groups on British-Pakistanis from Bradford. They exposed that traditional medicines especially among Pakistani migrants from Mirpur in Bradford are still alive. They also found that the majority of the popular remedies were little known in either Western herbalism or modern evidence-based phytotherapy. This could be due to the fact that the majority of the traditional medicines were in the form of food medicines rather than herbs. Pieroni et al.'s findings are very important as they provide an insight into the fascinating world of traditional medicines and herbal remedies and raise interesting questions for public-health stakeholders.

Hawthorne and Tomlinson (1999) researched diabetes knowledge and self-management and glycaemia control among British-Pakistani Muslims in Manchester. They conducted interviews with participants to explore knowledge of appropriate diabetic diet, suitable popular locally eaten foods, glucose monitoring, diabetic complications and service offered by diabetic clinics. They found that knowledge was good but using that knowledge to solve daily life problems was poor, and that men were much better at understanding and maintaining good blood glucose levels than women as a majority of the women were illiterate. They also highlighted that British-Pakistanis find it hard to refuse food at social events and regularly eat rice and sweet dishes, which in excess is not good for their diabetes control. Hawthorne (2001) conducted a follow-up study with 105 British-Pakistani women to

trial a one-to-one structured diabetes health education programme using pictorial flashcards. She found that the majority of participants improved their knowledge and glycaemia control after 6months. However illiterate women did not do as well as their knowledge only improved slightly but their glycaemic control did not improve suggesting that illiteracy and lack of education form a great challenge in the production of an effective health education programme for this ethnic group. As mentioned earlier on in this chapter most British-Pakistanis are literate in English and have received good education therefore illiteracy barriers may be outdated from a prevention perspective.

1.2.5 Ethnicity

Definition of what race or ethnicity is varies over time and between countries (Aspinall, 2002). Race refers to group of people who are thought to differ from each other in some biological way whereas ethnicity refers to cultural differences such as language or religion. Many researchers err on the side of caution when dealing with race as a concept in research on human health as they believe there is a limited scientific basis for the idea that groups of people sharing biological features is significant for health (Rathwell & Phillips, 1986). Ethnicity is defined in terms of the combination of common geographical origin and linguistic and/or religious differences from the majority or dominant population. The problem with the concept of ethnicity is that the notion of ethnic differences in health was previously used to imply that health problems in groups of people subjected to discrimination and racial harassment were due to their culture.

Aspinall (2002) stated that overall studies seem to support the idea that socio-economic position and circumstances are an important reason for such ethnic or racial differences. Health differences between racial or ethnic groups are not as clear or consistent as socio-economic differences. In many groups defined as ethnic minorities smoking, alcohol consumption and diet are more favourable to health than those of the majority population, despite the fact that most of the group studied are subject to various forms of discrimination. The environment in which people live in is also very important. Areas of high concentration

of certain ethnic groups seem to experience lower levels of services and worse environmental conditions that add to the disadvantages measured in individual socio-economic terms (Aspinall, 2002).

Landman and Cruickshank (2001) conducted a review of ethnicity, health and nutrition-related diseases in UK migrants and found that migrant status and ethnicity do not match. There are many differences in social, nutritional and health status within and between population groups. Some migrants differ in causes of death from the general population, for example there are fewer CHD deaths among African-Caribbeans and fewer cancer deaths among African-Caribbeans, South-Asians and East-Africans not born in the UK. Experiences of risk factors differ as well, such as higher prevalence rates of hypertension and T2DM in African-Caribbeans and South-Asians than the general population. Migrants experience long-term disadvantages associated with non-communicable diseases and lower reported physical activity. Landman and Cruickshank also reported that second generation offspring of migrants use more readily available foods which increase fat and reduce vegetable, fruit and pulse consumption in their diets compared with first generation migrants. Ethnic and younger migrant groups can raise and sustain high fruit and vegetable intakes but lower proportions of fat by adopting many dietary practices from older migrants. Objective measures of physical activity and longitudinal studies of diets among different ethnic groups can help to explain diversity in health outcomes and provide for evidence-based action.

Previous diabetes research studies among different ethnic groups have focused on living with the disease and its consequences (Chin et al., 2000; Maillet et al., 1996; Quatromoni et al., 1994) or causes or explanations (Alcozer, 2000; Thompson and Gifford, 2000; Gittelsohn and Harris, 1996) rather than focussing on factors which are good for health and therefore diabetes prevention.

In Pakistan, Pakistani people are suffering from a 'double burden' (WHO, 1999) meaning nutritional deficiencies and infectious diseases that dominated mortality previously have yet

to be diminished and now the chronic diseases associated with development have increased to become leading causes of death in the country. Pappas, Akhtar, Gergen, Hadden and Khan (2001) compared the health status of the Pakistani population with the US population to demonstrate an understanding of the health problems in a developing nation. Results indicated that in comparison with the US population, the Pakistani population has a higher rate of under-nutrition, a lower rate of high cholesterol, and an equal rate of high blood pressure. Pappas et al. reported that the gap between Pakistan (a poor country) and the US (a rich country) is dramatic and can be seen in patterns of diseases, risk factors and quality of health care. Mir and Sheikh (2010) reported that British-Pakistani Muslims have the poorest overall health profile in Britain making them an ideal research population group for this thesis project.

Pakistani communities in England are seen as an ethnic minority because they have ancestors from Pakistan, may still speak Urdu (or another Pakistani language) and almost all are Muslim. Ethnic identification in UK has been classified in many different ways which have differed over time as well as between England, Wales, Scotland and Northern Ireland (Aspinall, 2002). Islam emphasises mental and physical well-being and diet as important factors for promoting health which is in accordance with the recommendations for T2DM sufferers (Hjelm, Bard, Nyberg & Apelqvist, 2003). The Islamic religion functions as a societal order that influences the culture and civilisation within a particular kind of lifestyle whether one is a believing Muslim or not (Hjarpe, 1992; Svanberg and Westerlund, 1999; Samuelsson, 2001).

Diabetes is of growing importance and it is clear that ethnicity is a key variable in this development (Cockerham, 2007). One thing that makes ethnicity important with respect to health is the close association with being affluent or poor. On the whole studies have found that people tend to attribute illness to diet, heredity, weight, stress, lack of exercise and other intrapersonal natural variables (Landrine & Klonoff, 2002). However these studies have used white-European participants therefore it is not clear whether these causal attributions are the

same for ethnic minorities. Studies have shown that culturally diverse beliefs include not only intrapersonal beliefs but others like supernatural variables. Supernatural phenomena can be anything paranormal from supernatural beings (angels or ghosts) to supernatural event (life after death or reincarnation) (Barrett, 2003). A person inclined to religious beliefs is susceptible to paranormal beliefs and vice versa (Goode, 2000). Therefore these can be just as powerful if not more than intrapersonal variables. All the different health constructs need to be addressed in this project in order to thoroughly analyse, explore and understand the perceptions and behaviours of British-Pakistani women towards T2DM and the prevention (if any) of the disease.

1.3 Theory-Based Evidence

1.3.1 Psychological theories and models

Many researchers agree that there is a need to develop theory-based studies in order to develop educational programmes in order to combat the increasing incidences of non-communicable diseases such as diabetes (Abraham, Sheeran & Orbell, 1998). Hornsten, Sandstrom and Lundman's (2004) research on personal understanding of illness among T2DM people revealed a multidimensional picture. They found that good exemplar models comprise four or five underlying dimensions referring to disease label and the symptoms associated with it. The models include the causes as well as factors leading to the onset of the disease, the long and short term consequences, timeline or beliefs about disease course, and cure or control concerning recovery or treatment (Allan 1998; Cohen, Tripp-Reimer, Smith, Sorofman & Lively, 1994; Hampson, Glasgow & Toobert, 1990).

1.3.2 Protection Motivation Theory (PMT)

The PMT (Rogers, 1975) focuses on persuasive communication in behaviour change. PMT constructs consist of susceptibility, severity, response effectiveness, self-efficacy and fear, which produce behavioural intentions resulting in behaviour. The PMT describes severity,

susceptibility and fear as relating to threat appraisals, and response effectiveness and self-efficacy to coping appraisals.



Figure 1.2 A diagram of the PMT model (Rogers & Prentice-Dunn, 1997)

According to the PMT there are two sources of information: environmental (verbal persuasion and observational learning) and intrapersonal (prior experience). This information influences the five components which then elicit either an adaptive coping response (behavioural intention) or a maladaptive coping response (avoidance, denial). Applied to dietary change for the prevention of T2DM the PMT predicts that information about the role of a high sugar and fat diet in an illness increases fear, increasing the individual's perception of how serious the illness is (perceived severity), and increases their belief that they are likely to have a serious complication like a heart attack or blindness (perceived susceptibility). If the individual feels confident that they can change their diet (self-efficacy) and that this change will have beneficial consequences (response effectiveness) then they will report high intentions to change their behaviour (behaviour intentions) such as eat healthier, low-fat and low-sugar foods. This is seen as an adaptive coping response to the information. Plotnikoff and Higginbottom (1995) found that self-efficacy and response-efficacy are strong predictors of intentions to follow a low-fat diet in accordance with CHD and diabetes.

Weinstein (2000) reported that perceived probability and perceived severity are key attributes of health hazards and do not act independently on an individual's motivation to engage in protective behaviour. His case study examined how probability and severity combine to

influence interest in protection. Ratings of motivation to act, probability, and severity for 201 health hazards were collected from twelve participants and data was analysed for each individual separately. Analysis revealed the expected '*Probability x Severity*' interaction. He found that if a health problem is perceived to have no chance of occurring then there should be no interest in acting against it regardless of how serious it might be. He also found that when probabilities were in the moderate to high range, participants were less sensitive to variations in health hazard probability. Using the constructs of the PMT model will help to explore illness perceptions and behaviours among British-Pakistani women to aid our understanding of their knowledge and beliefs.

1.3.3 Common-sense Model (CSM)

The CSM (Leventhal, Nerenz, & Steele, 1984) is used when assessing illness perceptions (also known as illness representations) of population groups. Illness representations focus exclusively on an individual's beliefs about illness (McSweeney et al., 1997) which are crucial and central to this project. Different concepts are used to describe and understand illness such as personal explanatory models (Allan, 1998) and folk/lay models (Kleinman, 1988). CSM systems adapt to threats using coping procedures that make efficient use of resources based upon the environment. Characteristics of illness representation and coping procedures are critical to understanding human adaptation to problems of physical health (Leventhal, Leventhal & Contrada, 1998).

The CSM provides a structure for understanding the factors that influence how a person perceives illness threats, the relationship between these perceptions and illness symptoms, and how these personal beliefs influence decisions about self-care behaviours leading to either promoting or ignoring illness threats (Leventhal et al. 1984). Therefore when presented with an illness which threatens an individual's health, a coping strategy or behaviour will be implemented to deal with the experience or to reduce the threat. The role of personality and cultural context are acknowledged as potentially influential on

representations and could potentially influence outcome directly (Landrine & Klonoff, 1992; Diefenbach & Leventhal, 1996).



Figure 1.3 A diagram of the common-sense model (Leventhal, Nerenz & Steele, 1984)

There are five domains of cognitive illness representations: cause, consequences, identity, timeline and cure/control (Leventhal, 1990; Hagger & Orbell, 2003). The cause dimension represents a person's beliefs and factors that are responsible for causing his/her illness. There are a number of different cause factors on illness representations e.g. biological cause (Heijmans, 1998), emotional cause (Moss-Morris et al., 1996), environmental cause (Heijmans, 1998; Heijmans & De Ridder, 1998) and psychological cause (Moss-Morris et al., 2002). The consequences dimension refers to a person's beliefs regarding the impact of an illness on their overall quality of life and how it may affect their functionality. Identity refers to an individual's beliefs about the illness label and knowledge about its symptoms. Timeline refers to a person's beliefs about the course and time scale of the illness (i.e. acute/chronic). Lastly the cure/control dimension refers to a person's empowerment regarding performance of coping behaviours and the efficacy of treatment. Leventhal et al. (1980) proposed that the CSM is a parallel-processing model in that individuals make cognitive and emotional representations of their illness simultaneously, therefore an illness representation may comprise of cognitive as well as emotional representations (Moss-Morris et al., 2002). Early research demonstrated that identity was strongly and negatively related to the cure/control dimension but positively related to timeline and serious consequences beliefs of the illness

(Heijmans 1998; 1999; Heijmans and De Ridder, 1998; 1999; Weinman et al., 1996). This suggests that individuals who believed their illness was highly symptomatic (having a strong illness identity) would also believe that their illness was uncontrollable, chronic and had serious consequences for their lifestyle. Whereas individuals who believed that they had a high degree of control over their illness also believed their illness was less chronic with fewer serious consequences. These findings provide evidence of a common trend among illness sufferers on how they organise their lay beliefs about their illness (Hagger & Orbell, 2003).

Llewellyn, McGurk and Weinman (2007) found that although the CSM may be a useful framework for extracting and understanding patients' beliefs, there are concerns predicting longitudinal outcomes from baseline factors that may change over the course of an illness. Components of the CSM such as illness perceptions and coping strategies were found to be better explanatory factors of judgement-based outcome variables (Llewellyn McGurk & Weinman, 2006). For example diet therapy for T2DM includes cognitive processing of information to understand the complex relationship between carbohydrate intake and blood glucose levels, and how emotional processes relate to socio-cultural values about food and eating. A social experience may be more important than the cognitive processes because in certain situations individuals may choose to eat foods that raise blood glucose levels because they feel socially obligated to do so.

Jayne and Rankin (2001) examined the CSM with a group of Chinese immigrants with T2DM. By utilising the CSM they found that Chinese immigrants were unclear about the causes and complications of T2DM and interpreted the illness as stigmatising. Their coping strategies included wishful thinking, belief in powerful others, keeping T2DM a secret and avoiding social situations. Jayne and Rankin suggest that healthcare providers can help people with T2DM develop critical-thinking strategies instead of relying on sets of rules to control their blood glucose levels.

Walter and Emery (2006) reported how CSM factors can influence perceptions of family history of disease and how it varies between individuals and diseases. Therefore family history may be used as a tool in preventive healthcare as it considers an individual's personal understanding of disease risk and their ideas about cause and controllability of the familial illness. Perceived risk may then be used to motivate preventive health behaviours. This is very interesting and useful to consider when researching T2DM in British-Pakistanis as it may be considered as a genetic disease (Barnett and Kelly, 2009; Beale, Hammer, Antoine and Forest; 2004).

Previous research has supported using this model to explain illness behaviours across a range of chronic illnesses such as T2DM (Hagger & Orbell, 2003), therefore along with the PMT the CSM was used when exploring the perceptions, knowledge and behaviours of T2DM among British-Pakistani women for this project. The PMT and CSM model influenced the construction of the Illness Perception Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris & Horne, 1996). It is widely used and assesses five cognitive illness representations. A revised version of this scale, the Illness Perception Questionnaire-Revised (IPQ-R), extended the original scale by adding more items and making some modifications (Moss-Morris et al., 2002) (for further details please refer to chapter 3).

1.3.4 Health Belief Model (HBM)

The HBM's (Rosenstock, Strecher & Becker, 1988) key components are threat in terms of perceived susceptibility to an ill-health condition and perceived seriousness of the condition, outcome expectations expressed as perceived benefits of an action and perceived barriers to taking that action, and self-efficacy. Socio-demographic factors such as age, sex, education, race/ethnicity and income influence behaviour indirectly by affecting these components (Lai, Lew-Ting & Chie, 2004). Ratanasuwan, Indharapakdi, Promrerk, Komolviphat and Thanamai (2005) reported that diabetes requires patient participation thus the outcome of treatment depends on the patient health beliefs and illness perceptions. They used the culture consensus analysis model to evaluate the HBM and illness perceptions. They found that

past experience and culture play significant roles in HBM and diabetes as they form part of the participants' perceptions. According to the HBM the stronger self-efficacy is perceived to be the more active and persistent the individual. Outcomes interpreted as successful by an individual raises their self-efficacy and their positive mood enhances one's perceived self-efficacy (Bandura, 1995). Self-efficacy is one of the components of the PMT model too giving it more validity to be used in this project.



Figure 1.4 A diagram of the HBM (Rosenstock, Strecher & Becker, 1988)

1.3.5 The Theory of Planned Behaviour (TPB)

In contrast the TPB (Ajzen, 1991) model demonstrates that intentions are significant variables which are not accounted for by the HBM but are by the PMT. Intentions are affected by an individual's attitudes, subjective norms and perceived behavioural control (PBC) determining behaviour. Attitudes refer to the extent to which an individual has a favourable or unfavourable evaluation or appraisal of the behaviour under consideration. Subjective norm refers to the perceived social pressure to perform or not to perform a specific behaviour, and PBC refers to the perceived ease or difficulty of performing a specific behaviour. These reflect past experience as well as anticipated barriers and obstacles. The more positive the attitude and subjective norm with respect to a behaviour as well as greater PBC, the stronger an individual's intention to perform the behaviour under consideration. The relative importance of attitude, subjective norm, and perceived behavioural control in the prediction of intention is expected to vary across behaviours and situations. They represent an individual's motivation towards a conscious plan or decision to apply effort in performing a

specific behaviour. Performance or neglect of health behaviours are directly influenced by intentions and PBC. The stronger an individual's commitment to a behavioural intention, the more likely it will be followed through (Wilkinson & Abraham, 2004). Reviews of literature indicate that intentions are '*satisfactory predictors of behaviour*' (Ajzen, 1991, pg 179), accounting for 20-30percent of the variance in health behaviours (Sheeran & Orbell, 1998). Therefore people who have a positive intention to carry out health behaviours are more likely to do so than people who do not possess such an intention (Norman & Conner, 2006).

TPB has been utilised in previous eating behaviour research to determine the constructs of behaviour responsible for desirable or undesirable eating behaviours e.g. reducing fat intake (Armitage & Conner, 1999), skimmed milk consumption (Raats, Shepherd & Sparks, 1995), chips consumption (Towler & Shepherd, 1991), and restricted red meat consumption (Sparks, Guthrie & Shepherd, 1997). Masalu and Astrom (2001) used TPB to predict intention and self-perceived behaviour in restricting sugar consumption among Norwegian students. They found that the TPB provided significant predictions between TPB components supporting the TPB in predicting food choice-related intentions and behaviours among young adult students.



Figure 1.5 A diagram of the TPB model (Ajzen, 1991)

Despite the documented success of using the TPB to improve the uptake of healthy health behaviours it is heavily criticised for lack of understanding and research into the role of past

experience (Sutton, 1994) and it does not describe the precise details of the processes underlying food choice decisions (Armitage & Conner, 1998, 1999). In relation to healthy eating and with reference to T2DM both the HBM and PMT acknowledge the significance of past experience and offer thorough descriptions of each model component. The PMT shares concepts from the HBM and TPB, but central to PMT is the idea that fear motivates individuals to consider health behaviour change differentiating it clearly from the other two theories.

1.3.6 Other health and theory-related constructs

Unrealistic Optimism (Weinstein, 1987) explains that unhealthy behaviours are continuously practised due to inaccurate perceptions of the risks and susceptibility. There is a possibility of British-Pakistani women demonstrating Unrealistic Optimism especially British-Pakistani women without a diagnosis of T2DM. Weinstein described four cognitive factors contributing to unrealistic optimism. These are lack of personal experience with the problem, the belief that it is preventable by individuals, the belief that if the problem has not yet appeared it will not happen in the future, and the belief that the problem is infrequent. These factors suggest that one's own perception of self-risk is not a rational process and that individuals show selective focus. Weinstein also reported that individuals ignore their own risk-increasing behaviours and focus on their risk-reducing behaviours. Thus people either focus on the times they do something positive health-related rather than negative, or focus on the time others do something negative rather than themselves.

The locus of control model (Rotter, 1966) could also be useful in interpreting the data gained in this project especially among the British-Pakistani mothers with a diagnosis of T2DM as it focuses on experienced personal control over the environment. The model distinguishes between events related to one's own qualities or behaviour (internal locus of control) or circumstances outside one's own control as a result of luck, chance and fate (external locus of control). Those who feel they have control over their health are more likely to carry out health-related behaviours (Hjelm, Bard, Nyberg & Apelqvist, 2003). An external health locus

of control is associated with greater anxiety levels and young people who experience a disease that is unpredictable tend to have a greater external locus of control than healthy young people or those with a more predictable illness (Moss-Morris & Paterson, 1995, Eiser & Eiser, 1987). People often have no knowledge of when their condition may deteriorate or the different factors that can bring about disease status changes. This may have implications for the status of the diseases that are known to be stress-related and could also have implications for a multitude of psychosocial factors related to the disease such as peer relations, parental relations and functional and treatment issues (Walker, 2006).

A more popular construct that would help to explore and understand British-Pakistani women's perceptions and behaviours is self-efficacy (Bandura, 1977; 1994). Bandura defines self-efficacy as an individual's beliefs about his/her abilities to produce desired levels of performance that influence events that affect their lives. Self-efficacy determines how an individual feels, thinks, motivates his/herself and behaves. This is done via cognitive, motivational, affective and selection processes. Bandura found that people with strong beliefs in their abilities see difficult tasks as challenges to be mastered rather than threats to avoided. They set challenging goals and maintain strong commitments to them, and they quickly recover their sense of efficacy after failures or setbacks. They attribute failure to lack of effort, knowledge or skills required. In contrast Bandura reported that people who doubt their abilities refrain from difficult tasks as they perceive them to be personal threats. They have low aspirations and weak commitment to desired goals. They do not put much effort into achieving their goals and give up quickly when faced with challenges. They are slow to recover their sense of efficacy following failure or setbacks. As a result Bandura highlighted that an individual with low self-efficacy can easily become stressed and depressed, where an efficacious outlook produces personal accomplishments reducing stress and lowering vulnerability to depression.

A number of previous psycho-educational interventions are based on theoretical concepts such as self-efficacy and empowerment. Empowerment is when individuals gain control over

their own lives and become proactive with policy and change (Zimmerman & Rappaport, 1988). Key elements of empowerment include access to information, ability to make choices, affecting change in one's life, assertiveness and self-esteem (Rogers et al., 1997). The importance of empowering can be found using the example of childhood Type 1 diabetes, where mothers' sense of empowerment significantly contributes to children's treatment adherence and metabolic control (Florian & Elad 1998). Empowerment can have an impact on self-efficacy influencing our behaviours and actions. Few psycho-educational studies include health promotion or prevention. Barlow and Ellard (2004) found no reviews of psycho-educational interventions on either parents or siblings of young people with a chronic illness. They did however identify twelve reviews of interventions for children and adolescents. They found that these interventions focussed primarily on disease management (especially in asthma and diabetes) with less attention to psychosocial aspects of life with a chronic condition. Interventions incorporating cognitive-behavioural techniques on variables such as self-efficacy, self-management of disease, family functioning, psychosocial well-being, knowledge and metabolic control were effective. It is important to incorporate family members such as parents and siblings in the treatment and prevention of chronic conditions. Self-efficacy is an important concept to deal with when looking at British-Pakistani females' perceptions and beliefs in order to determine how likely they are to lead healthy lifestyles to prevent the onset of T2DM if they are not doing so already.

The PMT has been selected to examine and extract the in-depth data necessary from British-Pakistani women regarding their beliefs and behaviours towards T2DM for this project. The specific component differentiating it from other models is fear which can be used to learn about British-Pakistani women's experiences, knowledge and perceptions of T2DM. PMT also shares many components with other models e.g. intentions and self-efficacy, and exploration of the PMT constructs can provide crucial data from the participants in this project to explore the way British-Pakistani women perceive and behaviour towards T2DM.

1.4 Overarching Research Questions/Aims

1.4.1 Aims

This thesis project comprises of four studies. The first study consists a systematic review which was conducted to establish and evaluate the previous literature conducted with regard to T2DM prevention research and interventions. It is important to acknowledge and discuss previous prevention interventions and explore the reasons for non-compliance especially among British-Pakistanis.

The next two studies encompass a qualitative approach to understanding the perceptions and beliefs of British-Pakistani mothers and young females regarding T2DM. There is a need to use qualitative methodology with the British-Pakistani community to gain rich new data to develop effective prevention strategies for T2DM. The final study is a quantitative study following on from the qualitative studies, the aim of the final study was to see whether perceptions of the prevention of T2DM extracted from the qualitative studies could be generalised to a larger British-Pakistani sample and to further explore the links between prevention perception and illness perceptions.

1.4.2 Systematic Review Objective (Chapter 2)

To explore, examine and analyse previous T2DM prevention interventions and research literature to demonstrate the variety of T2DM prevention tools available and their effectiveness to prevent high risk T2DM individuals developing T2DM by changing behaviours. To also explore T2DM prevention interventions conducted with South-Asian population groups

1.4.3 Research Question 1 (Chapter 4)

What are the beliefs and perceptions of T2DM and its prevention among British-Pakistani mothers, with and without a diagnosis of T2DM, in themselves and their families especially their children?

1.4.4 Research Question 2 (Chapter 5)

What are the beliefs and perceptions of T2DM and its prevention among young British-Pakistani females?

1.4.5 Research Question 3 (Chapter 7)

Can the findings of the qualitative studies be generalised to a larger sample of Pakistani women, including similarities and differences between the illness and prevention perceptions of T2DM between British-Pakistani mothers with a diagnosis of T2DM, British-Pakistani mothers without a diagnosis of T2DM and young British-Pakistani females?

1.4.6 Research Question 4 (Chapter 7)

What is the relationship, if any, between the perceptions of British-Pakistani women on the prevention of T2DM and their perceptions of T2DM itself?

Chapter 2

Systematic Review

2.1 Introduction

Over the last few decades T2DM has been one of the major modern causes of premature mortality and morbidity worldwide (Roglic, Unwin, Bennett et al., 2005). Vigorous T2DM treatments decrease morbidity and mortality however treatment outcomes in many groups remain inconclusive (Wens, Vermeire & Hearnshaw, 2007). T2DM is common among most population groups, without any forms of effective prevention interventions and the problem continues to rise globally (Alberti, Zimmet & Shaw, 2007). As a result there is a crucial need to examine and implement prevention programmes to fight this problem.

According to recent figures Europe has approximately 187 programmes to prevent diabetes underway but fewer than 10 survived to the end of funding (Schwarz, 2012). Of the 150 million people in Europe at risk of developing T2DM, a minority are reached by prevention programmes (Smith, 2012). Previous literature has explored some T2DM prevention programmes and interventions especially targeting lifestyle and weight-loss (Davies, Tringham, Troughton & Khunti, 2004; Angelo, Huang & Carden, 2005; Norris, Zhang, Avenell, et al., 2005). Recently Gillies and colleagues (2007) conducted a review to quantify the effectiveness of pharmacological and lifestyle interventions to prevent or delay T2DM in people with IGT. They found 17 studies. They found that these interventions can reduce the risk of T2DM in people with impaired glucose tolerance, and lifestyle interventions seem to be at least as effective as pharmacological interventions. Lifestyle interventions that aim to reduce obesity and increase physical activity directly address T2DM risk factors. This systematic review goes one step forward by searching for any prevention interventions designed to target T2DM prevention and not just pharmacological and lifestyle interventions, and to also explore any prevention interventions using South Asian ethnic groups.

2.1.2 T2DM and the associations with other chronic illness and risk factors

Individuals diagnosed with T2DM have a higher risk of coronary heart disease (CHD), cerebrovascular and peripheral vascular disease, and some cancers compared to the rest of the population (Wens, Vermeire & Hearnshaw, 2007; Ogden, 2004). T2DM shortens life expectancy by an estimated 12–14 years (Manuel & Schultz, 2004). It is important to research T2DM with its associations with other chronic illnesses in this review in order to search for any potential studies that can be added and examined for effective prevention resources.

T2DM is especially linked to being overweight (Hartemink, Boshuizen, Nagelkerke, et al. 2006; Ratanasuwan, Indharapakdi, Promrerk, et al., 2005; Weinstein, Sesso, Lee, et al, 2004). Naser, Gruber and Thomson (2006) found that obesity is strongly associated with the developing and worsening of T2DM. The WHO (2006) estimated that there are over 1.1 billion people who are overweight and by 2015 they expect this total to rise to over 1.5 billion. The recognised average relative risk for T2DM is approximately 1.18 per unit increase in body mass index (BMI) (Hartemink, et al. 2006) however several studies indicate that the impact of BMI on diabetes incidence is greater when measuring BMI more proximal to diabetes outcome compared with earlier remote measures (Oguma, Sesso, Paffenbarger, et al., 2005; Koh-Banerjee, Wang, Hu, et al., 2004). Jacobs-van der Bruggen and colleagues (2010) tried to clarify the role of weight-change as a risk factor for T2DM by assessing the relationship between weight-change and diabetes incidence conditional upon either initial or attained BMI. They used 7,837 observations available from repeated measurements of 4,259 participants (men and women aged 20–59 years) in the Dutch Doetinchem Cohort Study (1987–2007) to analyse the association between five year weight-change and diabetes incidence in the subsequent five years. When adjusted for initial BMI, five year weight-change was a significant risk-factor for diabetes however no significant association was found between weight-change and diabetes if the association was adjusted for attained BMI. Jacob-van der Bruggen et al.'s findings suggest that weight-change is associated with

diabetes incidence as weight change determines attained BMI. They suggested that lifestyle interventions can contribute to diabetes prevention because they affect attained BMI. WHO (2006) also found that interventions focusing on reducing obesity reduce the incidence of T2DM.

2.1.3 T2DM and genetics

T2DM is caused by a combination of genetic and lifestyle factors (Alberti, Zimmet & Shaw, 2007). There are genes that predispose an individual to diabetes and these are activated via the interaction of environmental and behavioural factors particularly those associated with lifestyle (Stumvoll, Goldstein & Van Haeften, 2005). Alberti and colleagues (2007) stated that it is not yet possible to definitely identify the genes which relate to susceptibility to T2DM however the differences between ethnic groups exposed to similar environments supports a significant genetic link. Pregnancy and early childhood influences also play a role (Tuomilehto, Lindstrom & Eriksson et al., 2001; Roos, 2002). The prevalence and risk of T2DM also increases with age. The age of onset has moved down into younger adults and even adolescents and children recently (Feltbower, McKinney, Campbell, et al., 2003). The most dramatic increases in T2DM have occurred in populations where there have been rapid and major lifestyle changes, including changes in diet and reductions in physical activity with consequent increases in being overweight (Zimmet, 2001). This may explain why South-Asians have the highest prevalence rates of T2DM in the UK (Lawton, Ahmad, Hallowell, et al., 2005).

Previous research has highlighted that that South-Asian adults are a high-risk T2DM developing group as they are more insulin resistant with increased levels of body fat and visceral fat deposition at lower BMI levels (Ehtisham, Crabtree, Clark et al., 2005, Banerji, Faridi, Atluri, Chaiken & Lebovitz, 1999). Banerji and colleagues reported that the distribution of visceral fat may be a more important determinant of insulin resistance, diabetes, and CHD than BMI obesity indicator. They conducted a study in America to

research this and found that South-Asian have an unexpectedly high percentage of body fat relative to BMI and muscle mass which is associated with a proportionate increase in visceral fat. Insulin resistance and fasting serum leptin levels correlated with total visceral adipose tissue volume. Therefore the anthropometry between different racial populations may result in misleading conclusions about body composition, and this offers an explanation to why there is an increased CHD and diabetes risk in South-Asians.

2.1.4 T2DM and lifestyle

T2DM prevention interventions aim to achieve and maintain a healthy body weight through dietary and physical activity measures in individuals who already have impaired glucose tolerance (IGT) from a high-risk group (Alberti, Zimmet & Shaw, 2007). Dietary recommendations emphasise the reduction of fat intake and an increase in vegetable consumption. There is strong evidence to illustrate the benefits of healthy eating for those with T2DM in a range of settings using many different approaches to promote dietary change ranging from a prescriptive approach to a patient-centred empowerment approach (Povey & Clark-Carter, 2007). However there is still a lot of uncertainty surrounding the dietary factors involved in developing diabetes due to the limitations of collecting accurate dietary data (Hu, Manson & Stampfer et al., 2001).

Physical activity reduces the risk of T2DM by 30% in the general population (Bassuk & Manson, 2005). The risk of mortality amongst individuals with diabetes is also related to fitness level (Church, Cheng & Earnest et al., 2004; Hu, Willett & Li et al., 2004). Physical activity recommendations are usually 30–40minutes of moderate physical activity, varying between high-intensity and resistance training exercise, on five days of the week (Zimmet, 2001). The promotion of physical activity ranges from providing exercise goals and tips on how to increase daily physical activity to providing weekly supervised exercise training sessions (Valsania & Micossi, 1994).

2.1.5 Tailoring T2DM prevention interventions

There is growing evidence that T2DM prevention interventions can clinically reduce diabetes incidence, and its complications and co-morbidities in people with IGT and those in high-risk populations. The International Diabetes Federation's plan (Alberti, Zimmet & Shaw, 2007) for the prevention of T2DM was based on controlling modifiable risk factors in two target groups: people at a high risk of developing T2DM and the entire population. The IDF group believed that planning national strategies for the prevention of T2DM should target both population groups simultaneously. They also believed it is important to tailor all resources to specific local situations.

People of South-Asian origin form large population groups in many countries around the world and they have one of the highest T2DM prevalence rates (Khunti, Stone & Bankart et al., 2007). South-Asians are the second largest ethnic group in Birmingham (BEN PCT annual report 2007-08). This is a significant statistic as Lawton et al. (2005) found that T2DM is four times more common among the South-Asians in Britain than in the general population. There is also a higher prevalence of T2DM rates in South-Asians in Britain compared to South-Asians in South-Asian countries (Pardhan & Mohammed, 2004) due to their sedentary lifestyles and changes in diet. In Birmingham (UK), the community-based glucose tolerance testing service identifies more people with IGT (BEN PCT Annual Report 2007-08). The programme encourages people to improve their lifestyles in order to delay or prevent the development of T2DM. Assessing people's risks of developing illnesses like T2DM using screening methods such as measuring blood pressure or taking family histories has formed a vital part of the healthcare service for over 40 years (Shaw, Abrams & Marteau, 1999).

Khunti, Camosso-Stefinovic, Carey, Davies and Stone (2008) conducted a systematic review to determine the range of assessed educational schemes for South-Asians with T2DM living in Western societies and to consider their effectiveness. They too highlighted the difficulty of

designing, assessing and achieving an impact through educational interventions for T2DM South-Asians and emphasised the need for good-quality studies in these high-risk populations. Morris (2002) reported that people with T2DM find it difficult to follow treatment and lifestyle advice hindering their diabetes management. Diabetes education is recognised as important as it supports T2DM sufferers to acquire and use skills through which they can become empowered to take responsibility for daily self-management (Khunti et al., 2008). This is supported by The National Institute for Health and Clinical Excellence (NICE) which recommends that all T2DM patients be offered structured education (NICE, 2003) and the National Service Framework for Diabetes advocates patient empowerment through education and self-management (Department of Health, 2001).

During the last decade promising results have been reported from the Turin study (Trento, Passera, Borgo, et al., 2004), the XPERT programme (Deakin, Cade, Williams & Greenwood, 2006) and DESMOND (Davies, Heller, Campbell, et al., 2008) thus improving the effectiveness of educational programmes; the importance of which should be recognised especially within high-risk ethnic groups in order to develop T2DM educational initiatives aimed at improving outcomes (Department of Health, 2003). Khunti et al. highlighted the difficulties linked with language, literacy, beliefs and practices relating to health and culture which can present barriers as well as funding and delivery limitations to developing appropriate educational programmes..

2.1.6 Conclusion

Many RCTs and community programmes are being conducted and organised to help deal with the diabetes epidemic however a lot more needs to be done due to the magnitude of this problem. It is also important to identify which prevention programmes are working to allow for significant practical measures to be made. The aim of this review was to explore and analyse previous T2DM prevention interventions. A strict methodology was followed to gain specific relevant studies.

2.1.7 Systematic Review Objective

To explore, examine and analyse previous T2DM prevention interventions and research literature to demonstrate the variety of T2DM prevention tools available and their effectiveness to prevent high risk T2DM individuals developing T2DM by changing behaviours. To also explore T2DM prevention interventions conducted with South-Asian population groups.

2.2 Method

2.2.1 Search Strategy

Using a search strategy helped deal with the volume of potential studies and databases which needed to be explored. As there were two main areas to research, T2DM and Pakistani population group, the keywords were divided. The primary terms were *diabetes* or *type 2 diabetes* or *obesity* and *prevention* or *intervention*, and the secondary terms were *South-Asians* or *ethnicity* or *Pakistani*. Obesity was used as a keyword as obesity research overlaps with T2DM research, and a large volume of literature integrates both areas of research. In order to identify the relevant research and literature 13 electronic databases were searched: PsycArticles (12th February 2008), MetaPress (12th February 2008), IngentaCONNECT (12th February 2008), ScienceDirect (21st February 2008), EBSCO (21st February 2008), Oxford University Press Biomedical Collection (OUPBC; 2nd March 2008), Swetswise (2nd March 2008), PubMed (2nd March 2008), ISI Web of Science (ISIWeb; 17th March 2008), International Bibliography of Social Science (IBSS; 17th March 2008), The Cochrane Library (5th April 2008) and Google Scholar (5th April 2008). A replicate search was conducted again (16th April 2011) to check for any new studies that have been added on the 13 electronic databases. Due to a large number of studies found, limitations were added to the search criteria which were applied electronically particularly in order to remove duplicate copies (OUPBC, IBSS), use English language only (IBSS, MetaPress, and PubMed), journals only (OUPBC, IBSS, MetaPress, and PubMed) and humans only articles (IBSS, PubMed). In order to add more potential articles which were not retrievable via the search databases authors and researchers from article titles and abstracts could have been contacted. A few attempts were made but due to no responses this approach was abandoned.

2.2.2 Selection Criteria

Abstracts were included if they were from original experimental studies to explore a prevention intervention for T2DM and/or measures associated with risk factors (e.g. obesity), used a control group, used a human population sample, used quantitative methodology, including descriptive data, and were published in the English language only (for the author's understanding). Articles were excluded if they were epidemiological studies or reviews, there was no control group, they used an animal population sample, measured health behaviours not associated with T2DM (e.g. AIDS/HIV), lacked data (descriptive or analytical results), were published in any language other than English, and used a qualitative or a mixed methodological approach. Mixed methodological studies were excluded as it would be uninformative to judge a study on the quantitative results only when it was important to use both quantitative and qualitative research methods to reach conclusions. These inclusion/exclusion criteria were used to compile a list of relevant articles and are tabulated in Table 2.1).

All the abstracts identified through the database searches were read and a decision was made on whether or not they were applicable for this review. Articles were rejected if one of the exclusion criteria was met. On finalising the relevant selection full-text articles were retrieved. Full-text articles were then examined against the inclusion criteria. Again articles were rejected if one of the exclusion criteria was not met. The included studies represent the current prevention interventions that have been used for T2DM and obesity control, as well as highlighting data that have been collected from a sub group of South-Asian. The population groups included in this review either had a diagnosis of T2DM or were at high-risk of developing the disease. The T2DM group were included as the prevention interventions used for secondary prevention of complications are likely to be similar to those for primary prevention of the condition in those at high-risk.

	Inclusion	Exclusion
Study Group	Control group	No control group
Type of intervention	Prevention	Exclude others
Study population	Humans	Animals
Purpose of intervention	Primarily for T2DM but can also measure associated risk factors, i.e. CHD and obesity	Health behaviours not associated with T2DM, e.g. AIDS/HIV
Participant information	Demographic details, i.e. SES, age, gender, ethnicity	Lack or no demographic details
Geographic location	Any published in the English language	Any published in non-English language
Duplicate copies	Include only one copy	Exclude others
Literature	Quantitative	Qualitative or mixed methodology
Research	Original experimental journal articles	Epidemiological articles, reviews and book chapters

Table 2.1 Inclusion/exclusion criterion of journal article selection for systematic review

2.2.3 Quality Assessment

Each eligible prevention intervention journal article was quality assessed against a comprehensive checklist (see table 2.2). The checklist refers to 12 distinct items that assess the quality of randomisation, concealment of allocation, sample size, masking and completeness of trial. Quality assessments highlight potential biases within a study and are a good tool to use for appraising methodological quality (Bridle, Pattenden, Sowden, Mather, Watt & Walker, 2005).



Table 2.2 Quality assessment checklist for potential articles to be used in the systematic review (Bridle, Pattenden, Sowden, Mather, Watt & Walker, 2005)

2.2.4 Data Extraction

A thorough search strategy and selection criteria yielded a list of 197 eligible articles. The eligible articles were assessed for quality using the quality assessment process. No studies were excluded on the outcome of their quality. The process was done to only assess the quality of the articles. Each article was analysed systematically and methodologically by the author. During this process no further articles were removed. Data were extracted from eligible articles using a data extraction form (see Appendix 2.1), and placed in a table for analysis (see table 2.3 in the results section). The data were divided into 5 main categories; study, setting, method, prevention intervention, results and outcomes. Strengths and weakness of the studies were noted as well as any possible confounding biases or variables.

2.2.5 Study Characteristics

Descriptive data, methodology and outcomes were extracted from the final eligible studies. Descriptive data (including participant information i.e. age, gender and diagnosis) and methodology explored the design and format of the study, and outcomes summarised the statistical and overall results of the studies. On completing data extraction the main outcomes emerged. These outcomes formed the basis of T2DM preventative research.

2.2.6 Meta-analysis

Meta-analysis was conducted on the three main outcome measures from the eligible studies in this review: diet, physical activity and BMI. Effect sizes were used for the analyses. Where effect sizes were not given, means and standard deviations were used to calculate effect sizes, however if standard deviations were not reported then confidence intervals were used and the appropriate calculations conducted.

2.2.7 Data Synthesis

Data from the studies were compared in three ways. Firstly the studies were compared by the characteristics of those studies that produced statistically significant results with those that did not. Secondly data were compared by studies that recruited participants with T2DM to prevent complications with those at high-risk of developing the disease. Finally the data were compared according to the category of intervention used: lifestyle (targeting behaviour and information on diet and exercise) compared with others (studies targeting pharmacological approaches, motivation etc.).

2.3 Results

2.3.1 Study Flow

Initially the total number of potential relevant articles identified from all the databases after screening titles and abstracts was 197 (PsycArticles, MetaPress, 36; IngentaCONNECT, ScienceDirect, 34; EBSCO, 4; OUPBC, 15; Swetswise, 3; PubMed, 16; ISIWeb, 2; IBSS, 19; The Cochrane Library, and Google Scholar). From the 197 abstracts, 135 abstracts were rejected on the basis of relevance, duplicate copies and the other exclusion criteria. Sixty-two articles were retrieved for analysis and evaluation. A further 15 articles were removed as they did not fulfil the inclusion criteria. (Please refer to Appendix IV for a full list of the articles and reasons for why they were either included or excluded). Figure 2.1 illustrates the study flow.

From the 62 articles retrieved, a total of 47 articles were excluded. This was a surprisingly high proportion. However after further analysis of the excluded 47 articles, it became apparent that a justification for this high number was not due to relevance of the articles but due to the lack of information needed for analysis. These articles did not include fundamental quality measurements such as details on whether studies used a control sample, whether participants were randomly allocated into groups, drop out rates, etc. The original designs of the studies may have accounted for these factors, but details were not quoted so therefore these articles were excluded. On replication of the article search in April 2011, a further 39 potential relevant articles were identified from all the databases and were retrieved for analysis and evaluation. Thirty-four articles were rejected on the basis of relevance, duplicate copies and as they did not fulfil the inclusion criteria. (Please refer to Appendix IV for a full list of the articles and reasons why they were either included or excluded). Many of the excluded articles did not report the results of the interventions as they are currently under investigation, thus authors had only provided details of the methodology and recruitment procedures.

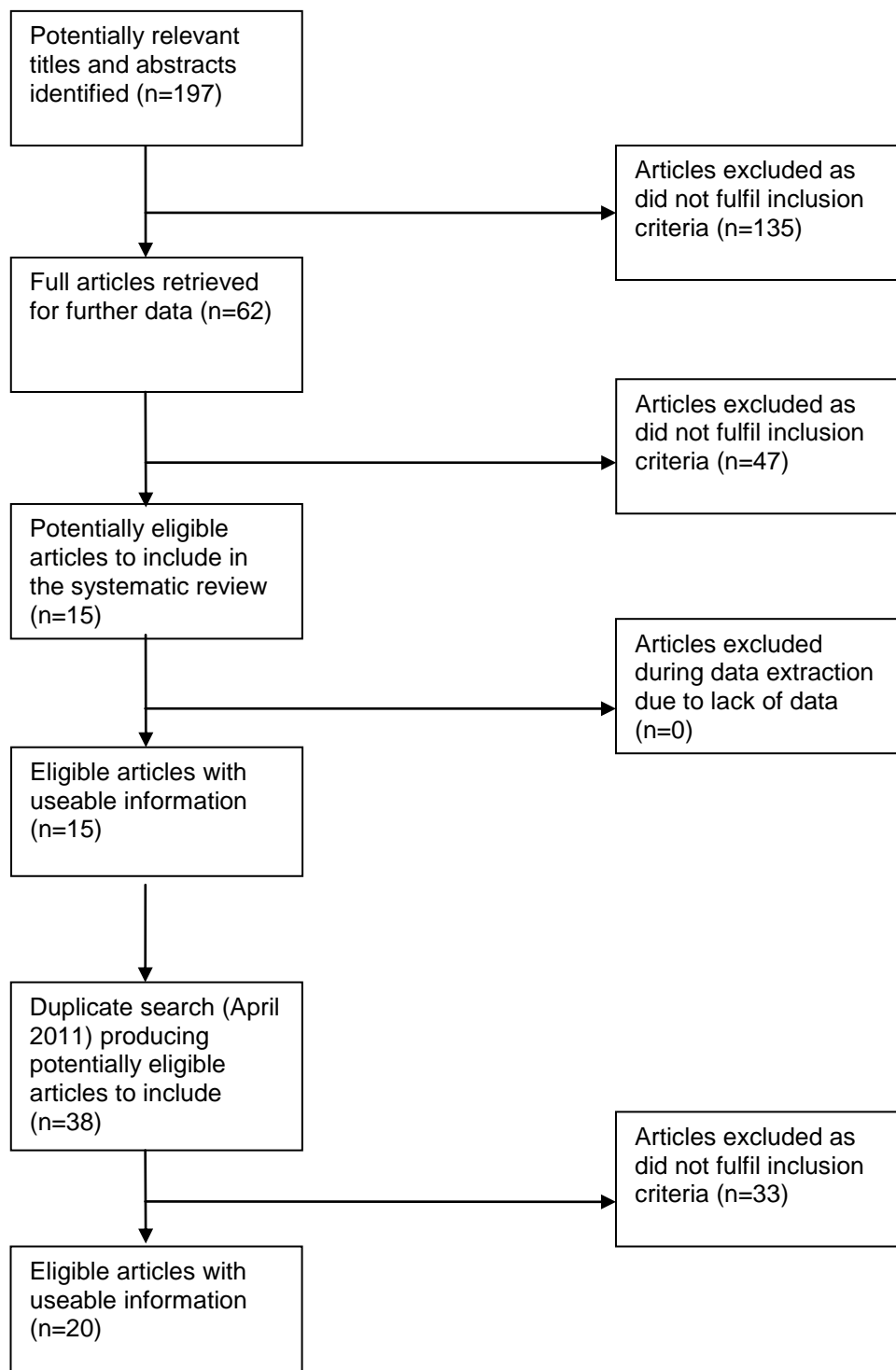


Figure 2.1 Flow chart illustration of article selection for systematic review. Please refer to appendix 2.3 for explanations of the excluded articles

2.3.2 Study Characteristics & Data Extraction

A total of 12,419 participants took part in the 20 studies in this review. Seven of the studies took place in UK, five in USA, three in Finland, two in the Netherlands, two in Japan and one

each in Canada, India and Sweden. Most studies provided descriptive details of participants e.g. gender, ethnicity and age. Hardeman et al. (2009) and Kinmonth et al. (2008) were the only studies which did not provide demographic details apart from the age range of the participants used. However they did provide full details on the recruitment procedure. Out of the 20 studies, nine provided details on the ethnicity of the participants (Baradaran et al., (2006); Carels et al., (2007); DPP Research Group, (2005); Gregg et al., (2007); Orchard et al., (2005); Kosoka et al., (2005); Ramachandran et al., (2006); Sakane et al., (2011); Warren et al., (2003)). The remaining 11 studies gave the impression that a sample of white western individuals was used, as authors mentioned the population area being white middle-class and/or gave the demographic places in which the research was conducted. Only two studies recruited South Asian participants (Baradaran et al., 2006; Ramachandran et al., 2006) therefore it was not feasible to conduct a separate synthesis on T2DM prevention interventions for South-Asians. Follow up and dropout rates were stated in the studies except the DPP Research Group (2005) and Siitonen et al. (2004) studies however the follow up/dropout details were stated in previous articles submitted by the authors.

Baseline measures were initially taken preceding follow up readings. The shortest follow up was taken an hour after baseline, and the longest was seven years. Nine studies only conducted one follow up; five studies at 1 year point, two at 6 months, one at nine weeks, and another at 2 weeks. Three studies used two follow up intervals; one study used 1 hour and 3 months intervals, two studies used 6 and 12 months, and one study used 1 and 2 year interval follow ups. Five studies used several intervals over 3 years, one study used intervals over four years, two studies conducted follow ups between 3 and 5 years, and finally one study conducted two follow ups at year 4 and year 7. In total approximately 37% of participants dropped out of the 20 studies. Glasgow et al. (2007) had the highest drop out rate with 52% and Carels et al. (2007) had the lowest with only 16% drop out rate. Lakshman et al.'s study (2010) and Warren et al.'s study (2003) used children and consent was gained from their parents and schools. The remaining 18 studies used adults.

All the prevention interventions aimed to measure the main health behaviours that affect the development and onset of T2DM i.e. diet and exercise. Other physical and psychosocial measurements were also taken, but were not the primary outcome factors under investigation in this review. Different data collection tools were used from self-reported questionnaires to physical health measurements (e.g. blood pressure, BMI, weight, etc.), depending on the health behaviour being assessed. A range of statistical tests were used for data analysis. All the studies used in this review were quantitative studies therefore statistical results were yielded for every investigation. The studies used a combination of different tests to analyse findings, parametric and non-parametric tests.

Overall enough information was retrievable from the 20 articles in this review regarding the prevention interventions to replicate them. From the 20 articles 13 prevention interventions were theory-based (Baradaran et al., (2006); Carels et al., (2007); DPP Research Group, (2005); Glasgow et al., (2007); Gregg et al., (2007); Hardeman et al., (2009); Kinmonth et al., (2008); Lakshman et al., (2010), Lindstrom et al. (2003; 2006); Sakane et al., (2011), Simmons et al., (2008), Venmans et al., (2007)). This was not an explicit requirement of the prevention interventions however this indicates strong theoretical underpinnings to help explain the success of theory-based interventions (if successful).

Type of Intervention	Number of Studies Assessing It	Number of Statistically Significant Studies	Percentage of Statistically Significant Studies
Counselling	3	1	33%
Dietary / Nutrition Advice	6	5	83%
Education	4	2	50%
E-Health	1	0	0%
Exercise Promotion	11	7	63%
Pharmaceutical Approach	4	3	75%
Weight Loss Emphasis	8	8	100%

Table 2.3 Statistical significance of prevention interventions used in the review

2.3.3 Outcome Measures

The main outcomes measures that emerged were recorded in Table 2.4.

Type of outcome	Specific measure	No. with statistically significant result/No. of studies assessing it
Knowledge	T2DM knowledge ^a	1/3
	Nutrition knowledge	2/2
	Understanding	0/1
	Knowledge of compliance & practice	2/2
Dietary intake	Fat	22/23
	Kcals	1/2
	Fibre	3/5
	Protein	1/2
	Cholesterol	1/2
	Carbohydrate	1/3
	Fruit	1/1
	Vegetables	1/1
	Confectionary/crisps	0/1
	Alcohol	0/3
	Overall nutrition intake	0/1
Lifestyle behavioural change	Dietary self-care/assessment	2/2
	Adherence to healthy diet and lifestyle change ^b	0/3
	Parental diet	0/1
	Physical Activity/exercise ^a	8/10
	Physical and Activity Energy Expenditure ^a	2/3
	Smoking	0/2
	Overweight/obesity	1/2
	Parental physical activity	0/1
Clinical improvement (non-invasive)	Weight ^a	8/12
	Body mass index	4/8
	Blood pressure ^a	5/10
	Body fat ^a	3/5
	Waist circumference	4/10
	VO2max ^a	3/4
Internal physiological biochemical & genetic	HbA1c ^a	4/6
	Fasting plasma glucose ^b	10/18
	Lipids	1/4
	Cholesterol	8/16
	Insulin ^b	5/8
	Fasting insulin	3/5
	HOMA-IR	2/1
Genotypes	1/3	
Other	Attitudes towards seriousness & T2DM ^b	1/4
	Intention to be more active	5/6
	Well-being ^a	1/2
	Acceptability of information/advice	1/1
	Perceived risk ^a	1/2
	Anxiety ^a	1/2
	Satisfaction of treatment	1/1
	Measures of TPB cognitions	1/1

Table 2.4 Main outcome measures from the 20 studies in this review

a One of the studies assessing this outcome measure did not report the result

b Two or more of the studies assessing this outcome measure did not report the results

Table 2.5 Description of the T2DM prevention intervention studies used in the review

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Baradaran, Knill-Jones, Wallia & Rodgers, (2006)	Day care centres and 3 GP surgeries in Glasgow, UK	145 participants with T2DM were recruited, 118 South Asians (85 Pakistanis & 33 Indians) who were randomized into 2 group (intervention & control) and 27 Whites who formed a separate control group, age range 31-93years (mean age 58.4years), mean duration of T2DM 8.5years, 51% male, follow up at 6months, 44 dropped out / lost to follow up	The intervention group were exposed to 18 educational sessions in 6 separate programs based on group education regarding T2DM, and both the ethnic and white control groups received routine care. A modified questionnaire was used to measure the knowledge, attitudes, and practice of diabetes at baseline & follow up. KAB was used as the theoretical underpinnings of the study	T2DM knowledge, attitudes and practice	The intervention group significantly increased in knowledge (p=0.04), attitudes towards seriousness (p=0.005), control of diabetes (p=0.05, and positive T2DM practice (p=0.005). In the ethnic control group the only significant difference were in attitudes towards seriousness (p=0.001). In the white control group there was a significant increase in attitudes towards seriousness (p=0.04) and practice of T2DM (p=0.007). There were improvements demonstrated in the intervention group compared to ethnic control group and greater change in the white control group compared to the ethnic control group, but no statistically significant differences	The intervention was not successful. The effectiveness of the intervention is debatable. Although clear improvements in T2DM knowledge, attitudes and practice were highlighted in the intervention group, improvements also occurred in both the control groups and no clear evidence was gained in the intervention group's favour

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Brekke, Jansson & Lenner, (2005)	Goteborg, Sweden	77 participants (male & female) without T2DM who had first-degree relatives with T2DM were recruited and randomly allocated into one of 3 groups (diet, diet & exercise and control), age range 25-55, they were followed up after 1 and 2 years, 13 dropped out / lost to follow up	The diet (D) group were given dietary counselling aimed at reducing saturated fat and high glycaemic index (GI) foods, and increasing the intake of monounsaturated fat, n-3 fatty acids, vegetables, fruits and low GI foods. The diet & exercise (DE) group received exactly the same dietary counselling and were also told to increase their physical activity levels. The control (C) group received a letter informing them that they should continue their normal lifestyle and would receive lifestyle intervention 1 year later	Lifestyle	Dietary changes were significant between most of the nutrient measurements between groups D & C, and DE & C but not between D & DE at both 1 & 2 years follow ups. There was no difference regarding physical activity between any of the groups. The only significant differences between groups D & DE were that at 2 years follow up cholesterol levels were reduced within group D compared to DE ($p < 0.05$), and fasting insulin was reduced within group DE compared to D ($p = 0.025$)	The intervention was successful. T2DM can be prevented in individuals who are at risk of developing T2DM by positive changes to their lifestyle, diet, blood lipids and fasting insulin

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Carels, Darby & Cacciapaglia (2007)	Bowling Green, Ohio, USA	55 obese sedentary individuals were recruited and randomly assigned into one of 2 groups (intervention & control), 24 weeks study duration, 87% female, 92% white, 69% married, 44% professionals, 9 dropped out/lost to follow up	The intervention group received a behavioural weight loss program with step care (BWLP + SC). This group received motivational interviewing (MI). The control group (BWLP) only received BWLP with no MI. The BWLP was based on the LEARN program, which encourages gradual weight loss, to increase physical activity, and decrease energy and fat intake through permanent lifestyle changes. Step-care approach and motivational interviewing were used as the theoretical underpinnings of the study	Weight loss	There were significant pre to post-treatment decreases in body weight ($F(1, 53)=45.3, p<0.01$) daily caloric intake ($F(1, 48)=20.71, p<0.01$); and percentage daily energy from fat ($F(1, 48)=8.77, p<0.01$) but no significant difference in weight loss ($F(1, 53)=2.0, p= 0.08$) between the BWLP + SC and BWLP groups	The intervention was successful. BWLP + SC (MI) participants lost significantly more weight and undertook significantly greater physical activity, therefore MI maybe very effective for individuals experiencing weight loss problems

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Corpeleijn, Feskens & Jansen et al. (2006)	Maastricht, Netherlands	147 participants with IGT were recruited and then randomised into 2 groups (intervention & control), 1 year follow up, 50 dropped out/ lost to follow up	The lifestyle intervention group received individualised dietary advice and were promoted to carry out specific physical activities, whereas the control group were only given oral and written information regarding the benefits of a healthy diet, weight loss and increased physical activity	Lifestyle measures i.e. diet, physical activity, BMI, insulin sensitivity	Although the intervention group lost more weight and illustrated positive changes across the different lifestyle measurements compared to the control group, no significant statistical data was found except for an increase in certain serum fatty acid profiles significantly correlated with a decrease in insulin resistance ($p < 0.05$)	The intervention was not successful although the importance of lifestyle on T2DM as it illustrated that the intervention programme effectively reduced the intake of total & saturated fat and obesity, increased physical activity, and improved insulin sensitivity and IGT

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Diabetes Prevention Programme (DPP) Research Group, (2005)	USA	3,234 participants were recruited who were at high risk of developing T2DM and they were randomised into one of three groups (placebo, metformin and lifestyle), 68% female, 55% white, 20% African-Americans, 16% Hispanic, 5% American-Indian, 4% East Asian American, average age 50years, follow up over 3 years	This programme investigated insulin sensitivity and insulin secretion to determine the transition from IGT to T2DM in order to delay or prevent the onset of diabetes. Participants received standard advice on healthy eating and physical activity. The lifestyle group were also set a goal of 150 minutes of physical activity a week, the metformin group were given 850mg of metformin to take twice a day, and the placebo group were given 850mg of placebo to take twice a day	Body-weight, Insulin sensitivity and insulin secretion	Risk reduction of developing diabetes was 30% for metformin and 55% for lifestyles each compared to placebo. The diabetes risk associated with lifestyle exceeded that with metformin by 37%. The lifestyle group had the greatest improvement in insulin sensitivity ($p<0.001$) and this was associated with decreased insulin secretion ($p=0.008$). There was also an improvement in the metformin grouping insulin sensitivity ($p<0.001$) with a significant decrease in insulin secretion ($p<0.001$). There was a non-significant change to insulin sensitivity but there was a significant decrease in insulin secretion ($p=0.03$) for the placebo group	The intervention was successful. Insulin sensitivity and insulin secretion predict the development of T2DM in high risk individuals. Lifestyle interventions are more successful at doing this compared to metformin and placebo methods, which may be due to improved insulin sensitivity associated with the preservation of β -cell function

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Glasgow, Nelson & Kearney et al., (2007)	Ohio, Colorado, Washington state and Idaho, USA	2,311 participants were recruited who were either overweight or overweight with a chronic condition (909 of these participants), randomised into 4 groups, 54% over 60years of age, followed up after 12 months, 52% dropped out / lost to follow up	This was an internet mediated weight loss program with four intervention groups: 6-week balance weight loss program alone (1), balance plus 8-week nutrition management module nourish (2), balance plus a simultaneous goal-setting component called achieve (3) or balance plus nourish and achieve (4). Self-efficacy was used as the theoretical underpinnings of the study	Weight loss	Majority of participants who enrolled were non-smokers and females who had low risk scores ($p < 0.001$), older participants ($p < 0.001$) and those with higher baseline motivation levels ($p = 0.04$) were more likely to engage with the program, African Americans ($p = 0.03$) and those with higher baseline self-efficacy scores ($p = 0.003$) were less likely to be engaged on an ongoing basis. Younger participants and those who had higher baseline levels of self-efficacy were less likely to participate in the follow-up. There were no significant effects of intervention type on data analysed	The intervention was not successful. This study had great potential to demonstrate the most significant eHealth base program for T2DM prevention, however emphasis was taken on exploring recruitment, engagement and retention

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Gregg, Callaghan, Hayes & Glenn-Lawson, (2007)	Low-income community health centre in San Francisco, USA	81 participants with T2DM were recruited from low SES group, and randomly allocated into one of 2 groups (control & intervention), 46.9% female, mean age 50.9 years, range of different ethnic backgrounds, followed up after 1hr and 3months, 15 dropped out / lost to follow up	The intervention group consisted of a one-day workshop with a combination of education and acceptance & commitment therapy (ACT), whereas the control group attended an education only workshop on managing T2DM. CBT was used as the theoretical underpinnings of the study	Coping strategies and attitudes	5 variables were analysed; the intervention group significantly different in self-management ($p<0.05$), acceptance & action ($p<0.001$), and glucose control ($p<0.01$) from the control group, however there was no significant differences for blood glucose levels and understanding between both groups.	The intervention was success as ACT improved self-management of T2DM and diabetic control are

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Hardeman, Kinmonth & Michie et al, (2009)	Cambridge and London, UK (Proactive UK)	365 participants who had a parental history of T2DM without known diabetes were randomly assigned into 3 groups (face-to-face intervention, distant intervention & control), 6 months and 1 year follow up, mean age 40.6 years, 55% in managerial or professional jobs, 62% female, 75% lived with children, 52% strong intention to increase their physical activity, 44 dropped out/lost to follow up	All participants were given a theory-based leaflet emphasising on the benefits of physical activity and advising them to increase their activity. Theory of planned behaviour (TPB) was to elicit changes in the intervention groups. The face-to-face intervention consisted of 4 home visits and two telephone calls in the first 5 months followed by monthly telephone calls. The distant intervention group included 6 telephone calls in the first 5 months followed by monthly postal contact. The control group received only the advice leaflet and no further support.	Physical activity	At baseline all three groups demonstrated intentions to increase their physical activity. After 6 months both intervention arms reported increased physical activity compared to the control group (d=.32). The TPB constructs also yielded significant outcomes in the intervention arms. After 12 months the interventions did not change perceived social pressure to increase physical activity.	The intervention was not successful as there was only a short-term improvement on physical activity in the intervention groups compared to control. Targeting affective benefits and addressing barriers to physical activity may strengthen intentions, but stronger intentions did not result in more behaviour change.

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Kinmonth, Wareham & Hardeman et al., (2008)	20 general practice clinics in the UK (Proactive UK)	365 participants who had a parental history of T2DM without known diabetes were randomly assigned into 3 groups (intervention by telephone, intervention by person & control), 1 year follow up, mean age 40.6 years, 55% in managerial or professional jobs, 62% female, 75% lived with children, 52% strong intention to increase their physical activity, 44 dropped out/lost to follow up	All participants were sent a leaflet with brief motivational advice on the benefits of increased activity. Intervention by telephone group consisted of a behavioural change programme delivered by a facilitator over the telephone (distance), intervention by person group was the same programme but delivered in the home (face to face) and there was a control group (advice). The comparison group received only the advice leaflet and no further support. TPB was used as the theoretical underpinnings of the study	Physical activity	There was no statistical differences between the intervention groups or the control group ($p=0.29$). Face-to-face method showed no advantage over telephone method. Over 12 months, the physical-activity ratio increased in all participants by an average of 0.11 (95% CI 0.05–0.18). The intervention did not affect worry about diabetes or perceived risk of diabetes, nor did it affect psychosocial or self-reported health. Intention to be more physically active was not stronger in the treatment group than in the control group at the end.	The intervention was not successful as it highlighted that a facilitated theory-based behavioural intervention is no more effective than an advice leaflet for promoting physical activity in an at-risk group of T2DM

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Kosoka, Noda & Kuzuya, (2005)	Outpatient clinic in Toranoman Hospital, Tokyo, Japan	458 males with IGT were recruited and randomised in 4:1 ratio into two groups (intervention & control), 80% government Japanese employees aged between 30-70, 42% had family history of T2DM, average BMI of 24, followed up for 4 years, 39 participants dropped out of the study during follow up years	Participants were informed of the risks of T2DM, leading a healthy lifestyle especially to avoid weight gain and obesity, and to maintain a BMI of 22kg/m ² . The intervention group was set objectives and these were repeated every 3-4 months at each hospital visit which included food advice, nutrition advice, reduce alcohol intake, not to eat more than once a day, special instructions on snacks and fruits, physical activity promotion	Lifestyle measures i.e. diet, physical activity, BMI	The overall incidence of T2DM in the intervention group during the 4years was 3% which was significantly less than the control group (9.3%), therefore there was a reduction in T2DM development of 67.4% in the intervention group. In the intervention group the rate of improved glucose tolerance from IGT to non-IGT was 54% compared to 34% in the control group (p<0.001).	The intervention was successful as it was individualised according to current lifestyle of each of participant to achieve the optimal BMI. It resulted in significant decreases in body weight as well as cumulative T2DM incidents. Increased weight within the control group was the main reason for the increased incidences for T2DM

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Lakshman, Sharp & Ong et al, (2010)	Primary schools in Cambridgeshire, UK	38 schools were recruited (2,519 children), aged 9-11 years, schools randomised into two groups (Intervention & control), 9 week follow up, 23 schools dropped out (1,386 children)	The control groups used the existing health eating curriculum in schools. The intervention group were taught the health eating curriculum using a card game developed 'Top Grub' based on the popular children's card game 'Top Trumps'. The aim is to win all the cards in the game. The cards were also used and integrated in the different parts of the curriculum. A questionnaire was developed and used to assess the nutritional knowledge at baseline and follow up. KAB was used as the theoretical underpinnings of the study	Nutrition knowledge	The mean nutrition knowledge scores was higher in the intervention schools (28/36) compared to the control schools (27/36), but both groups increased their knowledge compared to baseline (intervention group = 28.3-29.2, control group = 27.3-27.6)	The intervention was not successful. Although nutrition knowledge increased the ability to identify healthier foods did not improve.

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Lindstrom, Eriksson & Louheranta et al., (2003)	Research centres in Helsinki, Kuopio, Turku, Tampere & Oulu (part of the Finnish Diabetes Prevention Study), Finland	522 overweight, middle aged participants were recruited who were at high risk of developing T2DM due to IGT, they were randomised into one of 2 groups (control & intervention) and monitored over 3 years, 67% female, mean age 55 years, 88 dropped out / lost to follow up	The intensive lifestyle intervention group received personalised dietary counselling, circuit-type resistance training and they were advised to increase their overall physical activity, compared to the control group who received usual care	Lifestyle measures i.e. diet, physical activity, BMI	The intervention group showed significantly less sedentary behaviours compared to the control group during year 1 (p=0.0001) & year 3 (p=0.0028), dietary intake also significantly improved in the intervention group compared to the control; weight loss (p=0.0001), fat intake goal (p=0.0001), saturated fat intake goal (p=0.0001) & fibre density goal (p=0.0006), and during the study 22 participants (9%) in the intervention group and 51 (20%) in the control group developed diabetes (p=0.0001)	The intensive lifestyle intervention was successful as it was able to show long-term beneficial changes in diet, physical activity as well as clinical and biochemical components, and reduced the risk of T2DM

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Lindstrom, Ilanne-Parikka & Peltonen et al., (2006)	5 study centres in Finland (Follow-up of the Finnish Diabetes Prevention Study, 2003, pg 108 of this review)	522 overweight, middle aged participants were recruited who were at high risk of developing T2DM due to IGT, they were randomised into one of 2 groups (control & intervention), 67% female, mean age 55, after an average of 4 years of active intervention participants who were still T2DM free were further followed up for an average of 3 years (median total follow-up of 7 years), 47 dropped out / lost to follow up	During this follow-up study all participants had an annual visit with the study nurse, the same procedures were adhered to as during the previous intervention period in 2003, and were similar for all participants therefore no specific diet or exercise counselling was provided	Diabetes incidence, body weight, physical activity, fat and fibre intake	The intense lifestyle intervention significantly reduced the long-term risks of T2DM in the intervention group ($p=0.0401$). The success score analysis was repeated to analyse the effect of maintained lifestyle changes on T2DM incidence during the post-intervention follow-up; In the intervention group 7% of the participants did not achieve any of the lifestyle goals at the first follow-up visit compared to and 14% of the control group, 32% of the intervention group and 40% of the control group achieved one, while 18% of the intervention group and 7% of the control group achieved at least four out of the five goals ($p=0.0042$)	This lifestyle intervention was successful in T2DM high risk individuals in promoting and sustained lifestyle changes, and to reduce incidence of T2DM even after the individual lifestyle counselling has ended

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Orchard, Temprosa & Goldberg et al., (2005)	Research and community-based centres in Maryland, USA (part of the Diabetes Prevention Program)	3,234 participants with IGT were recruited and monitored for an average of 3.2 years, randomly allocated into one of 3 groups (control/placebo, metformin & intensive lifestyle), 68% female, ages: 1,000<45, 1,586 between 45-59 & 648>59, 5 ethnic groups: White, Hispanic, African American, Native American & Asian American, 1,313 participants dropped out / lost to follow up	There were two intervention groups; a metformin and standard lifestyle recommendation group and an intensive program of lifestyle intervention group. The control group consisted of standard lifestyle recommendations plus placebo. All participants' blood pressure was measured quarterly, fasting glucose levels at 6-months, and fasting lipid levels and waist circumference annually	Lifestyle measures i.e. diet, physical activity, BMI, metabolic syndrome	53% of participants had metabolic syndrome at baseline. Low levels of high-density lipoprotein cholesterol were common in younger participants (<45), and high blood pressure was common in older participants (>59). Occurrence of metabolic syndrome was reduced by 41% in the lifestyle group ($p<0.001$) and by 17% in the metformin group ($p=0.03$) compared with the placebo group	The intervention was successful as it demonstrated that both lifestyle intervention and metformin therapy reduce the development of the metabolic syndrome in individuals with IGT

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Ramachandran , Snehalatha & Mary et al., (2006)	Service organisations in Chennai, India (Indian Diabetes Prevention Program)	531 participants without T2DM were recruited and allocated into one of 4 groups, 79% males, age range 35-55, range of SES (low to high), 7 follow ups at 6 month intervals (3 years), 29 dropped out / lost to follow up	There were four groups; LSM group were given advice on lifestyle modification, MET was treated with metformin, and LSM + MET received both. The fourth group was the control group who were given standard healthcare advice	Lifestyle measures i.e. diet, physical activity, BMI, insulin resistance	The incidence of diabetes was 55% in the control group and significantly lower in all three intervention groups (LSM = 39.3%, MET = 40.5%, LSM + MET = 39.5%; $p < 0.05$), there was a significant increase in the control group at annual follow up and in the LSM group at 24 months ($p = 0.035$) for mean change in body weight, and physical activity improvement from 41.7% to 58.8% in LSM and 45.9% to 62.9% in LSM + MET group	The intervention was successful as lifestyle changes and metformin reduced the risk of T2DM from occurring in Asian Indians who are at high-risk of developing the disease

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Sakane, Sato & Tsushita et al., (2011)	Primary health care settings in Japan (part of the Japan Diabetes Prevention Programme)	304 middle-aged IGT Japanese participants were recruited and randomised into two groups (intervention & control), aged 30-60 years, mean BMI of 24.5kg/m ² , 3 year follow up reported, intention of 6 year follow up, 91 dropped out / lost to follow up	The intervention aimed to reduce body weight by 5% in overweight/obese and to increase physical activity. The intervention was delivered by a study nurse, part-time dietician for diet counselling, a guide on changing your lifestyle to prevent diabetes. Four group sessions took place in the initial six months based on theoretical concepts and techniques for behaviour change and the transtheoretical model. A food frequency questionnaire was also conducted. The intervention was reinforced monthly. The control group only received one group session during the trial.	Lifestyle measures i.e. diet, physical activity, BMI	The baseline characteristics were similar between both groups. There was an increase in physical activity and decrease in daily energy intake in the intervention group observed throughout the three years. There were some beneficial changes in the control group but to a much lesser extent. Between the two groups there were significant differences at the end of year 1 but not at the end of year 3. T2DM was diagnosed in 27 participants during the 3 years; 9 in the intervention group and 18 in the control group, which was 8% incident rate in the intervention group and 15% in control. There was 53% risk reduction in the intervention group however there was no significant difference (p=0.097)	The lifestyle intervention was successful as it decreased the risk of diabetes amongst the Japanese population

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Siitonen, Lindstrom & Eriksson et al., (2004)	5 different research clinics (part of the Finnish Diabetes Prevention Study), Finland	506 overweight, middle-aged participants with IGT were recruited, and they were randomly allocated into one of 2 groups (intervention & control)	Intervention group were given individually tailored dietary advice and were instructed to increase their physical activity, compared to the control group who received general information on the benefits of a healthy diet, physical activity and weight reduction. Anthropometric measurements and an oral glucose tolerance test were carried out at baseline and annual follow-up. In a subgroup of participants (n=83), a frequently sampled intravenous glucose tolerance test (FSIGT) was performed at baseline	Insulin secretion, weight loss	Similar anthropometric measurements, and insulin and glucose levels were found at baseline for both groups. A significant interaction was found between the intervention group and genotype (p=0.003). This group also showed significant weight loss. Control group participants with the Glu9 allele had an increased risk of developing T2DM compared with participants with the Glu12/12 genotype (p=0.003). However this increased risk was not found in the intervention group. In the subgroup who underwent the FSIGT, participants with the Glu9/9 genotype showed the lowest acute insulin response (p=0.005)	The intervention was successful as it highlighted that the 12Glu9 polymorphism of ADRA2B is linked with impaired first phase insulin secretion and can predict the development of T2DM in individuals with IGT

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Simmons, Griffin & Steele et al., (2008)	20 general practice clinics in the UK (Proactive UK)	365 participants who had a parental history of T2DM without known diabetes were randomly assigned into 3 groups (intervention by telephone, intervention by person & control), 1 year follow up, mean age 40.6 years, 62% female, 44 dropped out/lost to follow up	All three groups were examined to explore the association between change in physical activity energy expenditure (PAEE), total body movement (counts per day) and aerobic fitness (maximum oxygen consumption [VO ₂ max]). Clustered metabolic risk was calculated for all three groups. Self-efficacy was used as the theoretical underpinnings of the study	Physical activity and aerobic fitness	There was non-significant correlation between change in fitness and change in PAEE (r=0.1), no correlation between change in fitness and total body movement (r=0.0), but there was a positive correlation between change in PAEE and total body movement (r=0.3). Fasting glucose, insulin and HDL-cholesterol at follow-up were significantly associated with a change in fitness over time, and fasting glucose and insulin were also associated with change in total body movement over time	The intervention was not successful as the there was small increases in physical activity are associated with improvement in clustered metabolic risk

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Venmans, Gorter & Baard et al., (2007)	GP surgeries in Utrecht, Netherlands	200 participants with T2DM were recruited, equally randomised into 2 groups (intervention & control), 55% male, mean age 68 years, from rural and urban areas, and 112 participants dropped out / lost to follow up	Intervention group was given an educational leaflet aiming to improve knowledge and attitudes regarding T2DM and common infections of T2DM (LRTIs & UTIs). Outcome variables were measured via self-administered questionnaires. The control group completed the questionnaire but did not receive any literature. KAB was used as the theoretical underpinnings of the study	Acceptability of leaflet, and differences in attitude and knowledge	The intervention group understood the information in the leaflet (100%) and found it useful (83%). In this group participants' attitudes did not statistically differ from the control group, except the attitude for being more positively aware of signs indicating pneumonia (p=0.003)	The intervention was not successful as providing T2DM patients with an educational leaflet had limited effects on their knowledge and attitudes

Study	Setting	Participants	Prevention Intervention	Primary outcome measures	Results	Outcome
Warren, Henry & Lightowler et al., (2003)	Lunchtime clubs in primary schools in Oxford, UK	218 normal & overweight children were recruited and randomly allocated into one of 4 groups, 111 males / 107 females, mean age 6.1years, 89% Caucasian, follow up after 14 months, 37 dropped out / lost to follow up,	Be Smart program had four groups: In the Eat Smart (nutrition) group children's concepts of health were explored, in the Play Smart (physical activity) group a physical activity program was designed to promote activity, Eat Smart Play Smart (combined nutrition and physical activity) group received both nutrition and physical activity programs, and the Be Smart (control) group were provided with an educational program to learn about food	Nutrition knowledge	Significant improvement in nutrition knowledge were seen in all groups ($p < 0.01$), especially in the nutrition and combined groups ($p < 0.001$), fruit ($p < 0.01$) and vegetable (< 0.05) intake significantly increased, fruit consumption improved in the nutrition group ($p < 0.05$) and the control group ($p < 0.05$). There were no significant changes in the rates of overweight and obesity	The intervention was successful as it yielded positive results and highlighted that school may be a suitable setting for the promotion of healthy lifestyles in children, which will aid to prevent chronic illnesses

2.3.4 Data Synthesis

2.3.4.1 Descriptive statistics

The 20 eligible studies illustrate the varied approaches to T2DM prevention. Out of the 20 eligible studies, the majority were of medium quality; 2 studies scored 3 out of 6 and fifteen studies scored 4 out of 6. The remaining three studies scored 5 out of six so they were classed as high quality studies (Gregg et al., 2007; Orchard et al., 2005; Ramachandran et al., 2006) (see appendix 2.2). Gregg et al. and Ramachandran et al.'s research particularly warrants attention as they provided full detailed recruitment and demographical details which are easily replicable. From the studies used in this review, Corpeleijn et al.'s study (2006) was the most difficult study to dissect as it used a lot of technical terminology and jargon creating confusion and a lack of understanding of the author's views at times. Carels et al.'s study (2007) and Warren et al.'s study (2003) are the only studies out of the 20 used in this review that did not focus on T2DM. Instead they explore obesity interventions. Carels and colleagues focussed on obesity treatments using motivation interviewing whereas Warren and colleagues explored an obesity intervention with school children. A decision to use both articles was made as it has been proven that obesity is strongly associated with the developing and worsening of T2DM (Naser, Gruber & Thomson, 2006; Feltbower, McKinney, Campbell, et al., 2003). Thus the results and implications of these studies can be mirrored to T2DM preventative research. Venmans et al.'s study has also been included in this review though it does not specifically relate to T2DM prevention. It focuses on educating participants about the infections that they are prone to due to the fact that they have T2DM. The results of the study provide good preventative ideas, which can be adapted to preventing T2DM in individuals.

2.3.4.2 Significant v Non-Significant studies in this review

Out of the 20 studies in this review nine yielded significant results. Lindstrom et al. (2003) conducted the Finnish Diabetes Prevention study and found that the intervention group produced significant improvements in their health compared to the control group via intensive lifestyle prevention. Only 9% of participants went on to develop T2DM in the intervention

group compared to 20% of the control group. In the follow up study to the Finnish Diabetes Prevention study, Lindstrom et al. (2006) found that the intense lifestyle intervention significantly reduced the long-term risks of T2DM in the intervention group without any further nutrition or fitness recommendations after the end of the initial study. This was also the case in Japan where Kosaka et al. (2005) reported a significantly higher T2DM risk reduction in the intervention group compared to the control due to an intense lifestyle intervention and a significant difference continued during the four year follow up. Sakane and colleagues (2011) reported that a lifestyle intervention programme is beneficial in preventing T2DM in Japanese with IGT as they found a significant reduction in cumulative incidents in the intervention group. One year after the intervention, body weight had significantly improved in participants as well as their daily non-exercise leisure time energy expenditure. Three years after the intervention the incident rate was still lower in the intervention group compared to the control.

Another study that yielded significant results was Siitonen and colleagues (2004). They demonstrated that there is a significant interaction between the genetic makeup of insulin and the risk of developing T2DM, which can be prevented by healthy eating and regular physical activity. Orchard et al. (2005) study highlighted that lifestyle and metformin can aid the prevention of T2DM. Health improvements were documented across both intervention groups compared with the placebo/control group. Ramachandran and colleagues (2006) also found similar results. They conducted their study in India using a high-risk T2DM population as part of the Indian Diabetes Prevention Programme. They found that both lifestyle and metformin helped to reduce the risk of T2DM, lifestyle being more effective than metformin, but found there is no additional benefit in combining the two interventions. Orchard and colleagues documented better health improvements and a decreased risk of T2DM in the lifestyle intervention group compared to the metformin intervention group. The DPP research group (2005) complement the above findings as they reported that both the lifestyle intervention and the metformin intervention significantly improved the insulin secretion and insulin sensitivity in participants compared to the placebo group, however the lifestyle intervention group had better improvements compared to the metformin group.

Lastly according to Lakshman and colleagues (2010), by implementing an interactive nutrition knowledge intervention as part of the healthy eating curriculum in schools can help to improve nutrition knowledge in children compared to the normal teaching method.

In contrast Kinmonth et al.'s study (2008) produced non-significant results for all tests conducted. They looked at increasing physical activity levels via different delivery methods to prevent the onset of T2DM. A face-to face method did not illustrate any advantage over a telephone method. The behavioural change intervention did not change or affect the awareness or perceived risk of diabetes, and the intervention groups did not show an intention to be more physically active than the control group. Brekke et al.s (2005) also demonstrated that the intervention and control groups used in their study did not differ on physical activity. However they did find that the intervention groups significantly differed from the control group regarding nutrition. Hardeman et al.'s (2009) findings mirror those of the above two studies. They reported a lack of increased objective and self-reported physical activity in the intervention group which received brief advice plus telephone/face-to-face contact compared to the control group which received brief advice alone. The intervention failed to induce changes in TPB cognitions. Although the nine significant studies clearly show that physical activity can aid the prevention of T2DM, finding the appropriate delivery method required for people to uptake physical activity is the challenge. Venmans et al. (2007) study also highlights the barriers of education and participants adhering to practical advice. They highlighted that individuals understood and find written information such as leaflets helpful, but their attitudes remain rigid and unchanged.

Gregg and colleagues (2007) conducted a study with T2DM participants. The intervention group were exposed to a one-day educational and acceptance & commitment therapy (ACT) workshop. They found that the intervention group significantly differed to the control group on self-management, acceptance and action, and glucose control, but non-significantly on blood glucose levels and understanding. The significant results illustrate that ACT should be used as a psychological tool in T2DM prevention interventions.

Baradaran and colleagues (2006) found that their study also yielded mixed results. They predicted that an educational T2DM programme would aid in preventing the onset of T2DM. Significant improvements occurred in the intervention group especially in knowledge, attitudes and control of diabetes. However no significant results were found between the ethnic minority and white control groups, although the white control group showed greater improvement than the ethnic minority control group. Therefore there is a need to design culturally sensitive prevention interventions when dealing with specific ethnic groups. This is also supported by Glasgow et al. (2007) who found that females, older participants and African Americans were more likely to engage in an internet lifestyle programme, but this study did not yield any significant results between intervention and control groups either.

Similarly to Baradaran et al.'s study, Carels and colleagues (2007) and Corpeleijn and colleagues (2006) also found that improvements occurred in their intervention group but there were no statistical differences between the intervention and control groups. Corpeleijn et al. used IGT participants to explore a lifestyle intervention. Weight-loss and obesity were measured in their study but the main emphasis was T2DM prevention. Carels et al. primarily explored weight-loss as their study focussed on obesity. They also found that motivational interviewing may be of assistance to those individuals who are struggling with weight loss problems, like ACT in Gregg et al.'s study. Therefore practical behavioural therapies should be implemented into prevention tools.

Simmon et al.'s (2008) and Warren et al.'s (2003) studies also yielded mixed results. Simmon and colleagues explored physical and activity energy expenditure (PAEE) and found that there was no significant relationship between fitness and PAEE but there was between PAEE and body movement. Significant improvements occurred during the follow-up stages. In contrast Warren et al. found that the children in their study significantly differed on nutrition factors, but not on physical activity factors. At the end of the study there were no significant changes in the rates of obesity.

2.3.4.3 T2DM v High-Risk studies in this review

From the 20 studies in this review three studies used participants who were already diagnosed with T2DM (Baradaran et al., 2006; Gregg et al., 2007; Venmans et al., 2007) reporting that T2DM education is key to T2DM prevention. Preventative interventions are designed for a population group who have not developed a disease yet but are at a high-risk of doing so thus these three studies would have been more creditable if an additional IGT group or a group of participants who did not have T2DM were recruited as a control group. They have been included in this review as they illustrate some good ideas regarding prevention in at high-risk T2DM groups

Three studies used participants who did not have a diagnosis of T2DM (Lakshman et al., 2010; Ramachandran et al., 2006, Warren et al., 2003), and another four studies in this review used participants who did not have T2DM either but they did report having a parental history or first degree relative with T2DM (Hardeman et al., 2009; Kinmonth et al., 2008; Simmons et al., 2008; Brekke et al., 2005). These studies are especially crucial for preventative research, as individuals who have a family member with the disease are more likely to develop T2DM. Five of the studies in this review used IGT participants (Sakane et al., 2011; Corpeleijn et al., 2006; DPP Research Group, 2005; Kosaka et al., 2005; Orchard et al., 2005), another three studies used IGT and overweight participants (Lindstrom et al., 2003; Lindstrom et al., 2006; Siitonen et al., 2004), and two of the studies used overweight/obese participants (Glasgow et al., 2007; Carels et al., 2007).

2.3.4.4 Lifestyle v other studies

Ten studies primarily explored lifestyle factors to help prevent T2DM. Hardeman et al. (2009), Kinmonth et al. (2008) and Simmons et al. (2008) explored physical activity through the UK ProActive trial and found that that an increase in physical activity aids the reduction of T2DM development. Hardeman et al.'s and Kinmonth et al.'s studies are similar as they are the only studies in this review that utilise a theory to test and support their claims which was

the TPB (Theory of Planned Behaviour). They found that there was no difference between the delivery methods of the intervention (leaflet/brief advice only, over the telephone or face-to-face). All three ProActive lifestyle studies discussed the implementation of their findings in a primary care setting.

Both of Lindstrom et al.'s studies (2003, 2006) also promote the improvement of lifestyle factors to aid the reduction of T2DM onset. They found that the lifestyle intervention that the participants were exposed to created long-term sustained positive lifestyle behaviours and a reduction in diabetes incidence even after the end of the study. This was also supported by Sakane et al. (2011) and Kosaka et al. (2005) who reported similar results among Japanese IGT participants. Warren et al. (2003) findings state that positive lifestyles should be promoted throughout schools to promote long-term good health. They also recommend tackling the issue of obesity by teaching it through the curriculum subjects such as science, physical education and PSHCE (physical, social, health, citizenship and environment). Brekke and colleagues (2005) also found long-term positive health benefits and the prevention of T2DM from positive lifestyle behaviours. Lastly, Corpeleijn et al. (2006) found that lifestyle interventions are effective in reducing obesity, improving insulin sensitivity and glucose tolerance thus preventing an individual's chances of developing T2DM.

Alongside lifestyle interventions Ramachandran et al. (2006), DPP Research Group (2005) and Orchard et al. (2005) explored the use of pharmaceutical aids. The DPP Research Group found that both lifestyle intervention and metformin groups significantly reduced the risk of participants developing T2DM compared to a placebo group, and the lifestyle intervention group had a significantly lower-risk rate of developing T2DM compared to the metformin group. Therefore although metformin has some beneficial T2DM preventative functions, lifestyle interventions are more effective and can be used on larger population groups. Siitonen et al. (2004) conducted a genetic study into T2DM prevention using the Finnish Diabetes Study participants. They found that the genetic matter of impaired insulin secretion is the cause of IGT. Therefore tackling and solving the genetic problem can

prevent the onset of T2DM without having to subject oneself to lifestyle interventions. However a healthy lifestyle can help to reduce the risk on T2DM in a non-invasive manner. Carels et al.'s (2007) and Gregg et al.'s (2007) studies explored therapeutic approaches. Carels and colleagues investigated motivational interviewing (Miller & Rollnick, 2002) alongside a behavioural weight-loss programme. They found that individuals who received motivational interviewing lost more weight compared with those who did not receive. Gregg and colleagues found that patients were able to cope with their diabetes more when they applied acceptance and commitment therapy skills in dealing with diabetes-related issues, compared to those who only received an educational workshop on diabetes management and therefore such therapies should be utilised.

Another approach is educational interventions. Venmans and colleagues investigated the effects of an educational leaflet on infections in T2DM patients. They found that although the educational leaflet was accepted and read by participants, it did not significantly aid them in demonstrating preventative health behaviours. Baradaran and colleagues (2006) also evaluated the effectiveness of an educational programme. They found that knowledge and positive health behaviours improved in the intervention groups, but they also improved in the control group. Lakshman et al. (2010) reported an improvement in nutrition knowledge in children who were part of an interactive card game intervention compared to a normal school healthy eating curriculum programme. Although nutritional knowledge improved, the ability to identify healthier foods did not. Glasgow et al. (2007) is the only study that explored a prevention tool using ehealth. They evaluated the effectiveness of using the internet for weight-loss purposes. Results are unclear on whether the internet was effective in promoting weight-loss to help prevent T2DM, as the study focussed on the recruitment and retention of participants. In this review lifestyle interventions are more effective in eliciting positive health behaviours to preventing the onset of T2DM than educational or other forms of prevention interventions.

2.3.5 Meta-analysis

2.3.5.1. Aim

The purpose of the meta-analysis in this chapter is to provide a statistical review of T2DM prevention intervention data. In this review many different studies have been used i.e. lifestyle prevention, genetic studies and educational interventions. All 20 studies were experimental and did not contain any correlational data therefore an effect size (d value) could be calculated if not already documented. From the outcome measures listed above (table 2.5) the three main primary outcomes that emerged were diet, physical activity and BMI. Hence these three outcomes were used to conduct three meta-analyses respectively. Seven studies were used. The remaining 13 studies did not include statistical data required to calculate the d values on diet, physical activity or BMI. Six of these studies were knowledge/education interventions, two were genetic studies and one was a metabolic risk study targeting specific variables in lifestyle interventions to decrease the T2DM incident rates in the studies, two primarily focussed on risk and decreasing incidences of T2DM in T2DM prevention interventions, and a further two compared lifestyle interventions with Metformin as the primary outcome. The seven studies which were included were Brekke et al., Carels et al., Corpeleijn et al., Hardeman et al., Kinmonth et al., Lindstrom et al. (2003) and Sakane et al. Only Hardeman et al. and Kinmonth et al., 2008 reported the effect sizes (d values) which were needed. Therefore the d value was calculated using means, standard deviations and sample sizes for 5 of the studies used in this meta-analysis, and for the remaining one study the d value was calculated using means, sample sizes and confidence intervals (Higgins & Green, 2011).

2.3.5.2 Diet outcome measure

Table 2.6 illustrates the study data groups used to conduct the meta-analysis on diet outcome measures. There were two follow-up datasets for Lindstrom et al.'s study (2003) and the one year follow-up was used as it reflected the average follow up documented in this review. Brekke et al.'s study has been used twice as two intervention groups were used with the one year follow-up as they also used two separate follow-ups. Carels et al.'s study also

used two intervention groups hence was used twice, and Sakane et al. used two follow-up periods so the one year follow-up was used as it reflected the average follow-ups documented in this review. Therefore in the meta-analysis software used the data comes up as seven datasets.

No	Study details	Effect size
1	Corpeleijn et al., 1 intervention group, 1 year follow-up	0.10
2	Lindstrom et al. (2003), 1 intervention group, 1 year follow-up	0.31
3	Brekke et al., intervention group 1 (diet), 1 year follow up	0.45
4	Brekke et al., intervention group 2 (diet & exercise), 1 year follow up	0.21
5	Carels et al., intervention 1 (BWLP), 6 months follow up	0.11
6	Carels et al., intervention 2 (BWLP & MI), 6 months follow up	0.03
7	Sakane et al., 1 year follow up	0.24

Table 2.6 Study data used for diet meta-analysis

Variables	Results
K (datasets)	7
N	1025
D+	0.25
95% confidence intervals	0.13-0.38
Chi-square test of homogeneity	2.03
Fail-Safe N	1.90

Table 2.7 Descriptive and meta-analysis results for diet outcome measure

K=7 datasets (N=1025) were located that compared performances of diet among intervention and control participants. Meta-analysis was performed to quantify the size of the differences reported in these studies. The sample-weighted average difference was $d+=0.25$, which indicates a small-sized effect according to Cohen's (1992) classification. This suggests that performance on diet is better in intervention versus control participants. There was significant heterogeneity among the datasets (chi-square=2.03, $p>0.001$), thus encouraging a search for moderator variables. Studies 2 and 3 (from table 2.6) had the largest effect sizes therefore they were removed and the meta-analysis repeated, $d+=0.18$ indicating a small-sized effect according to Cohen's (1992) classification. The smaller sample ($n=476$), less heterogeneity (chi-square=0.63, $p>0.03$) and smaller-sized effect suggests that the research group in datasets 2 and 3 may moderate the effect size.

2.3.5.3 Physical Activity

Table 2.8 illustrates the study data groups used to conduct the meta-analysis on physical activity outcome measures. Hardeman et al. and Sakane et al. had two follow up datasets in each study therefore the one year follow-up was used from each study as it reflected the average follow ups documented in this review. Brekke et al., Carels et al. and Kinmonth et al. studies were also used twice as there were two intervention groups used. Therefore in the meta-analysis software used the data comes up as eight datasets.

No	Study details	Effect size
1	Hardeman et al., 1 intervention group, 12 months follow up	.21
2	Kinmonth et al, intervention group 1 (telephone) , 1 year follow up	.08
3	Kinmonth et al, intervention group 1 (one-to-one), 1 year follow up	.18
4	Brekke et al., intervention group 1 (diet), 2 year follow up	.01
5	Brekke et al., intervention group 2 (diet & exercise), 2 year follow up	.06
6	Carels et al., intervention 1 (BWLP), 6 months follow up	.19
7	Carels et al., intervention 2 (BWLP & MI), 6 months follow up	.62
8	Sakane et al., 1 year follow up	.05

Table 2.8 Study data used for physical activity meta-analysis

Variables	Results
K (datasets)	8
N	1088
D+	0.12
95% confidence intervals	-0.002-0.24
Chi-square test of homogeneity	3.82
Fail-Safe N (FSN)	-3.30

Table 2.9 Descriptive and meta-analysis results for physical activity outcome measure

K=8 datasets (N=1088) were located that compared performances of physical activity among intervention and control participants. Meta-analysis was performed to quantify the size of the differences reported in these studies. The sample-weighted average difference was $d+=0.12$, which indicates a small-sized effect according to Cohen's (1992) classification. This suggests that performance on physical activity is better in intervention versus control participants. There was a non-significant heterogeneity among the datasets (chi-square=3.82, $p=0.3$), thus a search for moderate variables was not applicable. The FSN is a negative figure which indicates that there is a possibility of a couple of studies with null effects, however due to the very small-sized effect there is no need to add more studies.

2.3.5.4 BMI

Table 2.10 illustrates the study data groups used to conduct the meta-analysis on BMI outcome measures. Lindstrom et al. (2003) used two follow up datasets therefore the one year follow-up was used as it reflected the average follow up documented in this review. Brekke et al.'s study has been used twice as two intervention groups were used with the one year follow-up as they also used two separate follow-ups. Carels et al.'s study also used two intervention groups and Sakane et al. used two follow-up measures so the one year follow-up was used as it reflected the average follow up documented in this review. Therefore in the meta-analysis software used the data comes up as seven datasets.

No	Study details	Effect size
1	Corpeleijn et al., 1 intervention group, 1 year follow-up	.17
2	Lindstrom et al. (2003), 1 intervention group, 1 year follow up	.76
3	Brekke et al., intervention group 1 (diet), 1 year follow up	.35
4	Brekke et al., intervention group 2 (diet & exercise), 1 year follow up	.79
5	Kinmonth et al, intervention group 1 (telephone), 1 year follow up	.11
6	Kinmonth et al, intervention group 1 (one-to-one), 1 year follow up	.02
7	Sakane et al., 1 year follow up	.00

Table 2.10 Study data used for BMI meta-analysis

Variables	Results
K (datasets)	7
N	1392
d+	0.34
95% confidence intervals	0.24-0.45
Chi-square test of homogeneity	39.02
Fail-Safe N (FSN)	3.00

Table 2.11 Descriptive and meta-analysis results for BMI outcome measure

K=7 datasets (N=1392) were located that compared performances of BMI among intervention and control participants. Meta-analysis was performed to quantify the size of the differences reported in these studies. The sample-weighted average difference was $d+=0.34$, which indicates a small to medium-sized effect according to Cohen's (1992) classification. This suggests that performance on BMI is better in intervention versus control participants. In order to achieve a small-sized effect, the FSN suggests including a further 3 studies. However, there was a significant heterogeneity among the datasets (chi-square=39.02, $p>0.01$), thus a search for moderate variables was conducted. From table 2.10 datasets 2 and 4 are from the largest effect sizes in this analysis. By removing these

studies the sample-weighted average difference was $d+=0.07$, which indicates a small-sized effect according to Cohen's (1992) classification. The smaller sample ($n=826$), less heterogeneity ($\text{chi-square}=1.49$, $p>0.14$) and smaller-sized effect suggests that the research group in datasets 2 and 4 may moderate the effect size.

2.3.6 Summary

On completing data analysis the main outcomes that emerged were that lifestyle has a big impact on the development of T2DM, and that the individuals at a high-risk of developing T2DM who have IGT need early prevention education to adhere to healthy and T2DM preventative behaviours. Also the meta-analysis highlights that across the three outcome measure of diet, physical activity and BMI, there are medium to small-sized effects therefore the desirable performances are being demonstrated in the prevention interventions groups versus the control groups. It was encouraging to have found T2DM prevention intervention studies conducted across the globe which complements the fact that T2DM is a global problem and needs to be tackled in every nation.

2.4 Discussion

2.4.1 Summary of systematic review results

This review found that lifestyle programmes clearly demonstrate their strength and validity in aiding in the prevention of the T2DM epidemic. The meta-analysis highlighted that across the three outcome measures of diet, physical activity and BMI, there are medium to small-sized effects producing effective improvements on health outcomes. Although significant results are not always gained, replication is good and focussing on the overall implications of research can help devise a practical and beneficial tool. Educational programmes are not shown to be very effective however using an educational component is plausible. Although pharmaceutical, counselling/therapy and educational factors can help it is more effective to have a lifestyle programme at the centre of a T2DM prevention intervention. It is also important to conduct research with the relevant population sample, e.g. overweight individuals, with IGT, participants without T2DM but with familial T2DM, etc. as appropriate prevention interventions can be developed.

2.4.2 Effectiveness of lifestyle prevention interventions

The fast growing prevalence rate of T2DM across the world demonstrates the significant influence of lifestyle factors and sedentary lifestyles thus providing the potential answer for reversing this global epidemic (Alberti, Zimmit & Shaw, 2007). A good healthy diet and regular physical activity are the key components to T2DM prevention as demonstrated in this systematic review. A significant finding from this systematic review illustrates that T2DM prevention interventions are more effective in changing peoples' health behaviors towards a healthy diet than in increasing physical activity e.g. Warren and colleagues (2003) found that the participants in their study significantly differed on nutrition factors, but not on physical activity factors. Also many of the non-significant studies explored physical activity as their

primary outcome (Kinmonth, Wareham & Hardeman, et al., 2008; Simmon, Griffin & Steele, et al., 2008; Brekke, Jansson & Lenner, 2005) however, intense lifestyle interventions also worked well when combined with a good healthy diet, supplemented with regular physical activity. Morrato and colleagues (2007) documented that aerobic exercise is as effective as antidepressant medications in treating mild to moderate depression which affects approximately one-quarter of individuals with diabetes and affects diabetes self-care. Therefore a conclusion can be drawn that even though physical activity may not be as effective in changing health behaviours on its own, a holistic approach in the form of lifestyle interventions is fitting.

The DPP reports that lifestyle intervention also improves lipid parameters of the metabolic syndrome and reduced the incidence of hypertension in addition to its positive effect on fasting glucose and glucose tolerance. Therefore lifestyle interventions targeting T2DM not only help to prevent the onset of T2DM but other diseases too such as CHD and obesity. Orchard, Temprosa and Goldberg et al.'s (2005) research supports the benefits of the DPP and raised the additional possibility of CHD prevention.

DPP is one of the largest RCT lifestyle interventions which can help to improve health more generally and an individual's quality of life. The Finnish Diabetes Prevention Study specifically examined the effect of an intensive lifestyle intervention in preventing T2DM (Lindstrom, Louheranta & Mannelin et al., 2003) which reported that lifestyle interventions providing individually tailored personal counseling focusing on achieving and maintaining healthy body weight, reducing fat intake, and increasing fibre intake and physical activity, reduce the risk of developing T2DM. The Indian Diabetes Prevention Program was another groundbreaking study as it was a large RCT community-based study conducted in India with IGT Asian Indians who are leaner and more insulin resistant than previously studied groups (Ramachandran, Snehalatha & Mary et al., 2006).

Diabetes prevention trials have documented the efficacy of intensive lifestyle interventions but all of these studies had a lot of health professional support to maintain diet and exercise goals in participants. Therefore it is less likely that these lifestyle changes will be as effective in a real-life setting compared to RCT trials unless constant encouragement is given at all times. It is unrealistic to suggest healthcare professionals do this and the role of family and friends should include this especially if children are involved (Lakshman, Sharp, Ong & Forouhi, 2010; Warren, Henry & Lightowler et al., 2003). Not many studies have targeted families as part of an intervention yet family involvement is logical and has theoretical support (Crockett, Mullis & Perry et al., 1989; Rowe, Hunt & Bradshaw et al., 1997).

2.4.3 Translating lifestyle interventions into practice

Most prevention intervention studies are efficacy studies meaning that they are conducted in ideal circumstances, opposed to effectiveness studies which explore whether the intervention will work in the real world rather than the ideal world (Smith, 2012). Basic science and efficacy studies are the territory of researchers whereas effectiveness and efficiency studies are part of translation research. Finding ways to increase the efficiency of the intervention, make it available, and distribute it to everybody is important (Smith, 2021). Albright (2012) stated that effectiveness studies need to be developed outside of the healthcare system and delivered by non-medical professionals, as medical professionals are too expensive. The best way to prevent diabetes is to create an environment in which healthy eating and physical activity are the norm. Training, quality assurance, an intervention site and marketing are all needed. An effective programme needs to identify those at risk, reach out to them, encourage them to join and stay in programmes, provide support, report on outcomes and manage the finances. Smith (2012) reports that most prevention interventions in Europe have failed, the US system has reached less than 0.001% of those at risk, and most programmes in low and middle income countries exist on paper only. Therefore there is a clear need for effective prevention interventions in society today.

The ProActive study is a theory-based prevention intervention promoting physical activity in the UK (Kinmonth, Wareham & Hardeman et al., 2008). This was based on a cross-sectional study exploring the association between total body movement and clustered metabolic risk (Ekelund, Griffin & Wareham, 2007). Kinmonth and colleagues aimed to examine the link between change in PAEE, physical activity, aerobic fitness and clustered metabolic risk in the ProActive trial. They found that the trial produced increases in physical activity and improvement clustered metabolic risk in T2DM high-risk groups. This was also supported by Simmons and colleagues (2008) who reported that the ProActive trial produced small increases in physical activity, which was associated with improvement in clustered metabolic risk in individuals at high-risk of developing T2DM. This study supports previous research confirming stronger evidence for the link between total body movement and metabolic risk (Ekelund, Yngve & Brage et al., 2004). The ProActive trial is a good programme as it allows objective measurement of the different elements of physical activity and fitness over a realistic period of 12 months in individuals accessed through primary care who are at risk of T2DM. This trial has huge implications for future UK prevention programmes.

In terms of secondary prevention communities and healthcare professionals are now doing more to fight the T2DM epidemic. In the UK as well as the ProActive RCTs the healthcare service runs '*The Expert Patients Programme (EPP)*'. This is a bilingual scheme that aims to help people with chronic conditions to manage their lives better (BEN PCT Annual Report 2007-08). The courses are delivered in a range of community settings and the PCTs have working relationships with GP practices, voluntary agencies, sheltered housing schemes and Work Directions. Other popular examples include the DESMOND (2008) and X-PERT Health (2009), which have been discussed earlier in Chapter 1.

2.4.4 Alternatives to lifestyle interventions

As not all T2DM high-risk individuals are able to adhere to lifestyle changes and achieve the desired results, other interventions are needed including pharmacological therapy (Odegard

& Capoccia, 2007). The DPP demonstrated that metformin twice daily with meals reduced the incidence of T2DM by 31% compared with the placebo. The IDPP group found similar benefit in both metformin and lifestyle modification groups (28%) with no added benefit when combining them together. In contrast to DPP, IDPP shows a benefit with metformin in those with BMI well below 30kg/m². The IDF also recommends that when lifestyle intervention has not achieved the desired weight-loss or improved IGT goals, metformin should be considered as a T2DM prevention strategy (Alberti, Zimmet & Shaw, 2007). However metformin is not recommended for everyone with IGT as there are standard contraindications, it may affect and be linked with lactic acidosis (renal, hepatic and ischaemic disorders) and it may be less effective in terms of prevention in those aged 60years or over. Pharmacological intervention is therefore predominantly recommended as a secondary intervention to use in conjunction with lifestyle interventions (Odegard & Capoccia, 2007).

As mentioned previously, genetics play a major role in the development of T2DM, even though it is unclear which genetic material is responsible for this. Siitonen and colleagues' (2004) research indicates that the 12Glu9 polymorphism in ADRA2B is associated with impaired beta cell function. This genetic polymorphism may predispose an individual to T2DM. They also found that insulin secretion does not work with Glu9 allele in participants with IGT, which increases the risk of T2DM especially in individuals who are not exposed to a lifestyle intervention. Lifestyle also affects the genetic makeup of an individual which in return affects their risk of T2DM. Corpeleijn and colleagues (2006) report that there is increasing evidence that serum fatty acid profiles and fatty acid desaturase activities are potentially influenced by lifestyle factors i.e. diet and exercise. They believe a lifestyle intervention programme improves glucose tolerance and insulin sensitivity in individuals without T2DM diagnosis, thus reducing the risk of T2DM.

Implementing psychological therapy as part of a prevention intervention may be useful. Research on coping styles has shown that acceptance of T2DM and diabetes-related cognitions are significantly related to HbA1C values, and negative thoughts and feelings are

associated with higher levels of depression, poorer quality of life, and lower adherence to medication (Gregg, Callaghan & Hayes et al., 2007; Weijman, Ros, & Rutten, 2005). Gregg and colleagues reported that their traditional diabetes education workshop was associated with improved reported self-management by participants but no improvements in actual diabetic control thus supporting the importance of an acceptance, mindfulness, and values-based approach to helping individuals develop the psychological resources to manage their diabetes. There is growing evidence that acceptance-based coping is associated with less distress, and passive coping is less effective than active coping strategies (Classen, Butler & Koopman et al., 2001, Gregg et al., 2007).

Motivational interviewing is another example of a psychological tool. It was originally used to treat addictive behaviours, for example the stop smoking services across the UK use motivational interviewing for smoking cessation purposes to help encourage smokers to quit. However they also use other strategies to help quitters cope with withdrawal effects as well as motivational interviewing. Motivational interviewing is now being used to enhance health behaviours including diet and exercise (Carels, Darby & Cacciapaglia et al., 2007). Carels and colleagues found that motivational interviewing increases motivation for change resulting in more positive behaviour which can help individuals who are struggling to lose weight. Participants who received motivational interviewing lost significantly more weight and exercised significantly more than comparable behavioural weight-loss programme participants. However it is the recommendation of this review for counselling not to be the sole element of a T2DM prevention intervention.

Previously the aim was to improve the knowledge and skills of individuals regarding T2DM but this approach has not been very successful in reducing obesity and increasing physical activity levels (Venmans, Gorter & Baard et al., 2007). Therefore it is more useful to focus on the environment and conditions that are helpful to achieving and maintaining an active lifestyle and healthy eating habits by focusing on engaging and interacting with participants. There is encouraging research regarding the efficacy of Internet-based weight-loss

interventions (Aaron, Dearwater & Anderson et al., 1995) however in this review Glasgow et al.'s study (2007) did not yield significant results with reference to T2DM prevention. The Internet can be a very powerful resource to use in providing effective information and interaction with a variety of population groups including the hard-to-reach and extroverted groups. It is a non-invasive and user-friendly tool which would allow individuals to gain support and advice from others going through the same thing they are. They could also use it to contact health professionals with any concerns. However the appeal and applicability of ehealth in real-world settings is still questionable (Koo & Skinner, 2005; Brandenburg, Bauer & Reusch et al., 1999). The downside to using the internet is that it is so vast that a new user could find it very challenging and a deterrent. However in today's society most individuals are computer literate or at least have a basic understanding on how to use the Internet therefore it would be a good resource to use in a prevention programme.

2.4.5 Tackling South-Asian communities

Developing nations especially in Asia face an enormous challenge dealing with the high prevalence of T2DM and therefore need primary prevention programmes (Ramachandran et al., 2006). At the beginning of the systematic review one of the aims was to also research and explore the number of T2DM prevention interventions for South-Asians. Only two (Baradaran et al., 2006; Ramachandran et al., 2006) were added to this review therefore it was not feasible to conduct a synthesis on T2DM prevention interventions for South-Asians. Baradaran et al.'s study reported clear improvements in T2DM knowledge, attitudes and practice in the intervention group but also in the control groups, and no clear evidence was gained in the intervention group's favour. Ramachandran et al.'s study was successful as lifestyle changes and metformin reduced the risk of T2DM from occurring in Asian Indians who are at high-risk of developing the disease. Literature has shown that South-Asians have the highest T2DM prevalence rates in the UK (Lawton, Ahmad & Hallowell et al, 2005) therefore both IDPP and JDPP offer an insight into developing culturally sensitive prevention strategies which were included in the analysis of this review. More RCTs are needed in the

South-Asian population groups. The progression rate of IGT to T2DM is very high amongst South-Asians however Ramachandran et al.'s study proves that lifestyle interventions can prevent the onset of T2DM in this group. It would also be interesting to replicate such a diabetes prevention programme within the UK among Pakistanis and then compare the data.

Another significant finding from this review is the importance of the delivery methods used to deliver a prevention intervention. Baradaran and colleagues (2006) illustrated that there are translation issues for non-English speakers in the UK. They also found that it is essential to find ways to involve people who would benefit most from T2DM education interventions in community gathering places and in the home, as well as finding the suitable intervention intensity and ideal providers. There is also the matter of how to integrate T2DM prevention education within primary care.

Educating individuals regarding T2DM is vital however simply supplying them with written information is not effective. Venmans et al.'s (2007) study showed that providing T2DM patients with an educational leaflet had limited effects on essential behavioural characteristics such as knowledge and attitude despite the leaflet being acceptable by participants. Leaflets need to be easy to read and easily understood to have an effect on an individual's knowledge. Information and education alone will not succeed (Albert, Zimmet & Shaw, 2007) and a more interactive approach is needed. Adding direct behaviour change interventions with education may be helpful (Norris, Engelgau, & Narayan, 2001). However Hardeman et al. (2009) and Kinmonth and colleagues (2008) found that a theory-based intervention was no more effective than an advice leaflet in the promotion of physical activity in an at risk group. This may be due to the lack of specific behaviour change techniques being employed or specific theoretical constructs being targeted.

Out of the nine various prevention interventions used in the 20 studies of this review (Table 2.3 in the results section) combined with current research, it would be plausible to predict that an intervention based on dietary change, weight loss emphasis and pharmaceutical

approach could aid health behaviour change in Pakistanis to decrease their risk of developing T2DM. A prevention intervention targeting exercise promotion may be beneficial as many Pakistanis lead a more sedentary lifestyle in the UK. Education and counseling methods may be less effective especially if not delivered in different languages. E-Health may be effective for younger generations but older Pakistani generations may not be comfortable using a computer to help with T2DM care and prevention as it is not part of their daily routine.

2.4.6 Good participant samples

A good population sample was used in this review. A range of ethnicities, ages, and both genders were used. For some of the studies used in this review further details were also provided regarding the participants, for example Venmans et al., (2007) conducted their study in a low SES group. Relevant sample groups were collected: individuals with T2DM and without, individuals with IGT and family history of the disease. Such an array of participants can be used to provide research on developing a global and generic diabetes prevention tool.

2.4.7 Conclusion

Intensive lifestyle change and pharmaceutical agents provide significant health benefits. Early interventions and avoidance of T2DM progression is of vast importance in terms of increasing life expectancy and quality of life and also in economic terms for society and healthcare payers. The majority of previous health economic studies demonstrate that diabetes prevention is highly cost-effective (Alberti, Zimmet & Shaw, 2007). Everyone needs to play a part in the fight against diabetes. Healthcare professionals need to continue with regular screening, educating and treating the public, as well as providing the resources for individuals to follow recommended preventative strategies. Incorporating family members and friends into a T2DM prevention program orientated around lifestyle changes can lead to

a community understanding, adhering and working towards the prevention of T2DM. This review highlights that a lifestyle intervention promoting positive dietary and physical activity will help to prevent the onset of T2DM in those at high risk and those at low risk from becoming high risk. There is also a lack of reported studies which include South Asian specifically Pakistani population groups hence there is a need for robust prevention interventions designed with Pakistani population groups.

Chapter 3

Methodology

3.1 Research Design

3.1.1 Research population

The aim of this project is to explore the perceptions and beliefs of T2DM prevention among British-Pakistani women in the UK. This research project includes three different population groups:

- Mothers with a diagnosis of T2DM
- Mothers without a diagnosis of T2DM
- Young single females

British-Pakistanis are one of the known ethnic communities who develop severe complications of the illness due to a late diagnosis of T2DM (Hawthorne & Tomlinson, 1999). As Pakistani women are at the forefront of familial responsibilities they are an ideal population to study. They are responsible for the dietary intake of their family as well as themselves and they are in the best position to encourage and support others to live healthy lifestyles. Women have been described as the mediators for change towards healthier diets in the family (Fagerli & Wandel, 1999). Research has shown that a family member being diagnosed with T2DM adds extra pressure on women as they have to manage the relationship between the family and food (Burns & Gavey, 2004).

Early screening and detection of T2DM can help prevent the onset, its complications and improve quality of life. Good knowledge and education regarding the disease among British-Pakistani women can prevent diagnosis of the disease. Exploring the perceptions and beliefs of British-Pakistani mothers without a diagnosis of the disease and the young female group will represent data of different age groups in a specific ethnic group illustrating any knowledge or preventative behaviours they currently demonstrate. The reason for recruiting

British-Pakistani mothers already with a diagnosis of T2DM is to compare their perceptions and beliefs with those who don't have it and to also compare knowledge and any preventative behaviours they carry out whether they were doing that before or after their diagnosis.

Previously T2DM was associated with old age however the onset age has changed as individuals at increasingly younger ages are being diagnosed with this disease (Ehtisham, Kirk, McEvilly et al., 2001; Ehtisham, Crabtree, Clark et al. 2005). Previously Diabetes UK stated that key risk factors for T2DM were being of South-Asian origin over the age of 40, now this has changed to being of South-Asian origin over the age of 25 (Diabetes UK, 2006; Chowdhury & King, 2007). Therefore it is significant to identify the knowledge and beliefs of T2DM prevention among young British-Pakistani women as well as older women in order to decrease the likelihood of them developing T2DM. It is predicted that the findings from the three population groups will provide sufficient knowledge and information regarding British-Pakistani women's perceptions and behaviours towards T2DM prevention and thus aid the development of culturally appropriate T2DM prevention programmes for the Pakistani population as a whole.

3.1.2 Comparison of qualitative and quantitative methodology

Quantitative research is a popular methodology in health psychology literature. It relies heavily on statistical empirical data to investigate quantitative properties and phenomena and their relationships. The purpose of this methodology is to develop and use models, theories and/or hypotheses applicable to the research. The measurement process is central as it provides the primary connection between empirical observation and statistical expression of quantitative relationships. Examples of quantitative surveys used in T2DM research are illness perception questionnaires (Weinman, Petrie, Moss-Morris & Horne, 1996) and nutrition knowledge questionnaires (Lakshman, Sharp, Ong & Forouhi, 2010). In contrast qualitative research describes the characteristics and constructs of an entity to provide rich descriptive accounts of the topic under investigation (Smith, 2003). Qualitative

research involves exploring, describing and interpreting the personal and social experiences of individuals. It tries to capture a small number of personal views of the world rather than trying to test a hypothesis on a large sample. The main emphasis lies in how meanings are constructed and shaped through conversation and human experience. It aims to develop a scientific understanding of the inner world of experience and unconsciousness. Interviews and focus groups have been used to capture data from participants regarding T2DM to understand with detail individuals' beliefs and knowledge (White, Smith, Hevey & O'Dowd, 2009; Lawton, Ahmad, Hanna, et al., 2006; Hornsten, Sandstrom & Lundman, 2004).

Quantitative research produces descriptive statistical accounts and seeks casual relationships. Qualitative research explores and analyses causal relationships further. There is a clear difference in terms of how data are analysed. Quantitative research views the data as numerical values in order to carry out statistical analysis whereas qualitative research involves collecting data in the form of naturalistic reports hence the analysis is usually textual. Qualitative data is mainly concerned with interpreting what the research means rather than finding the numerical properties of it. It focuses on the importance of language and the basic human communication, interpretation and understanding; helping people make sense of their social world and express that to themselves and others (Smith 2003).

The key difference between quantitative and qualitative research is their flexibility. Compared with qualitative research, quantitative research is less flexible because it generally uses highly structured methods to investigate the numerical properties, phenomena and their relationships. Participants are generally asked to rate the scales or choose their responses from closed-ended or fixed categories. It is stable in that participants' responses do not affect or determine the questions that researchers' ask and how they ask. Therefore the qualitative aspect of the research for this project will allow for the flexible approach to exploring perceptions, beliefs and preventative behaviours among British-Pakistani women and the quantitative aspect will offer numerical data.

The main challenge to mixed-methodology research is putting it into practice as the methods are not as practical in combination as they are on their own (Morgan, 1998). Combining qualitative and quantitative methods relies on different assumptions about the nature of knowledge and the appropriate means of generating knowledge (Creswell, 1994; Guba & Lincoln, 1994). Previously many researchers who have combined these methods ignore paradigm concerns and conflicting research issues. The best way to use both methodologies without disregarding rooted research issues is in a string of studies (Morgan, 1998), as demonstrated in this project.

3.1.3 The advantages of using mixed-methodology

The main practicality of combining qualitative and quantitative research is that this combination maximises the strengths of the two methodologies. Different methods have different strengths therefore by combining the two methods more strengths are produced to the studies than research studies would in isolation (Morgan, 1998). Many health researchers approve of this mixed-methodology because combining methods demonstrates the complexity of the many different factors that influence health (Carey, 1993; Goering & Steiner, 1996). Participants were explored in natural settings where conditions continuously develop and interact with each other to produce a process of ongoing change. For the qualitative studies interpretations of events were determined by participants and the researcher, allowing the researcher to understand why and how people behave and think. For the quantitative studies the participants were recruited from places which were intertwined in their daily lives and appropriate.

Johnson and Onwuegbuzie (2004) encourage mixing research methodologies as it allows for wider choices to be made in the process of research especially during the design stage. They describe it as a forthcoming form of research complementing each other and offering a diverse approach to conducting research. Giles (2006) reported that some researchers find that mixed-methods dilutes the quality of research however, Sechrest and Sidani (1995)

argue that these researchers overlook the similarities between different methods. They argue that both qualitative and quantitative methods describe the data collected, form arguments based on the data, and consider the research leading to the outcomes found. Biesta and Burbules (2003) also support this by stating that both methodologies provide knowledge about humans and the world in which we exist, as well as Sandelowski (1986) adding that both methods consider the quality of research and aim to minimise bias and maximise validity. As mentioned above both methodologies have their advantages, and by understanding the strengths and weaknesses of both methods allows researchers to understand when two methods can be combined (Johnson & Turner, 2003). Hence mixed-methodology is most suited for this project as it answers the research questions proposed in the best and most complete way.

Although qualitative and quantitative methods can be combined to answer a research question, there is a consensus in previous literature that the data provided by both methods should be analysed separately in order to preserve the integrity and maximise the quality of the research (Yardley, 2008). Therefore Marquart (2001) proposed a method of using mixed-methods without affecting the integrity known as parallel tracks. Parallel tracks mean treating the data as equal sets which do not cross. Each data set is analysed separately and findings are treated as separate components of the same research question. A combination of the findings can then be used to make inferences and conclusions about the research question in order to explore and learn the perceptions and prevention behaviours of British-Pakistani women.

By using mixed-methodology, this research project encompassed the stability of quantitative research and the flexibility of qualitative research producing in-depth and generalisable findings. As mentioned before the stability of quantitative research enforces participants' responses as well as not affecting or determining the following questions that a researcher asks and how they ask it, and the flexibility of qualitative methods allow the researcher to get

into the lives of participants and gain detailed and deep information regarding their personal beliefs and their own experiences of T2DM.

3.1.4 Quality and reliability of research

A significant part of research is making sure that the quality is of the highest standard. There are three broad principles for assessing quality of research (Yardley, 2000). The first principle is sensitivity to context illustrating an awareness of existing literature relating to the subject being investigated which relates to the underpinnings of the research method. The second broad principle encompasses commitment, rigour, transparency and coherence. Commitment can be tested by the level of participation demonstrated, rigour refers to the thoroughness of the study, and transparency and coherence refer to how clearly the stages of the research process are outlined in the write-up. The third principle explores impact and importance which include whether the research actually conveys anything useful, important, makes any difference or any possible contribution to social change or practice. Yin (1989) suggested that to check for the validity of a study the data should be documented so that anyone could follow the chain of evidence that has led to the final outcome. The alternative is an independent audit which is when the material and data is given to a researcher with no affiliation to the project and he/she checks that the final report is credible and that a logical progression exists through the chain of evidence.

Reliability is also important in research as constructs are often ambiguous, diffuse and not directly observable. It establishes the truthfulness, creditability, and/or believability of findings. Reliability means dependability or consistency suggesting that the same thing is repeated or recurs under identical or very similar conditions. The opposite of reliability is a measurement process that produces erratic, unstable or inconsistent results. Both qualitative and quantitative researchers want reliable and valid measurements.

Sale and Brazil (2004) argued that there is a lack of criteria for assessing the quality of mixed-methods designs. Teddlie (2005) suggested that mixed-methodologies should not be

equally used rather one be the more dominant research method, This way the quality assessment of the dominant methodology will be adhered to. Therefore in the case of this study it is a qualitative dominant mixed-methods research with a subsequent quantitative data input with the quantitative elements of the research being reserved as background data. Consequently the above mentioned quality practices will to be adhered to. As there is a lack of clarity in the matter of mixed-methods quality, this seems to be the best and most logical approach for this study.

3.1.5 Advantages of using focus groups

Focus groups are a widely used qualitative method. Merton and colleagues in the 1940s developed focus groups to extract information from groups about their responses to radio programmes. Before the 1970s focus groups were mainly used as a market research tool (Greenbaum, 1998). In the 1980s health researchers used focus groups in social action research for family planning and preventative health education and they continue to be used for health education and health promotion (Basch, 1987) as well as in health research more generally (Carey, 1995; Wilkinson, 1998). This makes it an ideal tool to be used as part of this project to collect rich valuable data from British-Pakistani women on their perceptions and experiences of T2DM. It will allow for free unrestricted and untainted viewpoints touching on numerous issues.

Another reason why focus group methodology is appropriate is because it allows for the collecting of qualitative data from a small number of people in an informal group discussion rather than one-to-one interviews which would be more time-consuming. There is a common misconception that people will be forced to reveal intimate or sensitive details. Focus groups are well suited to explore sensitive topics and the group context may actually facilitate personal disclosures (Frith, 2000). The aim is not for the researcher to ask questions of each participant rather to facilitate the group discussion by actively encouraging group members to interact with each other. This interaction is a key feature and the one which most clearly distinguishes it from one-to-one interviews (Morgan, 1997). Compared with interviews focus

groups are more naturalistic as they replicate everyday conversation including storytelling, joking, arguing, boasting, teasing, persuasion, challenge and disagreement. The dynamic quality of a group interaction is very high as participants discuss, debate and disagree about key issues. The advantage of focus groups is that they produce ideas, opinions and understandings. Group members trigger memories, stimulate debate and generally encourage personal accounts.

A focus group discussion is audio taped and/or videotaped and the data is transcribed and then analysed by a qualitative technique such as thematic analysis. As well as questions the group can be presented with relevant stimulus materials or they may be asked to engage in a specified activity. Focus group research is not tied to a specific theoretical framework. The method can be used either within an essentialist or within a social constructionist framework. An essentialist framework (Wilkinson, 1998) assumes that individuals have their own personal ideas, opinions and understandings, and that the task of the researcher is to access and extract these cognitions. Whereas social constructionist framework (Wilkinson, 1998) supposes that individuals make sense of things via social interactions between people, and observes how individuals engage in the process of sense making and how views are constructed, expressed, defended and modified within discussion and debate. Essentialist framework uses content or thematic analysis while social constructionist research is more likely to use narrative/biographical or discursive/conversation analysis. Using focus groups captures common ideologies, beliefs and perceptions of the discussed topic in order to gain valid informative data. This is also supported by BARRIBALL and WHILE'S (1994) study which reported that the use of open-ended questions allowed opinions about diabetes to be freely expressed.

The analysis of focus groups preserves participants own words by using quotations and analysis of group interactions. They are advantageous as one can collect a large volume of data quickly and cheaply. The main disadvantages which need to be taken into account are that it can be difficult to recruit and gather appropriate participants at the same time,

moderate a group effectively, and that data transcription analysis is tedious and time-consuming. However overall focus groups are a good choice to use in this project as the purpose is to elicit British-Pakistani women's own understandings, opinion and views as well as exploring the social and cultural context.

3.1.6 Focus groups questions design

PMT and the CSM are used as the theoretical frameworks for the design of the focus group questions in this project (please refer to chapter 1 for background information on PMT and CSM). Three focus group aide-memoires (see appendix 4.1, 4.2 and 5.1) were used in this project consisting of open-ended questions to guide the focus group discussions. There was no big difference between the schedules as the focus groups studies had the same purpose to explore perceptions and preventative T2DM behaviours among British-Pakistani women. The following are examples of the questions asked on the basis of the PMT for the different participants groups:

- Tell me about how you have had to change your diet? Have you been able to eat traditional meals? Have you had to eat differently from your family and friends? / Tell me about how someone you know with diabetes has to change their diet? Discuss if you think they can eat traditional meals?
- What effect has diabetes had on your life? / What effects do you think diabetes would have on your life?
- What effect has diabetes had on your family? What things have family members asked you, especially your children? / What effect would diabetes have on your family?

The above examples were developed from the coping appraisal, vulnerability and self-efficacy of the PMT. The following are examples of the questions asked on the basis of the causes and control/cure constructs of the CSM for the different participants groups:

- What do you think caused you to get diabetes? / What do you think causes diabetes?
- Right now, how much control do you think you have over your diabetes? How much

control do you think you have over your children get diabetes? / Right now, how much control do you think you have over you getting diabetes? How much control do you think you have over your family getting diabetes?

3.1.7 Advantages of surveys

Survey research is widely used and can be used in conjunction with qualitative research, which is ideal for this project. It is used to learn about people's beliefs or opinions in many different research situations. In survey research a questionnaire is used to gather information on the backgrounds, behaviours, beliefs, or attitudes of a large number of people. Participants are asked a set of questions in a short time. They carefully record answers. The advantages of surveys are that they can be given directly to participants, mailed to them or be uploaded on the internet. It is a very cheap way of collecting data and can be conducted by a single researcher. Questionnaires can be sent out to a wide geographical area. Mail and internet surveys offer anonymity and avoid interviewer bias.

3.1.8 Survey design

One questionnaire containing two components was utilised for the quantitative aspect of this project. The first component of the survey design was used to collect statistical data from British-Pakistani women in order to validate and generalise the focus group findings regarding preventative perceptions and behaviours. The main limitation of using qualitative methodology is that data is derived from a small sample of participants so results and findings are hard to generalise (Ogden, 2004). Therefore a 12-item prevention perception scale was produced from the main findings of the qualitative studies to explore British-Pakistani female T2DM perceptions on a larger scale. Participants were asked to score the 12 items in regards to how much they agreed with statements, how they felt about the disease in regards to different situations and common and lay beliefs, lifestyle factors and whether living in Pakistan rather than England affected an individual being diagnosed with T2DM. A Likert scale (1-5) was used to collect participant perceptions allowing for a single-item scale approach to assessing responses on a continuous linear scale. This survey

provided data highlighting British-Pakistani participants' perceptions and beliefs regarding T2DM and the effects on themselves and their immediate family. Two variations of this survey were used, one targeted mothers with T2DM and for the non-T2DM and young female groups the survey was modified to ask participants to score the items according to if they were to be diagnosed with T2DM.

The Illness Perception Questionnaire Revised (IPQ-R) (Moss-Morris, et al., 2002) was used as the second component of the survey for this project. This questionnaire uses the five cognitive illness representation dimensions of the CSM: identity, cause, consequences, timeline and control/cure. The IPQ-R builds on from the Illness Perception Questionnaire (IPQ) which provides a quantitative assessment of these five components. In addition to these five components the IPQ-R includes illness coherence and the emotional representation of illness. Illness coherence is useful to assess importance of how illness makes sense to the participant and could also be an important component in longer-term adjustment and the response to symptoms. The survey design measures emotional representations affecting coping behaviours and ultimately illness outcomes exploring connections between constructs and behaviour. The purpose of the questionnaire is to focus on illness perceptions of participants and their influences on coping, recovery and adaptation to illness for a range of conditions (Groarke, Curtis, Coughlan & Gsel, 2005; Scharloo, Kaptein, Weinman, Willems, & Rooijmans, 2000b). The IPQ has also been adapted so it can be used with spouses and carers of people with health problems (Figueiras & Weinman, 2003; Weinman, Petrie, Sharpe, & Walker, 2000). Therefore the IPQ-R is a good quantitative tool to use as it can be adapted to the three participant groups and because it provides a more thorough and psychometrically acceptable assessment of the key components of patients' perceptions of illness.

The format of the IPQ-R has improved the IPQ survey by separating the causal and identity subscales. Participants are asked to identify symptoms they experience and then to identify which of the symptoms they specifically associate with their illness. The causal scale has

been extended to include more causal items which can be divided into psychological attributions, risk factors, immune system factors and chance factors. There are positive relationships between the attribution factors and illness identity. Psychological and risk factor attributions are related to an increased sense of personal and treatment control suggesting that people feel more in control of their illness if they endorse behavioural and psychological causal factors such as smoking, diet, alcohol, stress, or overwork. On the other hand, immune attributions suggest a more external locus of control relating to a poor sense of treatment control, a chronic and cyclical timeline and serious consequences. Patients who make more psychological attributions also have a tendency to view their illness as chronic and were more distressed by their illness.

The IPQ-R also improves the assessment of perceived timeline of illness by including a cyclical timeline subscale. This increases the reliability of the original acute/chronic timeline subscale and is particularly useful when working with patients whose illness cannot be captured on a simple acute/chronic dimension. The IPQ-R provides support for Horne's (1997) argument that the control dimension can be divided into personal and treatment components. The new and revised IPQ-R dimensions appear to show logical inter-relationships. For example, beliefs in treatment and personal control and a sense of illness coherence are related to pessimistic beliefs about the timeline and consequences of an illness as well as to negative emotional representations (Horne, 1997).

There are limited studies focusing on how healthy people view and perceive health and illness, and how their ways of thinking relate to health-related behaviours (Figueiras & Alves, 2007). Weinman et al. (1996) expressed the opinion that adaptations can be made to the IPQ to test the psychometric status of it especially with different illness populations therefore in this study the IPQ-R is used with British-Pakistani mothers with T2DM and an adapted version of the IPQ-R for British-Pakistani mothers. Young people's illness perceptions are compatible with adults (Paterson et al., 1999, Chi et al., 1982) therefore the adapted IPQ-R was also used with the young British-Pakistani female group which consisted of young adults

(18 years+). The adapted version asked participants for their perceptions if they had T2DM. Using the IPQ-R across the three groups encouraged consistency and reliability of the study. Figueiras and Alves (2007) developed an adapted version of the IPQ-R to use with healthy people that explained significant variance in attitudes and intentions towards the adoption of preventive behaviours, justifying the appropriateness of using the IPQ-R across all the groups.

3.2 British-Pakistani women population group

3.2.1 Difficulties in accessing this population

Many British-Pakistani communities are considered to be hard to reach groups in the UK due to language/communication barriers and issues (Vyas et al., 2003; Lawton et al., 2006). Many Pakistanis especially those who have migrated or of the older generation are illiterate even in their first language. Hawthorne and Tomlinson (1999) recorded that there is a need for more intensive culturally appropriate health education and support especially as many Pakistani women who are illiterate are older, have poorer glycaemic control and find it difficult to apply their knowledge into daily life problems. They also documented that the healthcare terminology and jargon used was not understood or easily translated into other languages. The main challenges with this ethnic group are universal. These are illiteracy, low levels of education and poor language skills in the main language of the country they are living in (Hussain-Gambles, Atkin & Leese, 2004). Another universal challenge lies in the different health beliefs and behaviours that migrant populations have compared with the rest of the general population (Johansen, Bjorge, Hjellset, et al., 2009). It is crucial to research the British-Pakistani women population to learn and understand their perceptions and behaviours in order to produce effective and relevant resources.

3.2.2 Advantages of using British-Pakistani female researcher

A main concern in research is regarding ethnic differences between the researcher and participant as this may affect the genuineness and accuracy of what participants say

(Rhodes, 1994). This can also be mirrored in quantitative research situations whereby participants are given a survey to complete by someone of a different ethnicity to them particularly when dealing with sensitive topics (Davis, Janz, Caldwell & Resnicow, 2010). Ethnicity of interviewer effect refers to response bias and measurement error found in the changes people make to their opinions and attitudes when questioned by a researcher from a different ethnic group (Gunaratnam, 2003). Therefore it is not unusual for research studies to exclude ethnic minority research participants because they are difficult to reach as well as the language and cultural differences. However this project does not suffer from this dilemma.

The main researcher was the same race and ethnic group of the participants which allowed for many of the barriers to be overcome such as language and cultural issues. The researcher was able to understand certain phrases said in Urdu which do not have as much significance when directly translated into English, probing further discussions. The gender of the researcher was the same as the participants which was very important as many Pakistanis refrain from mixed-gender activities. This allowed for Pakistani women to feel more relaxed and willing to take part in the focus groups. Age of the researcher was also significant. The older Pakistani women opened up to the researcher as if they were parting knowledge and wisdom to a keen learner, and the younger generation did not feel as intimidated to open up in discussions as the researcher was perceived to be of similar age. The benefit of matching races between researchers and communities are stressed repeatedly (Blauner & Wellman, 1973; Stanfield & Routledge, 1993), thus adding further quality to this project. However the researcher was also mindful of disadvantages. For example participants may not be as open with their discussion because the researcher belongs to the same community as them so they may feel their confidentiality is at risk.

3.2.3 Ethical approval

For the British-Pakistani mothers' focus group study National Research Ethics Service (NRES) approval was sought from the Birmingham, East and North and Solihull NRES

committee. They approved the study with no major amendments. A minor change was requested to the consent form which was to reflect the accurate version and date of the information sheets. For the British-Pakistani mothers' questionnaire study NRES approval was sought from the West Midlands South Birmingham NRES committee. They approved the study subject to one major change. The first section of the adapted IPQ-R is a list of possible T2DM identity variables which participants answer 'yes' or 'no' to. The NRES committee requested a 'Don't know' column to be added to the section. On NRES ethical approval, HEFT and BEN Primary Care Trust Research and Development approvals were obtained. For both of the young British-Pakistani female qualitative and quantitative studies, Aston University ethics approval was sought. Approval was obtained with no amendments for either study. For all the studies Aston University and British Psychological Society (BPS) ethical guidelines as well as health and safety regulations were adhered to at all times.

3.3 Data analysis

3.3.1 Data analysis of focus groups

One of the focus groups was conducted in Urdu therefore the conversations were transcribed in Urdu and then translated into English by the researcher. In order to assure the quality of the translation, the translated English transcript was translated back to Urdu by a Birmingham Adult Education English for Speakers of Other Languages (ESOL) tutor using back translation.

The focus group data was analysed using thematic analysis (Braun & Clark, 2006). Thematic analysis was the appropriate method of analysis because it allowed the researcher to organise the data, describe it in detail and interpret various aspects of the subject under investigation, and was also a flexible analysing technique. Another advantage lies in it not being attached to any theory making it applicable with a wide range of theoretical models (Braun & Clark, 2006). Thematic analysis can be used with different methods including essentialist or realist methods, another reason for its compatibility with focus groups. This

analytical method allowed for the exploration and interpretation of perceptions and beliefs of T2DM as well as the prevention of it among British-Pakistani women via the construction of themes. The focus group data was analysed in accordance with the stages of thematic analysis which are data familiarization, initial coding generation, searching for themes, review of themes and finally theme definition and labelling (Braun & Clark, 2006).

3.4 Report writing

The report writing encompasses the final analysis of results both qualitative and quantitative, as well as the writing up of the reports. For the focus group studies the transcripts provided sufficient supporting extracts which were arranged into brief, attractive and logical accounts to illustrate the different themes and to highlight important issues and discussion points. The survey study provided statistical evidence to support or not relationships between prevention perceptions and illness perceptions of British-Pakistani women. The combination of methodologies allowed for the flexibility and generalisability of findings and supports the quality of this project.

Chapter 4

Perceptions and prevention beliefs of T2DM among British-Pakistani Mothers with and without T2DM

4.1 Introduction

Good diabetes education is important in diabetes prevention and management but many South-Asian communities in Britain have shown that they know less about diabetes and its management than white British people (Lawton, Ahmad, Hallowell et al., 2005; Hawthorne & Tomlinson, 1999). The findings of the systematic review (in chapter 2) found that good education is part of an effective prevention intervention when centred on a lifestyle component. According to Pieroni and colleagues (2008) diabetes among British South-Asians is a major issue for public health providers. They reported that public health policies need to concentrate on improving the efficacy of prevention and understanding the socio-cultural backgrounds within ethnic minorities in order to improve prevention programmes. The purpose of this study is to discuss with British-Pakistani mothers their perceptions and beliefs surrounding T2DM to establish T2DM prevention knowledge and/or behaviour among those with a diagnosis of T2DM and non-T2DM at high-risk of developing the condition.

4.1.2 T2DM labelling

Hornsten, Sandstrom and Lundman (2004) reported that T2DM is labelled in various ways. Mexican-American women with diabetes use the term 'sugar diabetes' (Luyas, 1991). For them the term sugar diabetes represented biological complications (particularly amputations and loss of eyesight) and table sugar in the blood. T2DM means different things to different people, especially regarding the consequences of the disease relating to many different factors such as the importance of taking care of oneself (Hunt et al. 1998), worry, anxiety and

depression (Hampson et al. 1990), body damage (Gregory et al. 1999) and dramatic change in lifestyle and relationships leading to social problems (Cohen et al. 1994). T2DM involves the whole individual as well as relatives and therefore has obvious influences on social life (Hornsten, Sandstrom & Lundman, 2004). This is also supported by the systematic review reported (in chapter 2). T2DM is acknowledged as a serious disease especially as it can lead to amputations, vision loss, renal failure and in extreme cases death (Gregory et al. 1999), and many people share a common and accurate perception that the disease will last throughout life (Cohen et al. 1994, Hjelm et al. 1999).

4.1.3 Physical Activity

Physical activity can help to prevent the onset of T2DM especially among British-Pakistanis who tend to lead a more sedentary lifestyle in the UK (Hayes, White, Unwin et al., 2002; Johnson, 2000). Promoting physical activity among Pakistani women is particularly challenging due to cultural barriers such as religious modesty, avoidance of mixed-sex activity and/or fear of going out alone (Rai & Finch, 1997; Johnson, 2000). Sriskantharajah and Kai (2006) reported that understanding beliefs and attitudes towards physical activity among this high at-risk group is lacking, and suggested the need for better health professional guidance on appropriate physical activity, the health benefits and safety by focussing on similarities rather than differences.

4.1.4 Prevention programmes

The National Health Service (NHS) is often criticised for failing to meet the needs of ethnic minorities however British-Pakistanis report high levels of satisfaction especially with GPs and in-patient hospital care, but not as much with casualty nurse care (Madhok, Hameed & Bhopal, 1998). Research found that South-Asians would benefit from this as one of the main barriers to care for them is language resulting in poorer access to care (Lawton, Ahmad, Hanna, Douglas & Hallowell, 2006; Shaukat, de Bono & Cruickshank, 1993; Hawthorne,

1994). A majority of the British-Pakistani women approached and recruited for this study did not have any concerning issues with the NHS and were able to engage with their services.

Poor T2DM outcomes among South-Asians especially Pakistanis have been credited to differences in access to care, inappropriate education, poor understanding of T2DM and different attitudes to health (Hawthorne, 1990; Greenhalgh, 1997; Szczepura, 2005). Major concern relates to the lack of culturally sensitive diabetes services due to a lack of user engagement (Hawthorne, 1990; Hawthorne & Tomlinson, 1997). Lawton and colleagues (2006) explored individuals' experiences and views about diabetes services in Edinburgh. They reported that participants did not like using interpreters as opposed to a bilingual professional with whom they could discuss their diabetes care directly. Lawton et al. also stated that link-worker schemes may meet T2DM patients' need to receive culturally sensitive information in their first language work but this needs to be assessed for its effectiveness and sustainability. This may provide an explanation for why many non-English speaking South-Asians prefer a family member to attend healthcare appointments so that they can discuss issues with healthcare professionals through an English speaking intermediary. Khunti, Camosso-Stefinovic, Carey, Davies and Stone (2008) highlighted the difficulty of designing, assessing and achieving an impact through educational interventions for T2DM South-Asians and emphasised the need for good-quality studies in these high-risk populations. An individual's personal understanding of illness is important and is a significant shared source for planning meaningful care.

4.1.5 Cultural considerations

Successful prevention of T2DM requires understanding the lifestyle, beliefs, attitudes, family and social networks of an individual (Greenhalgh, Helman & Chowdhury, 1998). Culture should always be viewed and studied in its particular context in order to correctly understand it. Greenhalgh et al. stated that there are three levels of cultural behaviour which are what people say they do, what they are observed doing, and the underlying belief which influences

that behaviour. An individual's beliefs are culturally determined affecting health, self-care behaviour, type of healthcare sought and agreement with the diagnosis and management (Helman, 2000; Glasgow et al., 1997). Cultural distance such as differences between cultures in language, social structure, religion, standard of living and values may influence an individual from living and behaving in a healthy way (Hjelm et al., 1997). There is currently limited research exploring the influence of cultural distance on health among people with diabetes from different migrant groups. Previously it was predicted that contact with ethnic minorities with diabetes will increase providing knowledge of health and illness beliefs for them (Bury, 1997; McCord and Brandenburg, 1995). Over the last decade the ethnic minority and migrant numbers in Birmingham, as well as the rest of the UK, have risen therefore it is vital to tackle this epidemic especially among Pakistanis who have a high prevalence rate. There is a lack of research conducted with British-Pakistani regarding T2DM prevention as demonstrated by the systematic review (in chapter 2). As there is a high prevalence rate within British-Pakistanis it is important to involve them in the research process to explore and understand their culture and lifestyles. Lai, Lew-Ting and Chie (2004) conducted a study on Taiwan participants to investigate Chinese people with diabetes' perceptions of illness and treatment strategies to encourage the use of patient-centred and culture-sensitive clinical skills. Chinese participants regarded treatment strategies as part of their daily life and routine in order to manage their T2DM, which is particular to Chinese people with diabetes.

Finucane and McMullen (2008) conducted a study to identify the cultural values, traditions, and perceptions of diabetes risk and self-care among Filipino-Americans in Hawaii with T2DM in order to highlight the key factors facilitating and impeding their participation in diabetes self-management education (DSME) behaviours and education classes. They recruited 15 participants and conducted focus groups and interviews that were coded thematically. Finucane and Mullen reported that Filipino-American culture was central to understanding the barriers to engaging Filipino-Americans in self-management behaviours and DSME. The first barrier was prioritising the family and maintaining social relationships

over their self-management of diabetes, second was changing their diet in accordance with preserving valued symbolic and social meanings of food. The third barrier was storytelling incorporating stigmas associated with diabetes, and lastly combining spiritual and biomedical interpretations of the causes and management of the disease. Participants also highlighted the role of perceived risk such as dread and control in influencing their behaviours. Therefore culture is important and awareness of cultural values in diabetes self-care behaviours and education programmes may improve teaching methods, materials and recruitment procedures. This study will explore the culture and traditional values, beliefs and perceptions among British-Pakistani women.

Hjelm, Bard, Nyberg and Apelqvist (2003) explored health and illness beliefs among women with diabetes from different religious backgrounds living in Sweden. They found that Swedes were active in enforcing self-care behaviours and leading a healthy and controlled lifestyle. Ex-Yugoslavian Muslims expressed their enjoyment of life and a passive self-care attitude. Arabs adapted to their diabetes and made a lot of significant changes concerning their diet yet they were reluctant to seek care. Arabs emphasised that being a believing Muslim meant they attributed the cause of diabetes as the will of Allah and they actively searched for information about diabetes management in contrast to ex-Yugoslavian Muslims. This study suggests that by simply knowing someone's religion does not explain their beliefs, thus these are cultural rather than religious factors. Hjelm et al. summarised their findings by stating that cultural and religious factors are both essential for understanding self-care practices and care-seeking behaviours thus they need to be considered in the planning of diabetes care and prevention.

Mellin-Olsen and Wandel (2005) reported that the Pakistani immigrant group in Norway are a high-risk population group in need of a T2DM-prevention approach. Therefore they conducted focus groups with 25 Pakistani women to provide information on dietary change and factors leading to these changes in order to design appropriate strategies for dietary counselling. According to these women, life in Norway had led to several changes in their

meal pattern, meal composition and intake of different foods. Meals on weekends tend to be more traditional than on weekdays because the whole family is together. Chapatti and curries are prepared in the same way in Norway as in Pakistan and eaten to feel full and satisfied. Also when they have guests, the women serve snacks that include both traditional and western food such as offering coke or juice or tea with some nuts, crisps, biscuits, Pakistani sweets '*mitie*' and/or samosas, pakhoras or kebabs. The focus groups revealed a rich variety of factors influencing dietary change including health aspects, children's preferences, work schedules, social relations, stress, traditional beliefs, climate, season and access of foods. Lawton, Ahmad, Hanna et al. (2008) explored the food practices and perspectives of Pakistanis with T2DM in Edinburgh and found that they consumed Western food items for breakfasts, lunches and snacks, and ate traditional meals in the evenings. The participants' perceptions of South-Asian foods was that it is bad for one's health but good for one's self as there are emotional and cultural meanings also attached to it. The importance attached to the consumption of South-Asian foods became clearer when participants discussed family and community life in Britain. This was previously reported by Simmons and Williams (1997) who conducted a study in Coventry, UK, between Europeans and different South-Asian groups. They documented that there were four major influences on food: regional, religious, acculturation and health messages. All South-Asian groups ate high fat English foods and enjoyed indulging in Indian sweets (*mitie*) and fried snacks. Mellin-Olsen and Wandel concluded that in order to develop an effective intervention strategy it is vital to understand how changes occur and the different factors influencing dietary habits.

4.1.6 Prevention behaviours

Good nutrition in early life is critical for growth and health, and preventing disease later in life (Oddy, 2001; Sarwar, 2002). Sarwar (2002) investigated infant feeding practices followed by Pakistani mothers in Pakistan and in England. He found that foods regularly being fed to infants were rice, eggs, fruit, vegetables and family food in Pakistan whereas fruit, vegetables, eggs, meat and convenience foods were more popular in England. Convenience

foods especially sweet options were being offered a lot by mothers in England. Sweet baby food options were given for desserts and snacks when a baby seemed hungry and unwilling to accept any other food. They were also being denied their traditional diet as mothers seemed to lack confidence in adapting family foods so that it was suitable for the infant. In both countries sweet drinks were being offered resulting in poor dental health. Sarwar suggested that this may be due to confusion between advice from relatives and health professionals especially in England. Previously researchers examined cognitive factors such as attitudes to healthcare and perceptions and knowledge about diseases (Bandura, 1977; Greenhalgh, Helman & Chowdhury, 1998) to gain a better understanding of human health behaviour. These cognitive factors are open to change and allow the development of more effective behavioural prevention interventions. Thus perceptions and beliefs regarding T2DM will be explored in this study.

Models of health behaviour describe how health risk perception affects carrying out preventive behaviours (Janz & Becker, 1984; Rogers & Prentice-Dunn, 1997; Weinstein, 1993). Medical models of disease typify risk in terms of probability such as incidence rates however extensive research (Slovic, 2000) has shown that lay perceptions of risk are more crucial as they reflect qualitative dimensions e.g. the point to which a risk is known or feared. Perceived risk is not independent of cultural context. Worldviews influence individuals' perceptions of and responses to risk (Finucane & Satterfield, 2005; Finucane, Satterfield, Slovic et al., 2003; Skinner & Hampson, 2001). A fatalistic worldview which is common e.g. among Filipino Americans increases feelings of dread related to T2DM which is attributed to a perceived lack of personal control yet at the same time fatalism may decrease the likelihood of engaging in risk-reducing behaviour (Finucane & McMullen, 2008). Research on T2DM risk perception is limited but the consensus is that many individuals are unaware of the risk and have misconceptions about the disease (Eiser, Eiser, Riazi et al., 2002; Fisher, Walker, Bostrom et al., 2002.)

4.1.7 Study aim

Limited qualitative methods have been used in studies of diabetes education participation rates (Gonder-Frederick, Cox & Ritterband, 2002; Finucane & McMullen, 2008). Therefore there is a need to use qualitative methodology and the British-Pakistani community to develop effective prevention strategies for T2DM. It is the purpose of this study to conduct focus groups with British-Pakistani mothers with and without a diagnosis of T2DM.

4.1.9.1 Research Question

What are the beliefs and perceptions of T2DM among British-Pakistani mothers with and without a diagnosis of T2DM and do they try to prevent the onset in themselves and families especially their children?

4.2 Method

4.2.1 Design

Focus groups were used for this study because they allow the researcher to create and facilitate an interactive environment enabling participants to share and explore ideas and opinions, and generate rich viable data. Participants are given an opportunity to divulge into their beliefs and experiences freely and without the fear of being persecuted for them. Focus groups are very beneficial in allowing participants to discuss their beliefs and experiences at length and confidentially especially as illness and lifestyle are sensitive and personal issues. It also allows open conversation to develop providing reliable research and better understanding towards the target research group. Participants may not been given this chance to develop and divulge issues into conversation in individual interviews (Kitzinger, 1994) thus the use of focus groups. Focus groups can also highlight emotions and feelings illustrating a participants' point of view via them querying each other and explaining themselves (Morgan, 1996).

Focus groups were a suitable methodological choice as they provided an opportunity to explore British Pakistani mothers' views, perceptions and experiences in depth, and were also a convenient data-gathering tool for use in areas which are under-researched. Focus groups have also been successfully used within ethnic minority community groups in other health-related research (Doshani, Pitchforth, Mayne & Tincello, 2007). The author of this study was suited to moderate the focus groups as she possessed essential interviewing skills, knowledge regarding group dynamics and experience of running group discussions. She was also multi-lingual allowing her to understand and transcribe sub-continental dialects and phrases to encourage the flow of the discussion.

4.2.2 Materials

Two aides memoire (see appendix 4.1 and 4.2, and tables 4.1 and 4.2) were developed consisting of open-ended questions and discussion points. The focus groups were kept to a semi-structured and informal format to allow conversations to flow. Answering the discussion points on the aides memoire in order was not at all important as the facilitator found that participants would discuss numerous points simultaneously or mention a discussion point on their own accord. The two aides memoire used were similar as they prompted the same discussion points and topics but were worded differently according to the two research groups. The aide memoire for the focus groups with participants with a diagnosis of T2DM included questions such as *'what do you think caused you to get diabetes?', 'has living in England instead of Pakistan affected you getting diabetes? If yes how? If not why not?'* and *'since your diagnosis who from the health service have you seen? What kind of support have you received?'* The aide memoire for the focus groups with participants without a diagnosis of T2DM included questions such as *'what do you think causes diabetes?', 'has living in England instead of Pakistan affected Pakistanis getting diabetes? If yes how? If not why not?'* and *'what kind of support would you expect someone with diabetes to get from the health service?'*

Resources from Diabetes UK were used to prompt and generate discussions during the focus groups. They were left on the tables in the research locations where the focus groups were taking place. A digital voice recorder was used to record the focus groups. Participant information sheets (see appendices 4.3 and 4.4), consent forms (see appendices 4.5 and 4.6) and debrief sheets (see appendix 4.7) were also used.

Number	Question
1	Can you tell each other how you were diagnosed with diabetes?
2	How did you feel when you found out?
3	How did your family react to your diagnosis?
4	What do you think caused you to get diabetes? Use prompt about high prevalence of diabetes amongst South-Asians
5	Does living in England instead of Pakistani, effected you getting diabetes? If yes, how? If not, why not?
6	Do you think your diet affected you getting diabetes? If yes, how? If not, why not?
7	Tell me about how you have had to change your diet? Have you been able to eat traditional meals? Have you had to eat differently from your family and friends? Prompts of traditional Asian (Pakistani) cuisine
8	During Ramadhan, does your diet differ from your family / friends' meals? If yes, how? If not, why not? Use prompts about healthy eating during Ramadhan.
9	During Eid, does your diet differ from your family / friends' meals? If yes, how? If not, why not?
10	Tell me how and where you are able to do exercise?
11	How have you changed your exercise routine since being diagnosed with diabetes? If yes, how? If not, why not?
12	Since your diagnosis, who from the health service have you seen? What kind of support have you received?
13	How often do you see a health professional regarding your diabetes?
14	What effect has diabetes had on your family? What things have family members asked you, especially your children?
15	What things do you say to family members especially your children to help them not get diabetes?
16	What do you do different from before now that you are aware of your diabetes?
17	What kind of things would you like to get from the health service to help with your diabetes?
18	Currently how do you feel about your diabetes? How do you feel about your children's health?
19	Right now, how much control do you think you have over your diabetes? How much control do you think you have over your children get diabetes?
20	Is there anything you want to bring up which we haven't talked about?

Table 4.1 Aide memoire for focus group British Pakistani mother participants with type2 diabetes

Number	Question
1	Can you tell each other your ideas about what you think diabetes is?
2	What do you think causes diabetes?
3	How would you feel if you were diagnosed with diabetes?
4	How would your family feel if you were diagnosed with diabetes?
5	Has living in England instead of Pakistani, effected Pakistanis getting diabetes? If yes, how? If not, why not? Use prompt about high prevalence of diabetes amongst South-Asians
6	How do you think your diet affects you getting diabetes?
7	Tell me about how someone you know with diabetes has to change their diet? Discuss if you think they can eat traditional meals?
8	During Ramadan, how would their diet differ from their family's or friends' meals? Use prompts about healthy eating during Ramadhan
9	During Eid, how would their diet differ from their family's or friends' meals?
10	How would it make you feel if someone with diabetes could not eat the traditional foods you like to eat? Prompts of traditional Asian (Pakistani) cuisine
11	Tell me how you think exercise effects someone getting diabetes?
12	What kind of support would you expect someone with diabetes to get from the health service?
13	What effects do you think diabetes would have on your life?
14	What effect would diabetes have on your family, your children?
15	What things do you and your family do to try any stop getting diabetes? How? If nothing, why not?
16	What kind of things would you like to get from the health service to help you understand diabetes better?
17	Currently how do you feel about your health? How do you feel about you children's health?
18	Right now, how much control do you think you have over you getting diabetes?
19	How much control do you think you have over your children getting diabetes?
20	Is there anything you want to bring up which we haven't talked about?

Table 4.2 Aide memoire for focus group British Pakistani mother participants without type2 diabetes

4.2.3 Participants

Twenty-eight participants were recruited for this study. Eighteen participants did not have a diagnosis of T2DM and 10 participants did. Of the 18 participants without T2DM one dropped out and of the 10 participants with T2DM two dropped out. Altogether 25 participants took part in this study. All participants were female, mothers and were from a Pakistani ethnic background. Participants without a diagnosis of T2DM were recruited from three SureStart centres in Birmingham (Adderley Children's Centre, Highfields Children's Centre and Ward End Sunshine Centre) (see appendix 4.8). SureStart children's centres provide a variety of advice and support for parents and carers such as professional advice on health and family matters, training and job opportunities and socialising opportunities. Their

services are available to people from pregnancy up until a child goes into reception class at primary school. There are many across Birmingham and four were approached to take part in this study and they accepted. These centres allowed recruitment to take place in the 'Stay and Play' and 'Mother and Toddler' sessions. British-Pakistani mother participants were recruited from Heartlands Diabetes clinics and the Birmingham East & North (BEN) community clinics (see appendices 4.9 and 4.10). Heart of England Foundation Trust (HEFT) is one of the largest foundation trusts in the UK providing general and specialist hospital and community care for the population of East Birmingham, Solihull, Sutton Coldfield, Tamworth and South Staffordshire. They provide services at the heart of their communities, and their hospitals include Birmingham Heartlands Hospital, Solihull Hospital, Good Hope Hospital and Birmingham Chest Clinic. They also provide community health services running a small number of satellite units allowing people to be treated as close to home as possible. One of the community services is BEN community service which provides expert diabetes help in the east and north of Birmingham.

Five focus groups were conducted; two focus groups with participants with a diagnosis of T2DM (DM4, DM5) and three focus groups with participants without a diagnosis of T2DM (NDM1, NDM2, NDM3) (please refer to table 4.1 for details). The majority of the non-T2DM sample of participants was housewives, three participants were in part-time employment and two were in full-time employment, age range 25-40 years. They had a varied range of educational qualifications from no formal qualification through to degree level. The British Pakistani mothers with T2DM were housewives and five of the eight participants did not speak English so they conversed in Urdu. The information sheets were not translated into Urdu script as participants were content with the main researcher discussing the information with them and then taking the information away with them to discuss with their families. Five of eight British Pakistani mothers with T2DM were born in Pakistan and moved to the UK when they got married. Their age range was 35-50 years. Most T2DM participants had no formal educational qualifications however three stated they were educated to college level, one in the UK the other two in Pakistan.

Focus group title	Participants
Non Diabetes Mellitus (NDM) 1	A B C D E F G H
NDM2	I J K L
NDM3	M N O P Q
Diabetes Mellitus (DM) 4	R S T
DM5*	U V W X Y
	INT= Interviewer

Table 4.1 British Pakistani mothers' focus group details

* Focus group conducted in Urdu

4.2.4 Procedure

Ethical approval was granted by the Aston University School of Life and Health Sciences Ethics Committee as well as the NHS Birmingham East and North (BEN) and Solihull Research Ethics Committee. The number of participants in each focus group was determined by the number of participants recruited at each location. This allowed for participants to be automatically sorted into groups where participants either had or did not have T2DM. Thus homogeneity was maintained in the groups allowing participants to openly share their experiences with other group members with whom they could identify (Krueger, 1988). The participants with T2DM did not know of each other prior to the focus group session. The participants without T2DM did know of each other prior to the focus group session as they were recruited from the same parent groups held at the SureStart centres.

Once gathered at the research site participants were briefed about the nature of the study. It was explained to them what a focus group is, and that there were no right or wrong answers. The focus group was not about the researcher judging their ideas, beliefs or behaviours. It was about understanding their views and opinions and thinking about ways that research can help them. They were given an opportunity to ask any questions or express any concerns they had. They were given the participant information sheet to read. They were then asked to complete the consent form. The participants were advised of their right to withdraw at any time during the study and up to one month after. They were informed that the focus group would be digitally voice recorded, but the transcripts would be coded so that any identifying

information will be changed or removed. The participants were notified that any data they did provide would be kept safe and secure in a locked filing cabinet and on a password protected PC. Participants were then informed that although the information shared in the focus groups would be anonymous it will not be strictly confidential, as the researcher will need to provide an analysis and report of the data which will be read by others. Participants were also requested to respect each others' confidentiality by not mentioning anything discussed by a participant outside the focus group. They were given a choice to opt for a pseudonym.

Each focus group lasted between 30 and 61 minutes. At the end of the focus group participants were debriefed about the nature of the study and about what would happen to their data. They were reminded of the confidentiality rules and thanked for their participation.

4.2.5 Analysis

The focus groups were transcribed verbatim. Thematic analysis was conducted. Transcripts were read several times and key points highlighted. These key points were placed in a spider diagram and then grouped together to form super-ordinate and subthemes.

4.3 Study 1 Results Part 1-

Perceptions and experiences of British-Pakistani Mothers with a diagnosis of T2DM

4.3.1 Introduction

Thematic analysis was used to analyse the focus group data. Five superordinate themes were identified: *Causal factors and symptoms*, *Management/control*, *Emotions*, *Moral support & social influence*, and *Pakistani lifestyle*. These themes are discussed in turn using data extracts from the five focus groups.

4.3.2 Causal factors and symptoms

4.3.2.1 Biological factors

Participants identified many causes for the onset of T2DM. Participants demonstrated an understanding that T2DM was related to blood sugar and explained how their blood sugar levels vary as a result of their diabetes. They also identify key biological factors that play a part in the onset of T2DM touching on some medical knowledge.

U: Sometimes it would go low and sometimes it would go high it, it was this way for a while but its high now (lines 10-12 FG5)

S: ...with my daughter even when she was ill and her immune system was down th::at her pancreas was attacked (lines 134-135 FG4)

W: but I've heard that there's something within a human that stops working and it's because of that it happens >only the doctors can find that out< the reason for that, we just we just guess it's because of this reason it's because of that reason (lines 186-188 FG5)

U: It depends on someone's (.) someone's body-bodyworks (line 276 FG5)

Participants shared their knowledge regarding the biology behind this disease. They were able to highlight the main mechanisms involved and had a vague idea about how the

production of insulin or lack of it contributes to the onset of T2DM. Participants did not display detailed and accurate medical knowledge; they understood that there was something innate that contributed to their disease but were not able to give any specific information.

4.3.2.2 Impact of other illnesses

Some participants discussed how they believed their diabetes was a direct result of another illness:

U: In 94 when I got ill (.) I had chest problems I went into hospital they gave me tablets (.) five year tablets I took them and I got sugar. They gave me a lot of tablets and stuff but they couldn't tell me why I got sugar and then they stopped the tablets and by stopping the tablets they found out that I got sugar and it was because of the tablets (lines 5-10 FG5)

W: Me (.) for me it has only been a little while, before I was fine I didn't have anything wrong-I had regular (.) check-ups and I was fine and >then I developed a back problem and whether it's from the medication I take for it< or (.) I still haven't found put how it happened but suddenly I would be in pain, and then I changed my GP and he did some tests and he said you have sugar (lines 24-29 FG5)

X: ...also I had a stroke (lines 215-217 FG5)

These participants explained how their previous illnesses have contributed to them developing diabetes more specifically as a side-effect from the medication they took. They believed that this could not have been avoided as it is crucial to take medication for the above mentioned illnesses (chest pains, back pains and stroke) therefore they believed that taking the medication regularly for a long period of time led to them developing the disease. Illness has an effect on other illnesses and so participants believe that they become interlinked. Whether an individual has one disease or several, participants illustrate that they become labelled as an ill person and it was less surprising when they are diagnosed with another illness. The T2DM group reported that their diabetes has an effect on other illness and vice versa. Participants discussed how T2DM is affecting them as they are suffering from it firsthand.

R: yeah and I've started to get aches in my legs and knees now

S: Yeah I feel like I'm tired more (lines 687-688 FG4)

W: [Yeah sleep late at night like I said] everyone's different they have different habits, different circumstances, what do you call it (.) kind of things that help you erm but with me when I go out I'm not in the mood, don't feel like going anywhere, meeting anyone, I just feel like staying indoors most of the time so I sleep. When I'm lying in bed in the mornings I'm just lying there I don't feel like getting up (lines 607-613 FG5)

Participants believed their disease causes more physical symptoms like aches and pains as well as tiredness. T2DM participants emphasised how they are suffering more since their T2DM diagnosis which seems to be a common trend among T2DM sufferers. It was not clear whether the T2DM participants attributed their diabetes as the cause or whether they believe they are now more prone to other health problems. Participant W mentioned before that she had depression being diagnosed with diabetes and since then her depression had worsened.

4.3.2.3 Gestational diabetes

Some had developed gestational diabetes during pregnancy and discussed the links with their condition now.

R: [I was] diagnosed diagnosed with my youngest child when I was pregnant
INT: Right [ok and its]
R: [yeah and then] it went away and then it came back again (lines 12-16 FG4)
T: Yeah and mine's the same. I had gestational diabetes and then it just continued (lines 20-21 FG4)
W: Yeah my daughter-in-law eldest daughter-in-law [had it like that and now she doesn't]
U: [but apart from that no-one else has it, my husband did have it]
W: They told my daughter-in-law it was because of her pregnancy and that it will go away [because she use to have it bad]
V: [Yeah it will go away its quite common] (lines 1013-1020 FG5)

Participants recognised this form of the disease. They illustrated awareness and knowledge regarding gestational diabetes. Some of the participants explained how their daughters and daughter-in-laws had the disease but it had gone after giving birth. This form of diabetes has become common among many pregnant women especially Pakistanis as Participant V voiced, however it also seems to spark the beginning of life living with T2DM (Nicklas, Zera,

Seely, et al., 2011; Oldfield, Donley, Walwyn, et al., 2007) which was the case for some of the participants in this study.

4.3.2.4 Psychological factors

Participants discussed stress as a psychological cause of T2DM and high blood sugars.

- S: Even in the evening when you've had something really light and you can't understand why=sometimes it's stress I think
- T: Yeah it [could be]
- S: [I think] it's stress as well. If you're stressed out it tends to be [a lot higher°] (lines 209-213 FG4)
- V: [But its caused by stress] (line 118 FG5)
- X: [Stress stress] stress I was always stressed. Remember my daughter's problem? That was stressful and the doctor said it was due to stress, it's down to stress (lines 215-217 FG5)
- W: She's saying that its stress related >she's saying that when it was her son's wedding she wanted it to be a success and she did a lot of worrying< and that's why it's happened because of stress but for the record I don't think it happens because of stress because when you're stressed-everyone gets stressed and that doesn't mean that everyone's got it (sugar) >yeah but no she's saying that 1 in 3 people has it and it's because of stress< and I agree that if you have sugar then stress will make it worse
Some participants agrees
- W: But I think that it's not the cause
- INT: Ok
- W: it's not the reason-it's not the reason that you get a lot of stress and this is the reason why you have sugar (lines 146-159 FG5)

A majority of the T2DM participants believed that stress can cause T2DM. They believed that stress and worrying is another causal factor of their diabetes as they recalled being highly stressed before being diagnosed. However Participant W disagreed. She emphasised that stress does not cause T2DM but it will affect it once diagnosed. They discussed stress as a causal factor from a psychological point of view as they have experience of the disease and can relate to it emotionally, physically or psychologically. For these participants being diagnosed with a disease that is permanent and life impacting is

stressful especially for Pakistani mothers who have familial responsibilities and a long list of other responsibilities.

4.3.2.5 Symptoms

Across the focus groups participants were able to recognise biological symptoms identifying the onset of T2DM.

S: Er::m (.) with me I found out that erm I was actually drinking more water

INT: Uhm

S: So erm there were signs there (lines 4-7 FG4)

Y: Laughs (.) <I would get> very sleepy-tired and I would get a lot of pain (lines 40-41 FG5)

W: But there's a big difference when you have sugar you feel tired all the time you feel weak indeed their weight-some people they put on weight I mean the tablets I'm taking >my weight has gone up since I've had sugar< my weight has increased-lots of people lose weight but instead of me losing it I'm putting it on

V: I've lost weight (lines 119-124 FG5)

All the participants illustrated knowledge regarding T2DM symptoms. The T2DM group shared their experiences and their main symptoms which were being thirsty, constantly tired, in continuous pain and weight change. This was the only time weight was mentioned by participants explaining how it changed as a result of the disease and/or its treatment. It is otherwise not mentioned among these participants as a causal factor.

4.3.2.6 Genetics

In this study participants clearly illustrated that another significant causal factor of T2DM was genetics.

S: INT:: (.) I thought maybe perhaps it's hereditary, you know you know where the family's got it so (124-125 FG4)

W: Yeah my mummy has it

V: My mummy has it

W: Her mummy and her sisters have it

V: my sisters and [my brother]

W: [her brother]

W: It's infiltrated her family and it's infiltrated mine

Y: Yeah so it's hereditary (lines 1043-1049 FG5)

Participants highlighted the familial pattern of T2DM within their own families. Genetics plays a vital role in determining the prevalence and susceptibility of this disease especially amongst these Pakistani female participants. Participants went onto describe T2DM as being very common due to a family trend which establishes once one family member develops it.

W: Well you never know no-one can say for sure I mean my brother has diabetes, my mother has it, my little nephew has it and he's only 11-12 years old so what can I say but he's got the other type the first type (lines 990-993 FG5)

Participants explained how a lot of family members are diagnosed with the disease, and how many participants are used to being surrounded by this disease.

S: Even though I have been really strict with the diets and everything, especially since my daughter has become diabetic, I wasn't thinking was going to hit me but being the oldest I was told that (.) you know that (lines 41-44 FG4)

S: you're at high risk (line 46 FG4)

S: Well I have to admit I was warned a lot by my mum and dad "be careful" (lines 75-76 FG4)

Participants were encouraged to live healthily in order to reduce their risk of developing diabetes before diagnosis. This was due to other close family members having a diagnosis and so they were regularly reminded to be cautious.

4.3.2.7 Bad diet

As well as genetics participants believed that diet is another main cause of T2DM.

R: yeah (.) I thought diet (Line 126 FG4)

V: I went Pakistan I went Pakistan and I drank loads of 7up

INT: Ok

V: and then here when I got back my fever wouldn't break and I would get a temperature all the time and then I got it checked and they checked it and told me that I have diabetes (lines 16-20 FG5)

W: How does it happen? Well they don't look after-control themselves do they?

INT: Yeah

W: they eat too much sweet things so it happens (lines 108-111 FG5)

Participants explained that their diet was one of the main reasons for them being diagnosed with T2DM. They especially emphasised the indulgence of sweet and sugary snacks leading to them developing T2DM. They believed that T2DM is to do with sweet foods mainly sugar.

W: they eat too much sweet things so it happens (line 111 FG5)

R: Well I'd still be having sugar in my tea and my sugar levels were really high (lines 249-250 FG4)

W: Well yeah of course that happens if you have diabetes and you start to eat more sugar [it's gonna go high]

V: [gonna go very high]

W: Yeah it's gonna go very high so yes you should control it

V: [Yeah I've given up mitie I stopped eating mitie] (lines 342-346 FG5)

Participants explained that it is sweet foods that cause blood sugar levels to fluctuate. They explained how sweet foods increased their blood sugar levels thus it is important to control sugar intake. Participant V reported she has given up *mitie* (Asian sweets) to do this. From the extracts above participants refer to their blood sugar level as 'sugar levels' and sweet things impact on these levels. This may explain why the Pakistani community label T2DM as '*sugar*' disease rather than diabetes. Sugar is the universal word amongst the Pakistani population used to describe diabetes especially T2DM. Another reason why Pakistanis refer to T2DM as sugar could be due to the translating of medical literature into lay literature in Urdu. There are certain English words that are not found in the Urdu language and in the case of diabetes especially T2DM it has been translated into sugar. Participants reported that South Asian GPs will tell their patients on diagnosis that they have T2DM and then follow it by the word 'sugar' in a South Asian accent. Pakistani individuals will tell their families on diagnosis that they have 'sugar'. It has become the generic term used to imply T2DM. Although participants throughout the study referred to T2DM as sugar and attributed it to sweet foods some acknowledged that diabetes is more than just a sugar problem. Participants acknowledged carbohydrates and fatty foods as problems too.

R: [sweet] and erm you really have to watch your diet

S: Yeah and fatty foods (lines 258-260 FG4)

W: [Well the thing is everything's got it in] everything's got
sugar
V: Yeah in roti
W: In roti, in rice, in potatoes (.) now we can't give everything up we
have to eat and even if we do give these things up we still have to
eat roti
INT: Yeah
W: Meat has sugar in it (lines 313-320 FG5)

Eating a diet of fatty, high carbohydrate and sweet foods can impact T2DM development through its impact on obesity (Chowdhury & King, 2007). From the extracts above participants suggested the foods that are bad for diabetes are so when consumed in excess. The sugar they are referring to here is glucose which is found in all foods. Participant W expressed that even if they managed to give up these foods they still need to eat *roti* (chapattis) which contains sugar. Roti is a main part of a traditional Pakistani meal.

4.3.2.8 Lifestyle factors

Participants believed there is a lack of control amongst themselves and other Pakistanis when it comes to diet. There was a consensus throughout this study that lifestyle factors are crucial to maintaining good health and diabetes control.

V: No diet affects it too
INT: ok
V: It reduces your diabetes (lines 339-341 FG5)

T: Yeah definitely more active (.) like doing the housework, even
hovering er:m (.) I was actually walking (.) you know outside I use
to do about half an hour walk as well
INT: Ummm
T: and it made a difference and now because of the lack of it (.) I know
that the sugar's high (lines 500-505 FG4)

V: [When I walk] it effect
it, when I walk, when I exercise, when I go to the sauna steam baths it
affects it. These things have a lot of affect on my diabetes to
control it mashallah (lines 352-355 FG5)

W: In my opinion I feel th::at I (.) I'm guessing here the doctors
haven't said this is the reason why it's happened, I was fine I use to
do all the housework, go for walks, but a while ago my back I slipped
a disk and I couldn't do any work... This is how bad my problem was I
couldn't move no walking about nothing and whatever I ate I think that
I didn't get any exercise I couldn't do any activities and because of
that I think I got a sugar problem (lines 163-175 FG5)

Participants recognised that a good diet and regular exercise can help to prevent the onset of T2DM as well as controlling it once diagnosed. Participants expressed that being active regularly and exercising is very beneficial and emphasised this more than diet. Participant W believed that lack of exercise due to her back pain was the reason why she developed the disease. Earlier on she attributed the medication she took for her back problem as another main cause. Participants illustrated that diet and exercise are among the main causal factors of T2DM therefore they recognised that diet control and regular exercise are important. Yet when this fails taking medication is essential.

4.3.2.9 No single cause

In summary participants were aware that this disease is not down to a single causal factor rather it is due to a combination of causal factors.

S: But it's not just the food I have to say (line 133 FG4)

T: Yes and no cuz like sometimes I can have exactly the same think that I've had the day before (.) and yet the sugars high (lines 193-194 FG4)

4.3.3 Management/control

4.3.3.1 Food & herbal remedies

Participants acknowledged that there are many lay beliefs regarding T2DM among the Pakistani community. They have learnt about the foods that helped them to control their symptoms of diabetes most likely through trial and error. As people vary in sensitivity and what works for one person may not work for another, some lay beliefs are not taken seriously.

T: E::rm (.) sometimes it's just women nattering

S: Yeah

T: and sometimes what they actually say is quite good for you (lines 908-910 FG4)

T: No some of the ladies told me to have like chick peas and stuff and I have noticed that if I eat *daal* it doesn't raise my sugar (lines 969-970 FG4)

Y: When I drink cold milk I feel good as well especially when I eat continuously (lines 514-515 FG5)

Y: Or if I eat *karelle* (bitter marrow) then my sugar levels stay good <even if I'm eating> it for four days

INT: A lot of people say that if you eat *karelle* it's good [for your diabetes]

X: [it's so yeah
it's] good for you you know because it's bitter

U: [yeah the reason is]

W: [bitter they're bitter]

X: Yeah they're [bitter]

U: [but I'm not sure]

Y: No no it helps to reduce stress too with *karelle*, loads of people say that it goes low low (lines 524-537 FG5)

W: [Oh they say cinnamon you know cinnamon] you should break it into pieces in the morning and have that and that can help to reduce your sugar (lines 569-570)

V: Yeah the cinnamon one is right because I tend to put that in my cooking now (lines 575-576 FG5)

Participants believed that there are many things that do help to control T2DM especially certain types of food. They vouch for these as they have tried them and found them to be beneficial. Due to their better understanding of their T2DM they believe they are able to distinguish between lay beliefs that make sense in accordance with their diabetes and myths that do not. A lay belief that is popularly trialled and accepted is '*desi illage*'. This translates into 'herbal remedies' which according to the participants in this study are very effective.

T: They work you know
S: They do work (lines 920-921 FG4)

T: it's just stuff that's not gonna harm you (line 925 FG4)

T: Yeah it's just plant-based you know that there's no chemicals in it no nothing (lines 930-931 FG4)

Herbal remedies are used by many Pakistanis to combat many different illnesses and physical disorders (Pieroni et al., 2008; Fagerli, Lien & Wandel, 2004). Participants who had tried *desi* alternatives viewed them as harmless and organic and perceived them to contain natural ingredients having homeopathic qualities. They believed that these natural organic resources are good for the body such as cinnamon and lentils (as mentioned in extracts

previously). Lentils and bitter melon are low GI (glycaemia index) foods which the body digests slowly releasing glucose gradually (Chowdhury & King, 2007). Thus they are good for T2DM sufferers. Participant W believed that diabetic individuals enjoy sweet foods more and crave it:

W: It's us sugar people who are eager to have dessert first (lines 445-449 FG5)

She explained that Pakistanis suffering with T2DM want sweet food more as they are forbidden to have it. This can hinder their control and management of T2DM. Participants discussed reducing their sugar intake as part of their T2DM control but struggled sometimes with glucose cravings. Some have found it hard to be healthy before and after diagnosis.

W: But I think in my case I haven't tried to do any controlling, whatever I use to eat before I eat now

INT: OK

W: I can't control myself I love my food too much (lines 330-333 FG5)

Participant W was the only T2DM participant who did not control her diet the way she should. She maintains the same level as before she was diagnosed. The rest of the participants reported controlling their diabetes by watching their diet as they believed that that is what is important.

4.3.3.2 Family control via diet

Participants controlled their diet and through this their families. In fact their families were adhering to the same eating styles as them.

T: [No] I'm not I'm eating exactly the same as what the family eat cuz we have always ate like that cuz mum's diabetic as well

S: Yeah (lines 313-315 FG4)

T: but the family are fine with it they want to eat it as well

INT: *(laughs)* That's good

S: Yeah same here because of my mum and dad its always been erm strict with t:the fat side of it as well as the sugar side of it so (lines 324-328 FG4)

T: yet now I think because (.) I do majority of the cooking everyone eats what I've cooked anyway (lines 355-356 FG4)

Participants realised that their change in diet is in fact a good thing and an improvement towards healthy living. Some of them have not had to change their diet as much as they were eating this way before they were diagnosed with T2DM as their parents had diabetes. They believed they are simply being healthier and so are their respective families which was beneficial for the whole family. It also has to do with the fact that these T2DM participants are the main cooks of their families.

4.3.4 Emotions

4.3.4.1 The norm

Few participants had some knowledge of the disease before they were diagnosed with it.

S: No it wasn't much of a shock no (line 48 FG4)

S: I mean I was expecting it (.) it's not because I was eating unhealthy or anything like that but you just in the back of your mind=every time I went to the GP he would say "be careful you're really at high risk" (lines 85-88 FG4)

Participant S demonstrated that she was prepared due to the family genetics before she was diagnosed. Another explanation for participants like Participant S being prepared could be that they are so used to being around the disease that it is the norm for them dealing and living with this disease on a daily basis. Thus they believed it is inevitable that they will develop it too.

4.3.4.2 Negative emotions

Some T2DM participants recalled how they were shocked and upset on being diagnosed with T2DM.

R: Well it came as a shock cuz it=I was pregnant

INT: Yeah

R: I didn't even think about it and then when I was pregnant they said that I can't have the tablets I had to have injections (lines 50-53 FG4)

T: Mine was a bit of a shock though it runs in the family as well but
 (.) I've always been quite healthy myself so I didn't expect it (lines
 62-64 FG4)

W: Obviously I was scared you get [scared]
 Y: [yeah scared]
 W: Yeah you get scared you get worried (.) obviously we were happy we
 (.) we were enjoying sweet dishes >we'd eat whatever we like< we don't
 need to do control ourselves we don't have sugar do we so as we don't
 have it yet we might as well eat whatever we like >we will eat we're
 fine thanks to Allah< we don't have a problem but when we got diabetes
 obviously [we were concerned]
 Y: [we had to start controlling everything]
 W: >why did it happen? It shouldn't have happened< (lines 61-71 FG5)

Participants R and T were shocked when they developed the disease as it was during pregnancy and prior to being pregnant participant R did not know about T2DM whereas participant T did but she considered herself to be healthy. Their feelings are in line with the worried feelings of the non-T2DM participants if they were to develop the disease (see next section). Participants W and V described how they were anxious facing life with T2DM as they were living carefree ways. Due to the onset of the disease they realised their lives would have to change and they needed to take control. It has impacted their lives dramatically.

W: A lot (.) I think it has affected me a lot
 V: No it has a lot (lines 818-819 FG5)

Participant W and V emphasised how much T2DM has impacted their lives. In this study the majority of the participants felt anxious when diagnosed and they understood it would have a significant impact on their lifestyles. There were clear negative emotions towards becoming diagnosed with the disease amongst all participants. A minority were not as anxious as they were prepared and were living healthy lifestyles anyway.

4.3.4.3 Concern from their children

Whether participants were anxious or not about them developing the disease many believed that their children would be scared to find out their mother had a diagnosis of T2DM.

S: No my other two girls are actually quite scared that they might get
 it cuz I mean when they see her struggling with the needles erm (.)

they they are scared so they've cut down on everything themselves
(lines 726-729 FG4)

T: Yeah too young but I mean my nephew and nieces are all like
interested and intrigued what's happening (lines 742-744 FG4)

R: I think they do think they probably think they will catch it (line
752 FG4)

V: Well they were worried a lot the whole family
Group agree and mumble together over each other for few seconds

W: Well they started to think and feel that it's happened to our mum so
obviously it can happen to us so obviously they all started to worry
about it (lines 97-101 FG5)

Participants believed that their children would be concerned for their mothers. They expressed how their children had reacted. By witnessing it for themselves their children are more careful and concerned regarding the disease. They experienced the impact it has on them firsthand, implying that the stress and worry of T2DM did not only affect the participants but also their children. Being diagnosed with a disease highlighted to the children how vulnerable they are to also being diagnosed. It is interesting how some children perceived T2DM as a virus rather than a disease how *"they will catch it"* rather than develop it. On the other hand some participants expressed that T2DM was so common that many families were used to it hence some children would be less worried if their mother were to develop the disease. They may see it as being inevitable.

V: They're used to it now (line 831 FG5)

With T2DM being prevalent in families, participants believed that everyone learns about the disease especially the changes that need to be adhered to in order to control the disease. Therefore even children become more aware and vigilant. Participants encourage leading healthy lifestyles more in their children as they have firsthand experience of the disease and their children were already worried about it. As a result they would be proactive. Participant T went on to mention that she believed change is more difficult for older people.

T: I have to say when my mum developed diabetes e::rm she found it
really hard the diet thing because we were trying to cook healthy for
her and now she's so use to it (lines 989-991 FG4)

Participant T described how her mother initially struggled with her diet change but later became accustomed to it. For older Pakistanis many of them are not just breaking routine but they also are changing their life habits. This is very hard as habits become embedded in an individual. However with perseverance and support it can be achieved, as voiced by Participant T above, and should be achieved so as to increase life expectancy and maintain a good quality of life.

4.3.4.4 Disease severity

As mentioned earlier in this theme a reason why many participants were anxious regarding this disease is because they class it as '*serious*'. They understood the severe and extreme complications of the disease.

W: ...yours is quite bad and that's why you have a lot of pain it's very bad your problem it's serious (lines 35-36 FG5)

Participants shared their knowledge regarding the severity of this disease, and emphasised the harshness of the disease and the pain it can cause the body. Pain is not recognised as a primary symptom of T2DM although it can be a symptom of neuropathy (Diabetes UK, 2006). This may be a reason for why Pakistani people in particular are very reluctant to get tested for T2DM as they portray it as a significant disease.

4.3.5 Moral support & social influence

4.3.5.1 Moral support from family

It is clear from the analysis of this study that participants were offered moral support from their family and friends when they were diagnosed with T2DM.

S: and erm (.) with my husband he was a bit shocked=he didn't think, because of the tightness of (.) of the diets that I have been doing and everything (.) he was quite shocked that I actually got it but erm (lines 80-83 FG4)

T: Yeah like I said my mum's got it, and a few of my aunts have got it as well and then my mum's friends, so soon as they found out that I had

it they were all around and they were all telling me do this do that
(lines 902-905 FG4)

Family members were surprised when participants were diagnosed. However their initial reactions would then change into concern and encouragement to live healthily.

T: My family is a lot more aware now cuz of diabetic being diabetic and they kind of say "oh you need to eat this" or "you need to eat that"
(lines 425-427 FG4)

T: My sister will say when she's shopping with me "oh you need to buy some sweet potatoes", "why?", "because that's good for your sugar"
(*laughs*) (lines 440-442 FG4)

U: The kids remind us you've got sugar
Group laugh

W: Yeah well if you [don't then my sugar it will]

U: [yeah the kids become the grown-ups] (lines 430-433
FG5)

W: [no I think] mine do because mine say to me mummy don't eat that you have sugar [don't eat it]

Y: [they don't let you] eat it the kids, my own daughter shouts at me (lines 842-845 FG5)

Participants expressed how they are given advice by family on what food to eat and to maintain their diabetes care. Some of this advice was mentioned earlier in the lay beliefs about diabetes theme. Whether it is factual or not family members are concerned for the participants. Some participants spoke about how their children encouraged them to eat healthily as well as adults. They care for the participants and had taken responsibility to ensure they give regular encouragement and advice.

4.3.5.2 Family hindrances

However sometimes family input and influence can be a hindrance in promoting the healthy living process especially when participants tried to maintain a healthy living balance for all at home.

T: Mum's like that she say's "its *kacha*" (line 1038 FG4)

W: Yeah I'll eat it, I'll eat fish and chips too not all the time maybe once a month, maybe a couple of slices a pizza again just once in a month not more. My kids eat it a lot but I don't eat it all the time with them (lines 423-426 FG5)

V: No they eat everything *mashallah* they're fine

W: Why should they control themselves? (*laughs*)

Group agree and laugh

U: They feed us things 'it's ok just have it' (lines 833-836 FG5)

Participant T highlighted comments that make it harder to achieve a balance at home such as "*its kacha*". *Kacha* means raw so her cooking was implied to be raw or undercooked emphasising the disapproval from her mother. If elders do not eat what is made then the younger generation could also refuse. Participants explained how sometimes they are encouraged to consume unhealthy junk food because it is what their children want. Yet they do not indulge too much only occasionally to satisfy their children. These participants were aware that their children did not control themselves and they regularly enjoy unhealthy junk but participants control themselves. Although participants are aware that their children are at risk of developing T2DM, they do not stop them from eating unhealthily as expressed by Participant W, "*why should they control themselves*". They do not want to deprive their children of enjoyment which in this case is in the form of food.

Partners can be a hindrance.

S: Yeah I've tried to get my husband around to the wholemeal flour thing, was a struggle he didn't like it at all. Especially when we make spinach and we leave the spinach not overcooked he can eat the vitamins but he thinks it's not cooked properly (lines 1033-1037 FG4)

Participant S explained how her husband was not very supportive when it came to mealtimes. She explained how she struggled with her husband to switch to healthy food options and cooking. She persevered but still the husband disapproved. The husband like Participant T's mum above believes this type of cooking is undercooked. Traditional Pakistani meals are very rich in fat and spices and are cooked for a long period of time. Therefore an individual will find it hard to change from this style of cooking and eating to healthier options.

4.3.5.3 Social influence

Another hindrance is factors external to the family. Participants believed that these influenced the younger generation to be less healthy and to eat less home-cooked foods.

- R: Yeah it's like my boys they get pocket money and straight away they're down the local shop (.) sweets (lines 809-810 FG4)
- W: Yeah especially when they always eat from outside we tell them off all the time that outside food isn't good and that you should eat healthy home-cooked food but they eat all this fried food and I tell them that you shouldn't eat fried food all the time and that all these things erm you know (.) you should eat a balanced you know keep a balance
- INT: Ok
- W: you know vegetables, fruit, daals, meat, it should include everything you know and as a mum I explain it all the time to my kids but when do kids listen? Whatever they want feel like they eat.
- INT: Yeah
- W: They don't listen
- X: That's true
- W: We try and we cook in the house like this you know every week daals, spinach, curry, vegetables, meat, chicken everything we try to do everything, and the kids who feel like it will eat it and the ones who don't get it [ordered from outside]
- V: [Get it from outside]
- W: so what can we do? (lines 851-870 FG5)

Participants emphasised that a hindrance to them trying to provide a balanced eating lifestyle with their children are social influences. Money in the hands of children is spent on sweets and junk food. It is perceived to be the norm for children. As they grow up participants believed they rebel more as they have the means to. They eat out more or they will order food rather than enjoying home-cooked meals. Participants highlighted that they try to encourage their children to eat fresh home-cooked food and to have a balanced diet but it falls on deaf ears. It is easier for adolescents to order food than to eat what is made if they don't like it.

- S: It's all that processed food (line 185 FG4)

Therefore it is very difficult for participants to try and control the eating habits of the family if they are not co-operative or supportive. Hence takeaways and restaurants are part of the problem.

4.3.5.4 Health service support

Participants appreciated that there is a lot of awareness, information and material out there and the government as well as the health service are involved in improving lifestyles.

W: They told me about one once where they invited someone externally, the GP called her and she asked about everything, ran some tests
V: Yeah she was telling us you should eat these foods, yeah she talked to us
INT: Ok so you attend them?
W: Yeah
V: Yes (lines 798-805 FG5)

W: Before they sent me so much information leaflets and stuff and all the information was on it you know like eat this and don't eat this, do that do this, they gave me so many books and stuff [it has everything written on it]
U: [They give you lists as well and lessons] you know lists of food
W: Yeah about food yeah she talked to [us about that]
U: [the ones you can put up] on the fridge I have they gave that to me (lines 807-815 FG5)

Participants supported this by sharing memories about the time they were called into attend a diabetes workshop. It was also helpful to be given the information to take away once they discussed it with them, to record details on. Participants also acknowledged that the health service provided a lot of information and contact with GPs and nurses but they did not believe that they received the necessary support from these sources.

V: Yeah three months
W: They take and check my blood tests every three to six months but otherwise they say that whenever you wanna come and get it checked you can come and get it done because they have nurses there to help so we can go whenever we want to the doctors whenever we feel like. You have to make an appointment but then >you can go if you feel like you have something-have a problem< we go and get it checked out (lines 788-795 FG5)

INT: Right ok erm (.) what kind of support have you received?
S: Apart from Partners in Health (.) none actually (lines 568-569 FG4)

T: I'm getting enough contact I don't know about support but I'm *(laughs)* getting the contact (lines 614-615 FG4)

W: INT the GP has started something with me erm (.) what do you call it erm from the NHS (.) erm when they call you up at your home and ask you about everything
INT: Alright yeah
W: Yeah they do that too with my mum because she has it too
INT: So they phone you up and
W: yeah they ask me everything about me, how I feel, this and that, do you have any other problems, what type of medication do you take, they ring every month and talk to me for about half an hour to an hour (.) hmmm yeah and she asks me about my mum too because she can't speak English so she asks me

INT: Right yeah ok (.) so the rest of you just see your doctors and nurses or do you get phone calls too?
W: No they don't get the phone calls
X: No
V: No we just travel to our doctors (lines 716-731 FG5)

Participants believed that the health service is clearly committed in making sure individuals get the right information and plenty of contact but it is not being effective as they believed they were not getting the appropriate support out of it. Participants expressed that they can go to visit their doctor or nurse whenever they needed. They travel to the health service when they need to but participants would appreciate it if the health service came to them like Participant W explained. She received regular telephone support calls regarding her diabetes however none of the other T2DM participants did. As discussed in the mixed emotions theme health care and services needs to be equal for everyone.

T: I think if you've got diabetes that you know (.) budgets need to be available to everyone not a case that you're pregnant so you're getting it free or somebody's not working and you're getting it free erm it should be available to everyone (lines 1095-1098 FG4)

Participant T expressed the need for funding to be available for all who are suffering with diabetes to ensure equal care and diabetes management. Furthermore participants suggested giving Pakistani individuals information on diagnosis and symptoms which will hit home rather than bombarding them with lots of data.

W: No I think they should do more
INT: Ok what else should they do?
W: I say everyone who has sugar they should call them in at least once a month everyone (.) call them in and give them the right information because the books and stuff that they have given who reads it? Even those who can read I mean I can read and write and understand it all and everything but I haven't read them (.) I'm telling you the truth I haven't read them and those people who can't read unfortunately how are they gonna read? Yeah right? (lines 886-895 FG5)

Q: especially if you've only recently been diagnosed and you didn't know that much about it
P: Yeah
Q: to be able to have somebody there you can ring up and say is this normal or can I do such and such
O: that would help (lines 319-324 FG3)
U: [yeah INT so if someone keeps it somewhere] then we will go there together

W: Yeah we will go all of us so they can tell us how we should do exercise, you need to eat this you shouldn't eat that, so you need to do this and I think this will be a very good idea

U: And it will be good for depression because when they use to call me to that place all the women were sitting together and just talking amongst themselves and they all use to ask me (.) tell us if you climb steps how many times you should climb them and come back down, how to do things and how not to do things, it use to refresh my mind just from meeting other women

V: It makes a difference a lot of

U: This should exist defiantly (lines 968-978 FG5)

In this study participants emphasised that people, in particularly Pakistani people, need to be advised to get tested and given small chunks of information rather than an overload of information. They need to be given facts as many people probably have the disease but are unaware. It is important for them to receive the appropriate treatment and make the necessary changes. As emphasised before by participants the health service need to provide more support. A support network was a suggestion put forward by participants for Pakistani women to get together and socialise and discuss their diabetes. Pakistani women can get the relevant diabetes information, lifestyle benefits and clarification when necessary. It will also help to give them an opportunity to go out and socialise. Participants explained that books and literature are given by the health service but they are not useful as participants did not read this information and it would be impossible for people who cannot read or understand English to do so. It is also crucial for the health service to tackle the language barrier issue. Participants expressed the need to employ multilingual staff and also produce their literature in various languages. However many of the older generation are illiterate and so it is more important to be able to verbally communicate with them than to give them written materials.

W: So the thing is that they need [to try and at least er::m]

V: [They need to tell them]

W: not in a week but at least once a month call together in some place all the people who have sugar and tell them all that you have to do these exercises, you know it becomes a reminder thing to drill into their heads time and time again you know these are things you need to eat and don't eat these things, you can do this but don't do this, they need to explain all these things and then people will hear it over and over and then they will remember it and take better care of themselves ok (lines 897-907 FG5)

Participants believed that it is important to discuss matters in Urdu with Pakistani individuals so they can understand their disease. It is also important to reiterate diabetes information to

older Pakistanis especially to reinforce diabetes care and management. This should also be done in Urdu. Overall the health service needs to continue to raise diabetes awareness and management according to participants.

T: I think it's about us being a bit more educated as well about it cuz I think our families you send your kids to school and you expect them to be back home at a certain time and then after that that's it then we don't encourage them to do any activities (lines 768-772 FG4)

Participants recognised the need to be educated and for the Pakistani community to be educated. Participants believed that they need to understand the disease and have the knowledge before they can adhere to healthy lifestyles. The elderly Pakistani community especially need efficient support especially those who already have the disease and then the younger generation so they can be encouraged to encourage others. Participant T also mentioned the need to promote physical activities in families especially children. Participants acknowledged that education is important as well as awareness.

4.3.6 Pakistani lifestyle

4.3.6.1 Diagnosis

Participants were asked how long they had the disease for and the response was a very long time. Therefore they must control it to stay illness-free.

R: For me about 7 years (line 27 FG4)

T: ... 2 years (line 31 FG4)

V: [12 years] 11years? 11 11 years yeah (line 26 FG5)

Y: It's been 6-7 years but I can't remember [next time] (line 47 FG5)

Participants demonstrate an understanding that T2DM is a chronic condition. Therefore for many Pakistanis diabetes becomes a part of their life and daily routine. This may explain why a lot of people assume it is an older person's disease because no matter when they develop it it will be with them until the end of life. However the participants in this study did not mention age as a common factor just that it stays with you for life.

4.3.6.2 Better management/control in Pakistan

T2DM is not a big problem in Pakistan according to participants.

- X: It's more [here less there yeah]
- W: [No it doesn't yeah] the reason is there in Pakistan activity-there there's more activity (.) the lifestyle as in walking around, doing work, the weather there is different, and a lot of people have it there as well but in my opinion I believe that if we were there we wouldn't have it now
- Y: laughs
- W: it wouldn't happen, it's he:re (.)
- X: It's a lot more here
- W: It's more of a problem here
- INT: Yeah
- W: My mum has it too since she came over here and she said I have it because I came here (lines 232-244 FG5)

There was a consensus that the lifestyle of Pakistanis living in Pakistan was healthier and better than those living in England. This is due to a number of reasons including activity and weather. A majority of the participants in this study believed that Pakistanis living in Pakistan enjoy fresh foods and less processed 'junk food'. The quality of food is better in Pakistan as many people grow their own food or the food they buy is bought straight from a farmer or butcher rather than a supermarket. Junk food and confectionary snacks are less accessible in Pakistan according to participants. Also their lifestyle is better as they are more active whereas in England especially the older generation confine themselves to their own homes. Participants believed that many Pakistanis live sedentary lifestyles here in England as they do not like to be surrounded by unfamiliarity. Even if they do go out they stick to their own communities. Their diet is much better and so is their lifestyle in Pakistan. Many participants blamed living in the UK for their ill health more generally.

- Y: My whole mouth gets sore now and when I stayed in Pakistan for two months it was fine
- W: Yeah it happens to you here
- Y: [Yeah and when I stayed in Pakistan for two months it was fine]
- W: [And now all the people who get sugar here] its worse and they go Pakistan and it gets better (lines 247-252 FG5)
- W: So she goes to stay in Pakistan a lot. She says 'that living in Pakistan (.) I have reduced taking my injections, I'll have the odd

one, reduced my tablets, and there's been a big difference'. She goes to Pakistan (.) she goes Pakistan and notices a big difference and when she's here it gets worse (lines 267-271 FG5)

Participants believed that living in Pakistan helps to control diabetes. Their health and diabetes care is much better, so much so that some have reduced their treatment regime. However participants failed to recognise that it is not the country or place that possesses the recovery solution it is the change in their behaviour when they go there to visit. They acknowledge that the daily routines in Pakistan are set and stable whereas they are surrounded by choice living in England; they could try to live the same way here in England if they choose but do not.

Another reason why participants believed that it is better to live in Pakistan than in England especially in regards to T2DM is due to the weather.

T: Cuz weather-wise as well, there er::m (.) there because of the heat you kind of sweat in- you know even if you do a little chore there you use a lot more energy than you do here so I think it makes a difference

S: [I have to agree] (lines 167-171 FG4)

S: That is true yeah my mum just come back and she use to find that er:m (.) where she has two injections now her erm (.) sugar levels still high but she keeps getting hypos because of the heat, she was burning off a lot of energy so I do find that it is this country=plus every things available as well (lines 177-181 FG4)

W: so the reason for this is the weather there, everything is good for them so that's why it gets better (lines 254-255 FG5)

The weather myth is shared among participants just like they believe sugar is a universal assumption many Pakistanis believe in. Participant S describes how the hot weather was responsible for her mum "burning off a lot of energy", which does not happen in this county.

However a small minority disagreed.

U: Some go and it reduces some-people over there also have it they have it really bad. So if it was due to the weather then no-one over there should have it but the people who go from here they do say it reduces-gets better so (.) it depends on every individual-their body

X: Hmm unique [for everyone]

V: [Sugar is unique to] the person too (lines 278-284 FG5)

These participants highlighted that weather cannot be a contributing factor to the onset of T2DM otherwise Pakistanis living in Pakistan would not be susceptible to the disease.

Everyone is unique and for some it may help living in a hot country but for others it may not have the same impact. As explained in the previous theme, there are perceived to be many different causes of diabetes which affect individuals differently.

4.3.6.3 Pakistani food

Participants emphasised that Pakistani food is stigmatised for being greasy and fattening. Yet this is not always the case as participants highlighted that the food and ingredients used are 100percent fresh, and no processed foods are used in their cooking.

- T: Well all my drinks are now sugar-free (laughs) or no added sugar I tend not to have pure juices as well cuz they tend to really raise the sugar level and the food that I eat is more er homecooked (lines 222-225 FG4)
- S: [Yeah] I would agree with that as long as you use olive oil, I find olive oil's really good
- T: We've always used olive oil and we've always had wholemeal erm flour
- S: Yeah
- T: So I've noticed when I eat proper chappatti with say daal or subzi made with little fat (.) it hardly raises the sugar yet if I have bread which contains yeast and sugar it goes high
- INT: Hmm ok
- T: so I would say that our diet with really kind of little bit of fat in it is really healthy then having something that's you know more English kind of food-based (lines 269-280 FG4)
- W: Curries in my opinion I think we use to cook them properly before like we do now there's no difference in them. From the beginning I have used olive oil it's been ages I've been using it I don't use ghee or butter or anything like that, these lot also use the same oil
- Group agrees*
- W: And apart from that (.) meat is high in sugar so we cook meat less maybe once a week yeah so we cook meat less it's mostly chicken and vegetables-make chicken more (.) so I have made changes (lines 389-398 FG5)

Participants agreed that Pakistanis mostly eat fresh home cooked meals which they perceived to be much healthier than some western home cooked meals and especially healthier than ready cooked meals. Participants recognised that traditional Pakistani cuisine made at home is beneficial for individuals with T2DM as they learn the types of food that affect their sugar levels and the kind that do not. Using olive oil seemed to be a universal trait among participants and they only used fresh ingredients to make curries.

4.3.6.4 T2DM prevention in children

A main aim for the participants in this study was to encourage their young to look after themselves in order to prevent the onset of the disease.

R: I didn't know that it runs in my family

INT: Oh ok

R: [inaudible] afterwards yeah

INT: [inaudible] yeah

R: so that's why I tell my daughters now you know (lines 97-101 FG4)

W: Yeah especially when they always eat from outside we tell them off all the time that outside food isn't good (lines 581-582 FG5)

Participants recognised that their children are at risk of developing the disease as they believe there is a genetic link and the children's diets are not as healthy as they should be.

They tried to encourage their young to be more careful and proactive. Participant T stated that portion sizes are just as important especially in controlling diabetes.

T: but you know you have the one or two and you're fine it's about (.) your portions size at the end of the day (lines 293-294 FG4)

From what participants in this study say one can see that a good Pakistani diet could be achieved as the food is fresh and home-made. Participants believed that by setting an example it is easier to motivate and encourage others especially children. They also appreciated the support of their partners and other family members. Many Pakistani mothers struggle to feed their children especially as they get older and explore different foods. They become very fussy which can make meal times very challenging. However participants emphasised that mothers should encourage them to eat different types of food and take charge at meal times therefore their children will have to eat what they are given.

S: exactly it's when they're a bit older they get fussy

R: Oh they get they get fussy, they won't eat veg or they don't what to eat this, but when they're smaller they're fine (lines 1152-1154 FG4)

Participants appreciated that it is easier to feed children when they are younger rather than when they are older. As they get older they decide for themselves what they want and what they like. Thus by embedding good habits early participants could have saved themselves a lot of hassle later on.

4.3.6.5 Lack of exercise

When it came to exercise participants in this study acknowledged they did not get enough exercise.

T: At the moment I am lacking in exercise (line 452 FG4)

S: I have to admit I (.) I mean apart from running around from ehh (.) what is it 8 o'clock in the morning sometimes-I don't actually get anytime^o for exercise but I'm always on the move though (lines 461-464 FG4)

W: I don't do any kind of exercise >not walking not exercise< not any type

INT: Is that because of your back or just?

X: I just move about in the house

W: Me (.) I'm too lazy (lines 598-602 FG5)

V: No I didn't do any exercise but I did do a lot of the housework, go to sleep and then wake up at sunrise erm [yeah I did do some walking] (lines 638-639 FG5)

Participants realised that they do not partake in any physical activity or exercise. They shared similar excuses for them lacking in exercise mainly the lack of time and motivation which other Pakistani women can relate to. Participants stated that they move about a lot at home whilst doing housework and chores and some enjoy walking but some of them did no exercise at all. A common perception amongst participants in this study was that Pakistanis use their illness as excuse not to exercise or do any kind of physical activity.

T: No but it's what you see as exercise even ironing is exercise

R: Yeah

S: Uhmm (agreeing)

T: it's just moving the body isn't it? (lines 537-540 FG4)

Participant T earlier mentioned hovering and housework chores as exercising (reported in the causal factors theme) and reiterates this point again. These participants have a good understanding regarding exercise but this may be because of the contact and advice they have received from health professionals. However the above extract indicates they are still not 100percent sure as they seek approval from one another. They do however try and encourage their children to do it.

V: They'll be fine no inshallah they will be alright because they are doing exercise now so yeah (lines 988-989 FG5)

Participant V suggested her children will be fine when they become adults as they are encouraged to exercise in their young age. Participants emphasised the importance of exercising and the benefits of exercising. They do need to take control of their exercise as well as their diets and maintain good habits.

4.3.6.6 Traditional food pivotal part of celebrations

Participants discussed the impact celebrations have on their health as all celebrations are centred on food. This is a major part of Pakistani lifestyle and is for all Pakistanis.

T: ... when we've got visitors coming over she expects the erm dinner to be a bit more traditional (lines 996-998 FG4)

All participants expressed that Pakistanis celebrate with traditional food. On special occasions participants enjoy the food as well as the company. Food helps to create a welcoming and celebratory atmosphere. Participant T emphasised when Pakistani people are expecting guests they cook traditional full fat and flavoured dishes. Although Pakistanis have the option to make and share healthy foods celebratory foods consist of fattening and 'naughty' snacks and dishes. Participants acknowledged this as the main problem with celebratory foods. They are mainly greasy and fattening, and that's the way they are wanted on special occasions.

S: Unfortunately during fasting when you open a fast you really [want something savoury]

R: [want yeah craving]

S: and erm yeah (.) they weren't big portions it was just a small portion but it was fried (lines 393-397 FG4)

W: Yeah I have done I use to make stuff on Thursday to say prayer with but now I don't make it anymore-a sweet dish in the house because if it's there I will eat it >so yeah now in the house we make it but on occasionally like on Eid or something< then I will eat it and if I go to someone's house and something is made then <I'll have a little bit to eat> but other people are worse than me (lines 380-386 FG5)

V: [Ramadhan] it's worse

INT: Yeah

V: fried food
X: Yeah fried food
W: Yeah in Ramadan I eat pakoras and stuff
Group agree
W: Because of my sugar I don't eat a lot of them it's not like before
V: Yeah it's all because of the sugar (lines 470-478 FG5)

Participants believed it is compulsory to have fried food on special occasions and when celebrating. The food needs to be fattening and full flavoured meaning spicy and rich. Participants were aware that their diets deteriorate during Ramadan especially as they constantly eat unhealthily for at least 30 days. They do enjoy the celebratory food but their portions are smaller as they control the amount they have because of their diabetes. They actively try to make less celebratory food. These participants also implied that other individuals even those with diabetes are worse than them as they administer no control.

T: You kind of like know that you probably shouldn't but you just (.) do
(lines 419-420 FG4)

W: Use to eat until our stomachs were full, didn't eat much roti (.)
that's it that was the way but now we have changed we don't have that
much fried food anymore. We try not to but you can't resist either we
want a little bit

Group agree

U: When it's cooking and you smell it [you just feel] (lines 487-492 FG5)

Y: Ye::ah I just eat roti when I open my fast erm and I eat one roti in
the morning

INT: Uhmm

Y: That's it that's all I eat^o >I don't drink drinks at all if I do I have
erm you know lemon green lemon-lime< I drink that (lines 502-506 FG5)

Participant Y recognised that there is an alternative to the greasy fattening food indulged in during Ramadan especially and that it is again in their control to make the right healthy decisions. Many of the participants explained how they refrain from eating unhealthily. They try their best to resist and if they cannot they only have a small amount. Participant U explained how she only eats chapattis during Ramadan rather than fried greasy foods and only drinks fresh lime water as an alternative to carbonated or sugary drinks. Many T2DM individuals do not fast at all as it is not compulsory for someone with an illness to fast especially the elderly. Yet many Pakistani Muslims believe as the blessed month only comes

around once a year they must make that effort to try and keep a few if not all. The participants in this study fast during the month of Ramadan.

W: I become so tired, mentally drained I mean usually I feel like my head is empty empty and when I keep a fast I feel like there's nothing there it's totally empty (.) feel very you know low^o (lines 464-467 FG5)

Participants acknowledged that it is not compulsory for people with diabetes to fast especially if they are on medication or insulin. If fasting caused an adverse reaction in the body this would be harmful to the individual. Therefore they are exempt from fasting. Participant W describes how fasting affects her. She struggled to keep fasts however the other T2DM participants managed fairly well with fasting; may be as they control their diabetes better.

4.4 Study 1 Results Part 2 –

Perceptions and experiences of British-Pakistani Mothers without a diagnosis of T2DM

4.4.1 Introduction

Thematic analysis was used to analyse the focus group data. Five superordinate themes were identified: *Causal factors and symptoms*, *Lay beliefs & attitudes*, *Negative emotions*, *Moral support & social influence*, and *Pakistani lifestyle*. These themes are discussed in turn using data extracts from the five focus groups.

4.4.2 Causal factors and symptoms

4.4.2.1 Biological factors

Participants identified many causes for the onset of T2DM across the focus groups. Participants demonstrated an understanding that T2DM has something to do with blood sugar levels whether it goes high or low.

F: I think erm (.) diabetes is when either the blood sugars go up or down (lines 46-47 FG1)

C: ... my dad's gets too hi:gh (line 9 FG1)

I: I personally think its just low sugar levels that's what I know about it nothing else (lines 4-5 FG2)

Participants reported that T2DM has something to do with inconsistent blood sugar levels. They do not have a clear understanding possibly as they have not experienced it for themselves instead they have heard close family members voice these problems. Participants were able to identify key biological factors that play a part in the onset of T2DM touching on some medical knowledge.

A: Erm what I thought it was when the body can't produce insulin anymore... that's my idea of it (Lines 28-30 FG1)

N: I'm just=insulin [aware of] (line 20 FG3)

M: oh yeah (.) it's something to do with the fact that its (.) your gut and the pancreas something to do with them as far I'm con=I know (.) and it's something to do with the fact that it produces too much

INT: Right

M: insulin in your body or sugar [levels]

O: [sugar]

M: sugar yeah (.) so I think (.) that's a biological thing but (lines 25-32 FG3)

Participants were able to highlight the main mechanisms involved and had a vague idea about how the production of insulin or lack of it contributes to the onset of T2DM. They understood that there was something innate that contributed to the disease but were not able to give any specific information. The knowledge demonstrated by participants could be what they have heard their family members/relatives say or by attending appointments with their relatives rather than firsthand experience. Some participants go on to explain how other biological factors contribute to the onset of diabetes.

D: ... I've heard you know they do say they have you know the circu you know how how big you are [as well]

INT: [yeah]

D: does affect [whether you get it]

INT: [the waist circumference]

D: yeah the waist circumference does [affect]

B: [>Oh does it?<]

D: it can if you go over a certain [size]

H: [You're a thirty-two] inch

D: it could be more higher [than a thirty-two inch] (lines 72-82 FG1)

A: Cholesterol is a factor to diabetes (.) I think

G: High cholesterol (lines 774-775 FG1)

They discussed the significance of BMI and waist circumference as well as cholesterol levels. They understood the significance of these factors and how they contribute to the development of T2DM.

4.4.2.2 Being overweight

Participants also believed that being overweight was another important predictor. These participants emphasised that individuals who are overweight tend to contract diabetes.

F: Too much fat equals diabetes
 INT: Ok right
 D: A lot of overweight people do tend to get it but it's not always the way though
 INT: So it's more likely that you will get diabetes if you're big?
 A: If you're overweight cuz there's type one and type two, so type two is more effecting for those people (lines 1243-1249 FG1)
 B: Or you you can be overweight (line 24 FG3)
 E: Hmm (.) I've got friends who have got it and they are are all the ones who are all overweight (lines160-161 FG3)

Being overweight has a huge impact on diabetes according to the participants in these focus groups. They believed that individuals who are overweight tend to be diabetic as they have witnessed this for themselves. Some acknowledged that this is not always the case but there is a trend with being overweight and having T2DM.

4.4.2.3 Gestational diabetes

Some participants mentioned someone they knew who had developed diabetes through pregnancy.

B: ... Err we we know someone who had it in pregnancy don't we
 A: Yeah (lines 112-114 FG1)
 L: Erm (.) I know about this because of when I was pregnant I had (.) erm (.) this problem (lines 42-43 FG2)

Not all participants recognised this form of the disease. A few shared how they knew of others who had gestational diabetes and Participant L explained how she had it herself previously.

4.4.2.4 Symptoms

Across the focus groups participants were able to recognise biological symptoms identifying the onset of T2DM.

D: but I mean they do say like some of the signs I remember like they're being thirsty constantly=going [to the]
 INT: [yeah]
 D: toilet a lot and you know just feeling I don't even like some people like to (*background noise*) pain in their feet you know (lines 180-184 FG1)

C: My dad when he found out he's got it he lost a lot of weight and he was constantly sleeping a lot (lines 195-196 FG1)

F: if you start if you're hungry your sugar levels drop or they drop more then you get like shakes and stuff

B: Oh yeah

F: you get sweaty and [probably faint (inaudible)] (lines 207-210 FG1)

I: ... I think it's just when you feel hot and flustered and when you feel like you're you're thirsty and stuff like that (lines 26-27 FG2)

M: Is it going to the toilet quite (.) quite yeah (.) go toilet a lot, is it dry mouth?

O: Getting thirsty a lot?

M: Ahh yeah thirsty a lot (.) you're eyesight as well

Q: You get tired a lot as well?

O: Yeah I think yeah (lines 796-801 FG3)

All the participants illustrated knowledge regarding T2DM symptoms. They speculated symptoms of this disease most likely based on what they have heard or witnessed. The main symptoms highlighted by participants were being thirsty, constantly tired and weight change.

4.4.2.5 Genetics

Participants clearly illustrated that another significant causal factor of T2DM was genetics.

G: [I think] it can also run in the family as well [so]

B: [yeah]

G: if other family [member's diabetic (inaudible)]

B: [yeah hmmm]

D: [and inherit yeah if its] in the family like I was saying erm with like my mum having it and all her side of the family had it and now my sister getting it, it's one probably <you never know> ten years down the line I could be getting it (Lines 58-66 FG1)

N: I wouldn't say it's an unhealthy e::rm (.) like menu of traditional food and yet my dad's diabetic (.) do you know what I mean and my mum isn't but but then my nan and her nan before her so I think I will probably get it and probably my brothers if it is genetic whereas my mom smokes I mean she doesn't drink and I'd say she wasn't as healthy as my dad but yet my dad's diabetic

INT: Right

O: yeah I think it is genetic (lines 661-669 FG3)

D: ... you get people thinking oh you're gonna end up with diabetes because you eat chocolate but I always say because it's hereditary you know it is hereditary (.) erm INT:: I'm prepared >in a sense< I'm preparing myself (lines 271-275 FG1)

Participants highlighted the familial pattern of T2DM within their own families and recognised that they are also at risk of developing T2DM due to hereditary and genetic factors. They recognised that genetics play a vital role in determining the prevalence and susceptibility of this disease amongst them. Participant N explains further how genetics is very significant.

N: I think my youngest e::rm (.) if you took her to the doctor he would say she's overweight (.) er (.) yeah but I think we eat quite healthily she eats a lot of fruit she's never really ever been into sweets or cakes or crisps or anything like that (.) and the school she goes to they have a lot of activities there so she's part of the rowing club, she does dancing, but she's still chubby bless her. I don't know they say that it's a myth to say that you know it's in your genes or that you're big boned but I don't believe that cuz she's quite chubby but then my other daughter who eats the same diet and she's like a stick (lines 611-620 FG3)

Participant N emphasises the important role genes play in our lives, and how people can be different sizes but share the same lifestyle.

Participants described T2DM as being very common due to a family trend being established once one family member develops it.

M: I think that within the Asian community it's just so:: common that for me it's like er::m my dad's got it, my mum's got it, my grandmother's got it, just about everybody in my whole family of a certain age have got it... it's so common in our community (lines 58-64 FG3)

D: ... my sister's just hit about forty and she's been told she's got diabetes the type two (Lines 21-22 FG1)

M: [No:: cuz it's] just so common nowadays especially in the Asian community cuz more or less everybody is diagnosed WELL (.) a lot of people are diagnosed with it (lines 70-72 FG3)

Participants described familial T2DM trends to emphasise their own point of view. They explained how a lot of family members are diagnosed with the disease especially those over the age of forty. Diagnosis at the young age of forty participants found acceptable and ultimately inevitable especially once it was so widespread in the family. Many participants

are used to being surrounded by this disease thus explaining why some of the participants are feeling they are prone to it.

D: [and inherit yeah its D if its] in the family like I was saying erm with like my mum having it and all her side of the family had it and now my sister getting it it's one probably <you never know> ten years down the line I could be getting it (lines 62-66 FG1)

Participant D demonstrated that she realised that she is at risk of the developing the disease due to family genetics. However some of the participants did not know anything about the disease or know anyone who is diagnosed with it.

INT: Yeah does anyone else know anyone with type2 diabetes?

O: No (lines 70-75 FG3)

B: I don't know anything about [>diabetes but if I was to get it<]... >I wouldn't=I wouldn't know how< I feel until I know exactly [you know] (Lines 86-89 FG1)

I: I personally don't know what causes diabetes so I don't know whether I'm doing anything right or wrong I'm just living life do you know what I mean we just eat (.) we do concentrate cuz we don't have that much takeaway we don't have that much greasy food that's when we eat as a family but (.) we're ok with our diets cuz we're not aware of what we're doing wrong or what we are doing right or what we are suppose to do to prevent it so (lines 522-528 FG2)

These participants are not aware of T2DM therefore they do not concern themselves with it. They assumed they lived healthy lives but they do not know whether it will prevent them developing diabetes. Although T2DM is perceived to be a common disease especially among Pakistanis there is still a minority who report not knowing about it or the risks.

A: [I think that you=know] it's just normal (*inaudible*) that's why it's easy to (*inaudible*) I've heard somewhere that you get pains in your calf and your body [suffers]... so they are easy signs that you can miss (lines 187-192 FG1)

I: ... some women they're all over the place because they don't have the information they don't know if those feeling what they're feeling do you know what I mean... So it's good if they are diagnosed and they are aware of it (.) do you know what I mean (lines 137-142 FG2)

Participant I suggested that people should get tested for T2DM so they can understand it better.

4.4.2.6 Bad diet

Diet is perceived as one of the main causes of T2DM.

J: The types of food you eat (line 10 FG2)

L: ... we don't know who have this problem (.) everybody knows this problem is with this food (lines 85-86 FG2)

R: yeah (.) I though diet (Line 126 FG4)

Participants understood that the types of food consumed and the diet people have contributes to the risk and ultimately the development of T2DM. They presume that everyone is aware of this. Participants believed that T2DM is to do with sweet foods mainly sugar.

B: ... I thought it was when somebody's blood sugar level went too erm low and they had to eat something sweet or drink something sweet >to bring it back up again< (Lines 3-5 FG1)

I: the amount of sugars in your food like (.) for some people say they're sugar has gone really high (lines 14-15 FG2)

Participants reported that it is sweet foods that affect blood sugar levels to fluctuate. Participants suggested that sweet foods or a lack of them reduced/increased blood sugar levels. From the extracts above all participants refer to their blood sugar level as '*sugar levels*' and sweet things impact these levels. Similarly to the T2DM focus group participants, these non-T2DM participants also refer to diabetes as sugar, supporting the generalisation that most Pakistanis refer to T2DM as sugar (see discussion above).

D: ...I was saying >that I was going to say like< you referring to sugar most of the Asian people do refer to it as sugar [rather than diabetes]

A: [I was just going to say] (lines 173-177 FG1)

B: ... "Oh I've got sugar", you know in our language in the language we only know (lines 833-834 FG1)

I: Asian people call it [sugar] (lines 14-15 FG2)

O: [sugar]

M: sugar yeah (lines 31-32 FG3)

Sugar is the universal word used to describe diabetes especially T2DM. Although participants throughout the study referred to T2DM as sugar and attributed it to sweet foods

some acknowledged that diabetes is more than just a sugar problem. Participants acknowledged other carbohydrates and fatty foods as problems too.

D: it could be the food you eat if you eat too much like you know you can get (.) even if it's just too much fat <and erm like sugary things> and all sorts to be honest oils everything like that=it's [not just]... based [on the sugar] (Lines 52-57 FG1)

A: I think food-roti and that does contribute not just sweet stuff it's the amount of white erm like (.) naans and things those do those are very high <GI food so> (lines 365-367 FG1)

L: ... normally my sugar level is high and I don't drink coke, sweet things, eat chapattis too many chapattis cuz it's got too much sugar in it and I control mine

K: sugar in the chapattis? (lines 188-191 FG2)

Participants highlighted that eating a diet of fatty, high carbohydrate and sweet foods can impact T2DM development. Participant A referred to these foods as high GI (glycaemia index) foods that the body digests quickly rapidly releasing glucose into the bloodstream. Participant L explained how she controls her sugar levels by monitoring the foods she eats. Participant K was surprised to learn that chapattis contain sugar, which is the main part of a traditional Pakistani meal.

4.4.2.7 Lifestyle

There was a consensus throughout the focus groups that lifestyle factors are crucial to maintaining good health and diabetes prevention.

J: Yeah I think it does because if (.) if you know you eat properly and exercise regularly I think there's less chances of you being diabetic (.) I think yeah it does (lines 349-351 FG2)

N: Well apparently it helps you prevent it doesn't it if you take regular exercise (lines 279-280 FG3)

Participants illustrated that poor diet and lack of exercise are among the main causal factors of T2DM therefore they recognised that diet control and regular exercise are important.

4.4.2.8 Old age disease

Participants perceived T2DM as an older person's disease. They believed it is one of the old age diseases people are susceptible to later on in life.

I: Oh its just diabetes (.) you tend to think it's for older people

K: it's not relevant to you so (lines 585-587 FG2)

I: yeah it doesn't bother me do you know what I mean I'll just sit away but then it's that thing of (.) it's what do you associate with diabetes it's always for the older ladies let them deal with it do you know what I mean (Lines 588-591 FG2)

J: Yeah it's older's disease you know what I mean it's something else you can have as well (lines 614-615 FG2)

Participants did not realise that they were at high risk of developing the disease as they believed it was a disease for the elderly especially elderly women. They did not perceive themselves to be at risk therefore they were not concerned for themselves in regards to diabetes. Participant B went on to explain how T2DM is more common in the UK and how it has started to affect children in her opinion.

B: [It's just bizarre the amount] of people in Pakistan who have diabetes compared to here it's more and I think children are getting it more here. In Pakistan it's usually older people near the end of their life say if they're not (.) can't eat something or whatever (.) it's it's erm attached to another illness but here it's children and it's more serious. There the people I know are older people who have got diabetes their "sugar". I don't know any young people that have got diabetes I have not come into contact with them, but I do know somebody who has had it when they were pregnant that's as much contact that I've had (lines 945-955 FG1)

According to the participants this disease is more common amongst older Pakistani women and Participant B believed it was more sinister for children and the younger generation than the older generations, implying that it is easily dismissed when an older person is diagnosed with T2DM.

4.4.3 Lay beliefs and attitudes

4.4.3.1 Misconceptions

Participants across the non-T2DM groups in this study acknowledge that there are many lay beliefs and hearsay regarding T2DM among the Pakistani community.

D: I mean there is these myths that I know there are loads of myths going around >it's like< (.) with fru::it eating fruit (.) I mean some the like the diabe-they're like specialis-you >can't eat mangos you can't eat bananas< fruit which is [good for you

B: [Because they're sweet?]

D: yeah but then again it's probably because it's got so much fructose in it (lines 231-239 FG1)

M: But I'm not quite sure is that a myth or not? If you eat=have too much sugar (.) that's what contributes to it? (lines 40-41 FG3)

Q: ...just there with you know the right advice and information cuz you said that there's sometimes like myths going around like aren't there (lines 315-317 FG3)

The extracts above illustrate the confusion amongst participants Regarding T2DM and lay beliefs. They are not sure about specific information they have heard so they label it as myths. For example Participants B & D try to make sense of the myth about rich exotic fruits but due to their lack of factual knowledge they are not sure of the correct answer. It is most likely that these participants have overheard conversations regarding these beliefs but have not understood them. Participant Q suggested correct factual information needs to be provided to disperse myths and provide solid facts. Another lay belief they have come across is diabetic individuals enjoy sweet food more and crave it.

K: [Yeah, but I think] you know people who are diabetes-diabetic kind of like the sweet things more

J: Yeah

I: yeah it's like what you're forbidden not to have d-you mean that's what you want more (lines 120-125 FG2)

These participants explained that Pakistanis with T2DM want sweet food more as they are forbidden to have it, and they also believed that cravings are caused by a lack of a particular nutrient in the body.

4.4.3.2 Worsening one's own health

Among the participants there was an impression that many T2DM individuals worsen their health and quality of life rather than their diabetes doing it for them.

- H: I know it can be serious but most of them tend to hype it up themselves, I think most of them do it to themselves, oh I'm diabetic I can't eat this, I can't eat that, I can't move, they do can do it to themselves and make themselves disabled
- B: My neighbour came to my house the other day and I actually took her a glass of orange juice out and she she was afraid (lines 827-832 FG1)
- I: your personal outlook some people get a little thing and it's like oh the world's come down you know what I mean (lines 453-454 FG2)

Participants did not believe that diabetics are controlling their diabetes. From witnessing the behaviour of close family members and friends with T2DM participants believed that diabetic individuals give in to their disease and succumb to being sick. Participants implied diabetes is just another illness to add to a list of other health problems. They have the means to get better but not the motivation or the right psyche. Participants support this notion by explaining the lack of care in diet among the people with diabetes they know.

- M: Well (.) my mother-in-law (.) well basically she knows what her diet should be like but it's not like that (lines 182-183 FG3)
- N: [I think a lot of diabetics] are like that
- M: yeah even though she's got all the information (.) she still likes to have erm takeaway foods, she still likes to have loads and loads of oil in her food (lines 188-191 FG3)

Participants expressed that Pakistani older women do not look after their health appropriately in accordance with their T2DM nor do they have the motivation to deal with it efficiently. The example of exercise was provided by the participants. Participants believed that Pakistanis use their illness as an excuse not to exercise or do any kind of physical activity, which forms part of the assumed diabetic's fatalistic view.

- D: My mother-in-law says she's not diabetic or anything "I can't exercise I can't walk around the park, you know like I've got this..." She can do it but because she's got high blood pressure she stops herself. (lines 1210-1213 FG1)

F: I think just because you've got sugar it doesn't mean you can't do certain stuff (lines 285-286 FG1)

A: I think that if you've got diabetes it is difficult to do exercise

B: Does it effect you? I don't know this bit?

H: I don't think it effects you, I think the more exercise you do they more it helps you

A: No if you've already got diabetes it will affect the types of exercise you can do, you're going to be thirsty, you're gonna be tired, you do you do feel drained yeah drained (lines 1200-1207 FG1)

Participants believed that this is a common problem amongst Pakistanis. Participant A in the extract above demonstrated her confusion regarding exercise and the effects on T2DM. This could be due to what T2DM family members have said to her thus she is confused regarding the impact the disease will have on an individual if they were to exercise. For those Pakistanis who do exercise, some were criticised by participants for doing it incorrectly. Participants explained that people do not put any effort in what they do therefore it is simply a waste of time.

D: And now you see all the older people get together and burqua people by Adderley park walking and that, but they do it wrong. They don't do it with the fact that with exercise they don't realise that you've got to do it like at least half an hour a day and they think that slow walking and standing does that but you've got to get it so that your heart rate goes up and you're heart's pumping, you can feel you're heart pumping hard, and you start sweating. That's when you're thirty minutes starts. (lines 1214-1221 FG1)

M: Is it 30 every 30 minutes [half an hour]

Q: [30 minutes 30 a] day or something

M: [in a day]

N: [twice a day?]

Q: [walking or]

M: and it's got to be you can either do it in 10minute blocks and it has to make your heart beat faster isn't it? (lines 285-291 FG3)

Some participants understood the government recommendations for exercise hence why they believed many Pakistani women exercise incorrectly, therefore they criticised the exercise attempts made by others. The participants have most likely picked up the information from a form of media advertising as they try to recall the recommendations amongst themselves through the discussion.

4.4.3.3 Better living in Pakistan

T2DM is not a big problem in Pakistan according to participants as they believed that less people there know about it. They also expressed that Pakistanis living in England are worse off health-wise than those who live in Pakistan.

B: I think living in England is more of a problem, living in this country whereas in Pakistan the whole fresh fruit, fresh (.) I think it's more the lifestyle is better... I don't know why but I feel that that would be better [for someone] (lines 933-938 FG1)

B: They don't usually make a [big deal about it in Pakistan]

D: [They're not educated] (lines 824-825 FG1)

F: Back in Pakistan it's like erm you got my exercise, you're walking to get your own water, you sweat it off, you hardly sweat here... You walk to get a car or whatever but you don't walk just from here to a bus stop, you have to walk to the main sarak (lines 958-963 FG1)

J: Because erm I don't know if if (.) if Pakistan have erm you know the kind of erm junk food that we have in terms of burgers and (.) donner meat and >things like that< I think because there are so many takeaways here in erm England that we just tend [to go for that] (lines 211-215 FG2)

M: No because er::m (.) well (.) no my family they just think that since they've come to England they've caught all these kinds of diseases (lines 118-120 FG3)

M: Ye::ah because I think (.) with my mother-in-law when she's in Pakistan she just has a stable diet basically three times a day meals nothing in between no chips no nothing its just you know a curry and chappati (.) and erm and if she's gonna treat herself it's gonna be with fruit (lines 138-142 FG3)

Participants acknowledged that the lifestyle in Pakistan is different and better than living here in the UK. They attribute this to a number of factors such as lack of education regarding the severity of diabetes in the UK compared to Pakistan therefore it is not taken seriously, as well as increased activity levels. Also the majority of the participants in this study believed that Pakistanis living in Pakistan enjoy fresh foods and less processed junk food. They perceive the quality of food to be better in Pakistan as many people perceive it to be fresher and home grown. Also participants believed that the lifestyle is physically better in Pakistan as people are more active whereas Pakistanis living in the UK lead sedentary lifestyles. Many participants blamed living in the UK for the ill health of Pakistani women. Therefore

they believe that many Pakistanis use going to Pakistan as part of their management of T2DM.

M: so all of a sudden they go to Pakistan and they are on no medication at all

O: Yeah

P: Hmmm

N: But I (.) a friend of mine has said that as well like that her husband is from Pakistan and he's diabetic but when he goes back to Pakistan he's not (lines 122-128 FG3)

M: So she comes to England for about a year and then she goes ok that's it I'm gonna eat whatever I like and then I'm gonna go back home and then I'll get better (lines 205-207 FG3)

Participants explained how acquaintances use going to Pakistan as part of their treatment regime as they perceive living there being better for their diabetes than here in England, especially as there are many more unhealthy distractions. However participants were aware that living in England they have access to everything they need and more i.e. they appreciated that what they perceive to be necessities here in England are luxuries in Pakistan such as healthcare costs in Pakistan from GP appointments to medicines. Participants realised that they are fortunate to be living in England and have the NHS to chase them up when appropriate but they didn't think that was available in Pakistan. Therefore they believed that, though fewer Pakistanis in Pakistan may have T2DM, there are probably also fewer Pakistanis diagnosed with T2DM as many people cannot afford to be tested let alone pay for treatment.

I: [yeah here] and you can get the doctors' notes to come in and have check-ups and stuff whereas I don't think anyone bothers there so, so unless you make an effort to go but that costs money as well so

K: Plus everything costs there from medicines to doctor visits, health care costs (lines 243-247 FG2)

Another reason why participants believed that it is better to live in Pakistan than in England especially in regards to T2DM is due to the weather.

D: [yeah the air] there's better, the quality of life, not much pollution (lines 939-940 FG1)

M: ... so maybe it's the climate

INT: Ok

D: I agree with you (.) yeah I agree with you it's the heat (lines 132-135 FG3)

The quality of the air is perceived to be better as many of the participants' families are from villages in Pakistan rather than busy big towns. Therefore the air seems fresher and the weather is much warmer and pleasant than in England. Many of the participants stated that Pakistanis believe that the weather aids diabetes care and management.

4.4.3.4 Deal with it when it happens

Whether participants knew about the disease and its complication or not they demonstrated the attitude that they will deal with the disease when it happens even though they know they are putting themselves at risk.

I: Yeah (.) I would deal with it but I'll know it was my own fault do you know what I mean so if I kept my sugar levels-I don't know (lines 267-269 FG2)

K: Er::m it's er::m cuz we don't have diabetes we eat whatever we want there's no emphasis on being healthy or anything (.) no (lines 542-543 FG2)

K: It's one of those things that's gonna happen (laughs) (line 666 FG2)

I: ... my mother-in-law she's not er::m diagnosed diabetic but she knows somethings are bad for her but she still tends to go and eat them she'd rather you know what I mean suffer with the consequences later do you know what I mean she goes "Oh I'll deal with it later" (lines 125-129 FG2)

P: [Yeah] when it happens we will deal with it

O: That's how we see it as well (lines 439-440 FG3)

Participants appeared to have a carefree attitude towards developing T2DM. They would rather deal with it and think about it when it happens not sooner even though they are putting themselves at risk. They would rather carry on with their current lifestyles.

4.4.4 Negative emotions

4.4.4.1 Concern and distress

Participants who are not familiar with the disease acknowledge that they would be very concerned by it.

G: In my family no-one's got diabetes so if I was to have it today I think it would be a shock until I [get used to it] (Lines 101-102 FG1)

J: Yeah upset (.) e::rm because it's it's it's not erm (.) it's (.) it's something that you know it's not erm how can I put it? (.)

I: I think it's just cuz you take yourself for granted do you know what I mean? (lines 151-155 FG2)

J: I don't know really er::m (.) overall it probably would (.) I'd probably be depressed (lines 446-447 FG2)

Many of the participants would be distressed if they were diagnosed with the disease. They believed it would take them time to get use to it and may lead to other psychological problems such as stress and depression. The participants who are worried displayed fear.

A: ...I'd be erm really really worried because I think it is quite serious (lines 106-107 FG1)

L: [Id be] worried (line 460 FG1)

Q: I think (.) me=I think I'd be quite at first quite scared cuz I don't know much about it and (.)
(Everyone agrees) hmmm

Q: I know it's quite a serious disease so I think at first I'd be quite sort of shocked and scared and then panicking thinking oh you know what's it gonna mean (.) you know if my life I'm gonna have to have injections everyday or make big changes to my diet that sort of thing (lines 49-56 FG3)

The participants would be very concerned if they developed the disease as they perceived it to be a serious health condition. They do not have much knowledge regarding the disease but have picked up information from immediate family and friends. Across the groups the majority of participants would feel anxious if they were to be diagnosed and they understood that it would have a significant impact upon their lifestyles. A minority were not as anxious as they were prepared and were living healthy lifestyles; however there were clear negative emotions towards becoming diagnosed with the disease amongst participants. Participants

mentioned that a significant factor which would determine how they would feel about being diagnosed depended on their responsibilities:

I: I don't think it would affect me that much cuz I haven't got much on my plate at the moment that I have to deal with whereas someone with three or four kids and a house to run (lines 431-433 FG2)

Participant I explained how she would cope better with being diagnosed than a mother running a more hectic household. She had less responsibility than other mothers and therefore felt if diagnosed she would be able to adapt and cope better than others. However most of the participants in this study acknowledged that it would be a burden on them and make their lives more difficult.

B: It would worry me because I've got four kids and it would worry me because within my own family how would I cope? (lines 264-265 FG1)

I: ... it would be stressful as life is stressful anyway but just having that added pressure would be like (.) like the lady says you know what I mean to have time to concentrate whereas normally like like you're not bothered with time you know what I mean it would be like it's like a pressure (lines 496-501 FG2)

M: and then that e::rm basically if I was cooking something at home for myself and I'd have to cook something different for my mother-i::n-law that would actually pee me off (lines 265-268 FG3)

B: ... he use to eat a lot of red meat and erm the doctor actually told him that you're not allowed to eat red meat anymore and he has to limit the amount (.) and erm yeah he's been told what he can and can't eat (.) and he's actually distressed about it because he feels like he's living half a life, he can't eat what he wants (lines 810-815 FG1)

Participants expressed how they would feel extra pressure and stress if they were diagnosed with T2DM. It would make them anxious regarding looking after their family and would make them change their ways which they seem reluctant to do. Being diagnosed with the disease would add extra responsibilities to their daily routines like extra cooking which participants would resent. There are many negative emotions towards change. Participant B explained how her immediate relative has had to give up something he enjoyed which caused him a great deal of distress. Change is always stressful especially when having to make changes in your life and you do not want to. Participant B described such changes as living half a life

rather than a complete one because they are being told how to live it. Participants went on to mention that they believed change is more difficult for older people.

I: ... if they go to the doctor's to get all the information that's where the doctor's get a bit wound up as well cuz they're thinking we're giving you all the information we're telling you to eat sensibly, keep your balanced diet healthy, have your fruits, have your vegetables (.) but it's like we just go-we listen to it but you come back and you still do what you wanna do do you understand? That's what a lot of Asian people do older Asians do. (lines 332-339 FG2)

Participant I stigmatised old Pakistani people as rebellious to change. She expressed that older people do not adhere to diabetes management advice or recommendations. They would rather do what they want to do and lead their lives the way they desire. For older Pakistanis many of them are not just breaking routine but they also are changing their life habits. This is very hard as habits become embedded in an individual.

4.4.4.2 Severity

A reason why many participants were anxious regarding being diagnosed with T2DM was because they class it as '*serious*'. They understood the severe and extreme complications of the disease.

A: I'd be erm really really worried because I think it is quite serious=where there is a lot of e:rm information on the news about gangrene and having your feet (*background noise*) hurting=it does lead to other things >and it worries me< if someone were to say to me >turn around< and say you've got diabetes=it would be really I I'd be really (Lines 1069-111 FG1)

B: ... any operations that you have what's the first thing they ask you they ask you about these illnesses (.) so this is always on forms as serious (lines 315-318 FG1)

I: I've noticed with Asian parents they are reluctant to go to the doctor's to to be diagnosed cuz it's like a big disease to them do you know (lines 29-31 FG2)

L: ... I have the same problem with this and I feel this is (.) big thing (lines 63-64 FG2)

Q: I know it's quite a serious disease (line 52 FG3)

Participants shared their knowledge regarding the severity of this disease. They emphasised the harshness of the disease and discussed the worry it would cause them as they perceived the disease to be life impacting, as well as discussing the effects the extra strain would have on their body. Many individuals have also come across literature that refers to T2DM as a serious illness increasing their fear. For example T2DM would delay the recovery of an individual after an operation or even a simple procedure and make them more susceptible to post-operative infections; therefore after finding this out participants believed their concern is valid as diabetes is confirmed as a serious illness on hospital forms. Pakistani people in particular are very reluctant to get tested for T2DM as they portray it as a significant disease. The realisation of the severity of the disease provoked some participants to be pushed into fear mode generating consequences and implications of the disease.

D: erm you're right there because I do know an aunty even=this is back in Pakistan actually she did get erm=she hurt her toe and then it ended up affecting going up the calf so she ended up >having to have her< up to her calf amputated

B: Amputated Oh my God

D: Cause it was so bad and err another I know quite a few people and even people in the UK that ended up having toes amputated because of [diabetes] (Lines 120-127 FG1)

A: erm it's to do with your eyesight as well [because my (.) with]... I wear glasses anyway to [to have that]

D: [gla:ucoma]

A: extra strength no extra [worry]

H: [strain]

A: strain on my you know [body with]

H: [eyesight]

A: eyesight and then you've got the you your feet and you've got to take care of everything=I I'd be really [horrified] (Lines 128-139 FG1)

H: ... you can go blind with that (Lines 151-152 FG1)

C: my dad's got sugar and erm everytime he gets a wound or something it takes twice as long to heal... he ends up getting cellulites a lot now... and it takes longer to heal and he ends up getting worse so he has to go into hospital cause they can't bring medication like the doctor's can't he has to go into hospital to get the medication that he needs... he has to be quite strong to get it to heal and it [takes]

INT: [Okay]

C: very long to heal (lines 153-166 FG1)

These participants illustrated T2DM as a terrible chronic condition with life debilitating consequences. They discussed the physical pain it can cause the body especially the external extremities. Participants discussed the complications diabetes can have on the feet which can lead to amputation. The eyesight implication hit home with many participants as some already have eyesight problems so if they were to develop T2DM it would make the situation worse for them and may in the extreme case cause blindness. Living with T2DM not only has its own consequences but also has a knock on effect on the body causing more health issues. As Participant C explained it takes longer for her father to heal because he has diabetes. The majority of participants acknowledged the harshness and severity of this disease yet there was a minority of non-T2DM participants who were not convinced about the severity of the disease.

I: Yeah I don't think people believe it's that serious that's why so what if your sugar goes down

J: I don't think I'm not sure it's whether it's er::m serious or not I think it's a lack of information (Lines 597-600 FG2)

Q: I think I'm more aware of cancer and heart disease and things like that rather than diabetes

INT: Right yeah

Q: that would probably come further down the list of things to worry about in terms of you know healthy lifestyle (lines 430-434 FG3)

This minority of participants illustrated their lack of understanding concerning T2DM. They were not convinced that it is a serious disease maybe because they have not heard about the serious side. As participant J suggested it could be due to a lack of information to do with this disease. These participants were probably more aware of other health diseases which are more predominate within their families therefore view other diseases as more serious and life threatening than T2DM.

As well as negative emotions of concern, fear and severity a few participants felt that close friends and family would display pity even empathy towards them if they were diagnosed with T2DM and they would not like that.

N: I wouldn't like it [it's]

- M: [But] I wouldn't like it personally if I couldn't eat (.) a lot of those (lines 245-247 FG3)
- M: I'd feel really e::rm (.) you know if someone like, people feel sorry for me you know I'd hate that. Oh you can't do this because you're <diabetic> you can't do this because of sugar, it would be constantly in my head and I'm one of these people it would bother me... you can't do certain stuff and you can do certain stuff but it's always there behind your head oh you can't exhaust yourself cuz you'd be you know (lines 279-289 FG3)
- K: I know somebody who is who watches his chillis so he makes his separate food (lines 284-285 FG2)
- A: When you see people who have got diabetes well back (.) in Pakistan when I went down, that's her curry it would be bland watery with a bit of floating chicken because she's diabetic. That's her dinner, you've eaten way before everyone else, isolated, and that's your dinner
- D: Like a leper (lines 816-821 FG1)

These participants would not like having to give up food they enjoy and would not like being treated differently. They would not appreciate other people's pity towards them as it would affect their emotional and psychological life. It would make them feel incompetent even though they are not. They would feel like this because they believe T2DM individuals are treated differently and therefore isolated. They believed that having diabetes they would be forced to make and eat bland and unsightly foods and would be singled out from the rest of their family and friends.

4.4.4.3 Effect of T2DM diagnosis in their children

Whether participants were anxious or not about them developing the disease many believed that their children would be scared to find out their mother had a diagnosis of T2DM.

J: [Yeah I] think they would be worried (.) (line 503 FG2)

P: They would get scared (line 355 FG3)

Participants believed that their children would be concerned for their mothers. They speculated that as they would feel anxious therefore they thought their children would too. On the other hand many participants emphasised that T2DM is so common that families are

used to it hence some children maybe less worried if their mother developed the disease.

They may see it as being inevitable.

M: I think my kids are kind of use to e::rm seeing all the medication and seeing all the blood pressure machines and (.) she's=my mother-in-law's got that prick (.) (lines 364-366 FG3)

A: ... and her child use to say to her you can't have grapes while you have your dinner because that's too much sugar >and the child was only< 6 years old (.) so obviously having it in the family does make you mor::e aware

All: Aware yeah (lines 243-247 FG1)

With T2DM being so common participants believed that immediate family members are exposed to the disease without being diagnosed through a relevant other. They learn about the disease especially the changes that need to be adhered to in order to maintain the disease. Therefore even children become more aware and vigilant. There were also negative emotions demonstrated by participants if any of their children were diagnosed with T2DM.

A: I'd be mortified if one of my children got it because I

D: As a mother yeah

A: as a mother I-a::t such a young age it would be ab::so::lutely horrific (.) if they were on injections for the rest of their life I'd be like oh God you know

All: Yeah (lines 299-304 FG1)

Q: I think I'd worry as well then that they would then inherit it (lines 390-391 FG3)

Participants believed they would be very distressed. There were mixed reactions regarding knowledge and understanding of the disease therefore they would be more confused and scared. When thinking about their children they assumed the worst case scenario i.e. using injections and this was distressing for them. Thus these participants believed that it is more important that their children remain diabetes-free, therefore their children's health is more important to them than their own.

B: I think you can take it you-you for yourself if you had it before your children not your children you would rather have it take it all for them

INT: Right

B: you know I'd [still love my child but]

H: [in audible]

- B: you can't even look at them when their ill with a cold never mind anything else it's just hard. With children their whole future's in front of them it affects their-it does (lines 307-315 FG1)
- A: I'm so good at making sure all the food is prepared and organised and all the children and my husband, but I'm no good with it for myself. I know that eating that is going to make me a bit sick, yeah you know it's a chocolate cake and I've had a bit too much you know simple things like that making a decision right then I think that's what I can do to make it better for myself but my children are fine in the way I do the food. It's myself I'm more worried about. (lines 917-924 FG1)
- I: I know I concentrate on my son's health... I'm happy with his diet. (.) My own I should concentrate on myself a bit more like eat regularly and eat healthily foods (lines 627-634 FG2)
- K: Yeah it's ok er::m (.) sometimes it's like erm (.) running around and that do you know but (.) try and concentrate on him more than myself (lines 653-655 FG2)

Participants highlighted that their children's and family's health was more important than their own. They voiced the concern that their own lifestyles were not good but they would rather ensure everybody else's was better. They are so busy looking after significant others that they end up neglecting themselves.

4.4.5 Moral support & social influence

4.4.5.1 Moral support

It is clear from the analysis of this study that participants would be offered moral support from their family and friends if they were diagnosed with T2DM.

- I: I don't know I think they would be worried for me (.) but because my family know what type of person I am they think I will be able to look after myself anyway (lines 196-198 FG2)
- J: [Yeah I] think they would be worried (.) I think er worried and they would be more aware of what I'm eating and whether I'm taking having my regular exercise or not cuz at the moment I'm not watching my diet I'll just eat whatever I can get my hands on so I think they would be worried yeah (lines 503-508 FG2)

Family members would be surprised if participants were diagnosed with the disease. However their initial reactions would then change from concern to encouragement towards living healthy.

F: The first thing they will say is get some exercise and stop eating sugar <I think> (lines 252-253 FG1)

Participant F shared that she would be encouraged to exercise and reduce her sugar intake. It is unclear whether this would be said because she does not exercise and has a lot of sugar in her diet, or because her and her family believe them to be causal factors. Participants recognised that they require the support of the whole family to promote a healthy lifestyle especially healthy eating. They expressed that the key to being successful is to lead by example. They must lead the way in encouraging the rest of the family to do the same.

A: So parents do influence their children then (line 479 FG1)

J: No no eat healthily as a family (.) yeah (line 515 FG2)

D: [I do try] and control what they eat >I do try and help them eat healthy< and do try and encourage them by [eating healthy]

H: [and exercising]

D: showing them that we're doing it it's s::o so I should lead in our footsteps (lines 325-331 FG1)

D: I do try and tell them to eat fruit rath::er than the crisp >and I try< and encourage them by like saying that "mum's having it why don't you" (lines 387-389 FG1)

M: What I found that with my children (.) if I buy food for them for example like mangoes and melons and watermelons (.) it could be in the fridge and they won't even touch it but if you cut it out for them and put it out on the table they actually do eat them (lines 601-605 FG3)

A: My husband is really good er::m I think he's learnt with me, we've learnt as a couple (.) to when we're eating just to encourage our children (lines 795-797 FG1)

Participants believed that by setting an example it is easier to motivate and encourage others especially children. They also appreciated the support of their partners and other family members. Many Pakistani mothers struggle to feed their children a healthy diet especially as they get older and explore different foods. They become very fussy which can make meal times very challenging. However participants emphasised that mothers should encourage

their children to eat different types of food and take charge at meal times therefore their children will have to eat what they are given.

H: They tend to grow up as you bring them up (lines 564 FG1)

N: I think it depends on their age (.) I think when their young like you said yours is very young (.) it's good to start off those habits early their eating habits and exercise and whatever but then my children are adults so (lines 740-743 FG3)

Participants appreciated that it is easier to feed children when they are younger rather than when they are older. As they get older they decide for themselves what they want and what they like. Thus by embedding good habits early participants believed that they could have saved themselves a lot of hassle.

4.4.5.2 Family hindrances

However sometimes family input and influence can be a hindrance in promoting the healthy living process especially when participants have tried to maintain a healthy living balance for all at home.

D: [I don't buy coke but my mother]-in-law comes home with coke (lines 499-500 FG1)

G: like when family comes over they have bags full of sweets, chocolates and mitie (lines 505-506 FG1)

M: so if I say I'm gonna cook with (.) you know a little (.) you know little oil obviously they're not gonna enjoy the food (.) so it's a bit different it's quite difficult when you have to balance it with when your living with extended family and your own children (lines 412-416 FG3)

M: O::oh (.) I think that mine (.) I try to control what they eat (.) erm but at the end of the day I'm not there

INT: Yeah

M: and at the end of the day they get a lot of takeaways as well sometimes with their (.) grandparents so depending on what their grandparents are eating (lines 573-578 FG3)

Participants emphasised that they do not bring sugary drinks and snacks into the house but other family members do. They are treated regularly with confectionary and Asian sweets. They stated that it is sometimes difficult to find a balance when living with extended family and your own family. From the above extracts one can see that it is extended family who

can hinder the healthy living process especially grandparents who just want to spoil their grandchildren.

D: ... if I do tell her certain things like don't bring this she won't bring it and sometimes she think's oh God the children deserve a treat (lines 514-517 FG1)

F: I wouldn't give I mean I don't buy fizzy drinks I mean I live with my girls and don't have much sweets and chocolates at home but then they run down-my mum lives a couple or doors down and they run down to hers and have whatever cuz they know mum's got them and not gonna say no

B: My mum's like that she'll come round and bring lollipops for the kids

G: Sound like grandmas (lines 518-525 FG1)

N: And like for my mum it's like you know "what are you doing he can have a milky bar he can suck on a milky way" but "no mum it's full of sugar" and she says "blimey" (*laughs*) so it's hard getting that balance (lines 765-776 FG3)

Participants believed that grandparents and other family members want to spoil children out of love and they see the parents as the enforcers not them. They want to be liked and revered. They believed that children should enjoy sweet foods as they are treats and foods of enjoyment. They cannot say 'no' to the younger generation. According to the participants it is not just grandparents and extended family that can be a hindrance but husbands too.

H: It's not my children it's my husband. If I make something the kids will happily eat it but my husband won't be >he will be expecting me< to make something else (lines 733-735 FG1)

C: They don't co-operate, they don't have the co-operation (.) they're just like stubborn (.) they want their own way (lines 739-740 FG1)

Some participants explained how their husbands were not very supportive when it came to mealtimes. The husbands turned into children becoming very stubborn and wanting their own way. They do not co-operative with participants therefore they do not set a good example for their children. If they were not happy with what was made they expected something else to be cooked for them. Traditional Pakistani meals are very rich in fat and spices and are cooked for a long period of time. Therefore many individuals will find it hard to change from this style of cooking and eating to healthier options.

4.4.5.3 Hindrances in the form of friends

Another form of hindrance recognised was friends. Participants believed that they influenced the younger generation to be less healthy and to eat less home-cooked food.

D: ... my son started hanging around his friends and so now he takes pocket money and say's oh I wanna go and get something for lunch with my friends and they end up in the burger shop (lines 565-568 FG1)

D: [It's combination like outside it's their] friends and who they hang out with they all influence them

E: Yeah you hear I went out I went with my friends, I went to pizza hut with my family, or I went here with my family (lines 571-575 FG1)

Participants emphasised that another hindrance to them trying to provide a balanced eating lifestyle with their children are friends of their children. Participants stated that their children want to go out with friends at lunchtime rather than eating school dinners or packed lunches. They are easily influenced by their friends. It is seen as cool to go out for meals with friends and family rather than staying indoors.

4.4.5.4 Junk food

Participants believed that a significant reason why Pakistanis are at high risk of developing T2DM is because junk food is readily available in homes and it is these unhealthy foods that are used as treats.

D: they have ready access to crisps and things they grab them even though I say I'm gonna put them under lock and key, I know that's bad (lines 385-387 FG1)

G: ... they will be treated with a sweet afterwards... Bribe them (lines 391-394 FG1)

Participants realised that having junk food in the house is not good as they are allowing their children and family members ready access to unhealthy snacks. They also understood that using these unhealthy foods as incentives and treats was wrong. They did so as it got the children to do what is asked of them. Participants frowned on elders earlier who gave their children sugary drinks and snack as treats, yet some are doing it themselves. Some acknowledged that it should not be this way.

- A: I think treats shouldn't be sweet things you know that's the [thing, lollipops and stuff like that] (line 532-533 FG1)
- D: [inaudible] sticker charts and at the end of the week having bu::t actually you know that that there's that owl advert going on about the health thing?
- A: Change for life, I've got the chart (lines 535-538 FG1)
- D: I think it's good cuz it's got their name on it it's about them I said look (child's name) you're eating too much of this, you're not getting enough of exercise, you know >this that and the other< and I include myself in it (lines 544-547 FG1)

Participants demonstrated the effective use of sticker charts as incentives and rewards. They are being used and promoted by Pakistani mothers as an alternative to sugary treats. This simple but effective resource is not only encouraging children to be healthy but also getting the participants involved too. These resources have come from the children who got them from their schools. Participants recognised other options to junk treats and some are utilising them whereas others are not.

Another reason for having junk food in the house is because children control meal times.

- F: Even though you do make healthy food at home and stuff kids nowadays they don't eat
- B: Yeah
- F: They do want to eat burgers, chips, pizza and [coke and biscuits]
- E: [where do they all get that] from though? Parents (lines 403-410 FG1)

According to Participants F and B children dictate what they what they want to eat at mealtimes and Pakistani mothers surrender to their demands. Therefore parents are to blame for their children's bad eating habits. They should control them from a young age and not expose them to bad eating habits and unhealthy lifestyles. However it is difficult to control other individuals' diets when there are so many hindrances as discussed. Also there is a consensus between participants that junk food is cheaper in fact much cheaper than healthy foods, convenient and time-saving.

- G: I use extra virgin olive oil... sixty pounds for five litres
- D: Can I just say that I think what does influence children is that you can buy a burger for a pound
- Group agrees: Yeah

- D: It's difficult to buy-what fruits can you buy for a pound?
B: Fast food is so cheap (lines 609-616 FG1)
- F: Have you noticed at home time most of the parents are in the takeaways getting stuff for their kids (lines 621-622 FG1)
- F: No matter how healthy we want to be it's hard for me in the day cuz [I've got no one with me, I'm just gonna go]... to the chip shop today just for the sake of my two little ones, it's a need for me at times (lines 680-684 FG1)

As children enjoy the taste participants understood the temptation of buying out rather than cooking at home. Restaurants and takeaways have started to promote and make healthier eating options and foods however children still opt for the unhealthy foods.

- G: They are starting to provide healthier options now like (shop name) they do grilled salmon, but then you go there and you can still smell the fries and the kids want the fries
F: Kids expect the fries at a takeaway (lines 694-697 FG1)

Participants believed that as long as these eating places offer unhealthy junk food options healthy food options will not work. People especially children will want the junk food. However participants explained that they need to take control of these situations and enforce healthy eating habits in their family.

- B: we took the kids out but we had dinner and I think it was a good choice cuz I made the choice (lines 711-712 FG1)
- A: I just cook the one curry and we all have to eat it whether you like it or not (lines 724-725 FG1)

Participants reassured each other that eating out does not have to mean eating junk. They can make the choice to eat somewhere healthy or choosing the healthy options on the menu. If they do cook at home then they should cook one dish forcing everyone to eat the same thing and not give into any stubbornness or rebelling. Participants felt they need to take control of their family's eating habits and to be more assertive in their food choices. Participants went on to also place some blame on the media and local businesses. They alleged that takeaway, restaurants and franchises are all part of the problem.

- M: whereas (.) here it's like everyday you know takeaways... you know they're readily available (lines 144-146 FG3)

H: I don't think it's from parent's house I think it's from the outside.
Takeaways are on every corners of the street... The smell does draw
you in (lines 412-417 FG1)

D: (inaudible) then my little says I wanna go McDonald's (line 420 FG1)

Junk food outlets are available everywhere and cheap. Participants did not believe that the problem existed within Pakistani homes. Takeaways and junk food places are to blame as food is processed and extremely unhealthy but the smell disguises this and draws people in. Participants believed that part of this problem is the advertisements and gimmicks used by businesses as they lure the children in.

C: Advertisements

F: It's advertised too much (lines 430-431 FG1)

B: I personally think it's the happy meals and the toys

E: I was just gonna say

B: and everything luring kids in with toys and you going past and they go we want a happy meal and all they are doing is giving them a two pence toy (lines 433-437 FG1)

D: The kids do tend to drag their mum's along cuz they moan at their dad's so much that mum's give in (lines 446-447 FG1)

Participants blamed the advertisement campaigns of the junk food businesses for luring in their children. However participants felt that they and other Pakistani parents are not succeeding in their roles as they give into these temptations and adhere to the pleas of their children.

4.4.5.5 Increasing awareness

Participants came up with some ideas on how media resources can be used to increase the awareness of T2DM.

J: I'm not sure if they've got ads on TV at the moment but I know that
the new stroke ad they've got on TV which often comes on so something
like that

K: Something eye-catching [cus that one really got me]

J: [something when you're] watching TV and it just
comes up and makes you aware you know that er::m (.) (Lines 550-555
FG2)

Q: I think I have seen posters around things like e::rm (.) what the
symptoms could be and saying you get free diabetes tests so just go
and ask your doctor or go to the pharmacist things like that just get

you thinking (.) oh yeah I am a bit more thirsty than usual, tired a bit more than usual, maybe I'm a bit overweight perhaps I need to get it checked out sort of thing just to put the idea in people's minds (lines 503-509 FG3)

Participants appreciated that billboards and posters are being used to raise public awareness of T2DM and they do seem to be having an impact. They believed that TV advertisements should be utilised as well to raise T2DM awareness as they too are effective. Participants found other health TV campaigns to be memorable so a similar TV campaign should be used for T2DM. Another suggestion made by some participants was using the internet especially to raise awareness among youngsters. Advertisements and site links should be on commonly used sites by Pakistanis so they can be drawn into find out more.

- I: yeah cuz you have to be more (.) cuz younger people know with being more on the web and everything and the internet so it's a different media now that they have to use cuz sometimes people just walk past and they don't pick up on these whereas something will suddenly come on the internet on their website or something like that
- J: Yeah something like on MSN or just like an advertisement for a new phone if they had something like that (lines 556-563 FG2)

The internet is a very powerful tool. Participants believed that the internet is regularly utilised by young people especially therefore it should be used to advertise T2DM awareness. Participants also emphasised how the government and schools can do more to help promote awareness of this disease especially with children. The sticker charts mentioned earlier came from preschools and primary schools and were a good idea therefore participants suggested that schools could incorporate health issues including T2DM onto the curriculum.

- B: I think they can do more in schools. They are so tough on numeracy and literacy, let's get the facts in about health. No ones put health on the curriculum
- D: Basically we wanna bring in a health worker to talk about things like health issues (lines 1276-1280 FG1)

Participants expressed the need to incorporate diabetes health awareness in schools and educational institutions. They believed it would be a good idea to bring on an expert to discuss diabetes awareness.

4.4.5.6 Healthcare service expectations

Many participants had a lot of expectations of the health service and there is a common belief among them that the health service needs to do more to help those with T2DM or those who are at a high risk of developing it.

D: ... they do have link workers they do have dieticians, but do they do enough? I mean the doctor sees you, gives you medication and that's it. You see the nurse every so often, they need to do a bit more (Lines 1256-1259 FG1)

I: I think for those who are diabetic and still choose to you know eat er::m foods that they have been told not to eat (.) I think for them they should push them a little more harder... I think they should really be on those peoples case, making sure that they eat regularly you know healthy food and taking regular er exercise (lines 393-399 FG2)

I: ... I would like to know what f-what can cause diabetes so that before you get it (child interrupts the participant who is her mum) so I would know what to do (.) like at the moment I'm not aware of what would cause diabetes so that's why I'm like you know what I mean just carry on (lines 410-414 FG2)

L: ... I was actually asked to be at a diabetes thing one of the ones but I didn't want to go into it when I haven't got it (lines 1254-1256 FG1)

I: I think the talks are a bit do you know what I mean probably the visits but the talks seem a bit boring cuz I've noticed when someone's talking people just tend to walk off

INT: Yeah

I: it's like oh they've going on about diabetes

J: Yeah personally myself if someone's talking to me I kind of switch off (.) if it's not interesting if it's not something I don't wanna hear then I kind of just yeah (lines 573-580 FG2)

Participants believed that many health professionals are involved in delivering diabetes care but more support is needed. They must motivate and encourage T2DM sufferers more to look after themselves especially those who are not adhering to healthy lifestyles. Participants expressed the need to explain what causes diabetes so they can try to prevent it and understand it. They also believed that health professionals need to make appropriate campaigns relevant otherwise at risk Pakistanis will not be interested especially as they have the attitude of dealing with T2DM when it happens.

Participants appreciated that there is a lot of awareness information and material out there and the government as well as the health service are committed to improving health.

J: But I think here more information is available here whereas there I don't think there is much information centres or someone coming in and having a chat and everything (lines 225-227 FG2)

I: I mean if you bother going look-if you go to the doctor's it's there but they just haven't put it across do you know what I mean (lines 605-607 FG2)

M: so if I if I y (.) for example e::rm if I did get if I did have diabetes tomorrow (.) then I would know exactly where to go and I know exactly what is avail what is available [cuz I] (lines 471-473 FG3)

L: They gave me leaflets, they called me every week and check my diabetes sheet, they gave me a book where I write morning time, this morning, afternoon time, this (.) and the (.) put apple erm fruit, what I eat (.) eat more fruit , chapattis, little rice, little spice, erm (.) (lines 372-376 FG2)

Participants acknowledged that T2DM information is available and they would know where to go to get this but it would be more practical if health workers talked to them about diabetes. It would be more beneficial than them trying to read up on it on their own. They would understand and be more proactive if they had someone to discuss it with. As they do not have a diagnosis of T2DM they are not concerned about getting the information but they would be receptive to someone who would talk to them about it. Furthermore participants suggested giving Pakistani individuals information on diagnosis and symptoms which will hit home rather than bombarding them with lots of data.

Q: to find out if they have got it or not (.) rather than giving people everybody the information and it might not be relevant

INT: Ok

Q: Yeah just get them to find (.) cuz isn't it that a lot of people have got it but they don't even know that they've got it

INT: Yeah

Q: so we got to get people properly diagnosed and then they can start getting treated or making the changes that they need to (lines 511-518 FG3)

Q: especially if you've only recently been diagnosed and you didn't know that much about it

P: Yeah

Q: to be able to have somebody there you can ring up and say is this normal or can I do such and such

O: that would help (lines 319-324 FG3)

Participants emphasised that Pakistani people need to be advised to get tested and given small chunks of information rather than an overload of information. They said that information needed to be given as facts as many people probably have the disease but are unaware. They believed that it is important for them to receive the appropriate treatment and make the necessary changes. They also discussed that it is crucial for the health service to tackle the language barrier issue. Participants expressed the need to employ multilingual staff and also produce their literature in various languages.

D: Yeah you know which people don't understand English it's good to tell them in Urdu
INT: Right
D: so they can properly understand and find out what to do and where to go (lines 521-525 FG3)

Participants believed that it is important to discuss in Urdu with Pakistani individuals so they can understand the disease, and to reiterate diabetes information to older Pakistanis especially to reinforce diabetes care and management. Overall they believed that the health service needs to continue to raise diabetes awareness.

A: It's knowledge, the knowledge is there... It's explaining it
B: I think we need educating in how to explain it (lines 1286-1290 FG1)

D: It's all about educating people about diabetes, you're just not educating the elderly, educating from the start (lines 1294-1295 FG1)

B: I think it would be good to educate the children when their young, cuz because I'm this age and I don't know anything about it
G: And then they can go home and educate their family as well then (lines 1301-1303 FG1)

Participants recognised the need to be educated and for the Pakistani community to be educated. Participants believed that they need to understand the disease and have the knowledge before they can adhere to healthy lifestyles. The elderly Pakistani community especially need sufficient support especially those who already have the disease and then the younger generation so they can be encouraged to encourage others. Education is important as well as awareness.

4.4.6 Pakistani lifestyle

4.4.6.1 The right food at the right time

Participants believed that Pakistani home-cooked food is healthy and freshly prepared.

B: A lot of chicken and heavy foods but in our defence everything is cooked from scratch, it's not processed food. We start with fresh food, onions, tomatoes.. I think we're slightly more healthier. You can choose how much oil you put in at the end of the day, whether you fry it or whether you grill it, you have choice (lines 597-604 FG1)

Participant B echoes the perceptions and feelings of the rest of the participants that home-cooked food requires fresh ingredients and they can choose the amount of oil to use. They even have the option to grill rather than frying. Participants believed that living healthy lifestyles is for their own benefit though many did not adhere to this. Yet they expressed that it is up to every individual to do the best for themselves.

K: You've got to control yourself (line 170 FG2)

D: ... I'm now I'm trying to you know in advance (*background noise*) watch what I eat (.) watch you know with the exercise and health (Lines 69-72 FG1)

I: But they think they if they are having a smaller portion do you know it won't get so bad (.) they would still take it but in a smaller portion but I think it's personal choice cuz you put yourself at risk and you're gonna deal with the consequences of it yourself (lines 311-314 FG2)

M: We have 100% control its how we do it isn't it (line 641 FG3)

I: I think that's just common sense actually if you just look after your body naturally... do you know what I mean, you're not overweight... you're suppose to have balance diet, exercise... so it's like a whole balance you know what I mean it's (.) it's got to be a whole package (lines 328-345 FG2)

This group felt that they needed to take control of their lives and make the right changes now. Participant I went on stating that it is common sense to look after one's body and that you need to watch what you eat as well as exercise. There are numerous factors to consider in preventing the onset of T2DM and making significant changes in one's diet will be a huge improvement and start. Participants who encouraged healthy lifestyles especially healthy

eating did not do it with reference or concerns regarding T2DM onset. They did it to ensure good health.

H: [I do think we limit over children but we don't have it in mind about the diabetes I mean I don't anyway I don't have it in my mind that I'm going to limit my child just for the sake of diabetes] (lines 354-357 FG1)

Participants took comfort in knowing that they look after their children's health in general.

They were not concerned about T2DM as they do not have it themselves. As part of a good balanced diet participants understood that eating on time and having regular meals are very important.

F: Yeah I know like for some people they have to eat like at erm (.)
A: regular intervals
F: Yeah regular intervals as well they have to make sure that >you know what I mean< >they are eating on time, they are making the right stuff as well<
A: More meals a day (lines 221-227 FG1)

D: With food with meals you should actually eat the set times, breakfast, lunch and dinner... I don't eat really much in the day I eat if I eat I'm eating at seven eight o'clock when the kids are asleep and I've always done that like my breakfast will be la::te (.) like late afternoon or something (lines 454-464 FG1)

These participants acknowledged that it is not just the types of food that needs to be healthy to maintain a good diet but also the times one eats at. Eating at set times is important and the participants in this study regularly encouraged this in their children but they do not act on their own advice and parenting. They understood that eating too late is bad for you as well as eating large portions, and that a Pakistani lifestyle when controlled is worth living.

D: you're controlling your diabetes with right medication and with the right eating you'd do just as well as everyone else cuz you get children with diabetes and you get all sorts of people but I'd say that it you were controlling it and it was under control
F: Yeah
D: then you could do just about the same as everybody else (lines 292-298 FG1)

Participants realised that T2DM does not spell the end of life rather it is a wake-up call to look after one's health. When T2DM is maintained a diabetic individual is just as physically functional as a person without T2DM.

4.4.6.2 Celebrations and traditional foods

Participants discussed that food is a very important component for celebrating and socialising.

- F: Eid isn't Eid without food, it's all to do with family and food, celebration food, everyone getting together you don't get to see your brother and sisters everyday and your uncles and aunties
- B: It's the same for Ramadan, that's a celebration of food for us as well (lines 1160-1165 FG1)
- A: Yesterday we had a celebration and I asked everyone to bring food in, I myself brought chocolate fingers and cakes and coke cola. No one bought anything healthy (lines 1179-1181 FG1)
- B: Socialising is done around food, it's like at schools and stuff, bring some cakes, socialising around food (lines 1167-1168 FG1)
- D: When its school parties what do we bring in? The teachers want pakoras and samosas, and they ask our children bring samosas, kebabs, pakoras. We just want to grab pack of crisps and tell the teachers we can't, but when they ask you you feel guilty (lines 1185-1189 FG1)

Pakistanis celebrate with food, mostly unhealthy foods. Even for school parties Pakistani children are encouraged to bring unhealthy traditional foods mainly *samosas*, *pakoras* and *kebabs* all of which are deep fried. Although Pakistanis have the option to make and share healthy foods, celebratory foods consist of fattening and naughty snacks and dishes. Participants acknowledged this as the main problem with celebratory foods. They are mainly greasy and fattening, and that's the way they are wanted on special occasions.

- C: During Ramadan people tend to eat a lot more greasy food like I mean (.) I:: know my family I try not to but my mum, brother and sisters like to have pakoras and samosas and it's all greasy food
- B: I think it's compulsory (.) to have pakoras it's like I have to do the frying. It's like everyday I mean like everyday everybody fries in Ramadan and it's all just junk. (lines 991-997 FG1)
- J: because people tend to go for more fried food [and erm]
K: [Spicy food]
J: yeah erm spicier and [sweet dishes] (lines 94-96 FG2)
- P: They change their diet in Ramadan
M: Yeah you mean it gets worse
O: I think it gets worse
M: because they have more oily foods and (.) you know they cook with (.) have more samosas pakoras everyday whereas normally we don't

P: Oily foods yeah we do (lines 216-222 FG3)

Participants believed it is obligatory to have fried food on special occasions and when celebrating. The food needs to be fattening and full favoured meaning spicy and rich. Participants were aware that their diets deteriorate during Ramadan especially as they constantly eat unhealthily for at least 30 days. As mentioned earlier there are other healthier options to these greasy and fattening foods but it is the individual's choice to make these changes.

D: ... that's traditional food that people don't understand you can make them in the oven and do them like that

F: Yeah grill them, oven them (lines 1015-1017 FG1)

L: But somebody can control (.) like my mum my mum didn't [eat it, it's up to you] (lines 118-119 FG2)

Participants across the groups recognised that there is an alternative to the greasy fattening food indulged during Ramadan especially and that it is again in their control to make the right healthy decisions. Participants also acknowledged that the problem in Ramadan is that even if one decides not to make fried or fattening food they will always end up with it as they will receive it from friends or family. Part of celebrating is sharing.

D: ... like if I made pakoras I'll pass them to friends and they do the same so my mother-in-law says don't even cook them... If I made seventy samosas I'd end up distributing them in the family, that's what I end up doing (lines 1025-1030 FG1)

B: In Ramadan you know if I don't cook something fried she'll send me some because she literally lives around the corner, everyday something fried. (lines 1037-1039 FG1)

During Ramadan food is shared not only in gatherings but also from house to house. However it is important to remember that this is not the participants' daily routine. Many T2DM individuals do not fast at all as it is not compulsory for someone with an illness to fast especially among the elderly. Yet many Pakistani Muslims believe as the blessed month only comes around once a year they must make that effort to try and keep a few if not all.

D: ... with diabetes some people don't fast cuz they've got diabetes I mean I know my mum God rest her soul use to fast all the time but then for the last two years she got to that point that she was on insulin so

she couldn't but when she was on the tablets she would, she would say I don't care no matter what I will fast. (lines 1003-1008 FG1)

D: With fasting you're actually, if you don't take you're insulin you're damaging your body and causing yourself harm. At the end of the day Allah would rather you not harm yourself and you know just pay for it, there are other options you know, give some money to an old person (lines 1059-1063 FG1)

I: Well you know due to the er injections some people like in the month of Ramadan don't fast (lines 54-55 FG2)

Participants acknowledged that it is not compulsory for people with diabetes to fast especially if they are on medication or insulin. If fasting caused an adverse reaction in the body this would be harmful to the individual. Therefore they are exempt from fasting. Although some understood the effects of fasting on diabetes many of them were unclear and confused about diabetes and fasting especially.

B: You know when you're fasting I think that if you've got insulin you don't fast do you? (lines 1053-1054 FG1)

L: I think it's bad for you (lines 66-67 FG2)

J: During Ramadan you think it effects you bad

I: I don't know cuz does it depends on what you have at night time when that can't compensate for how you feel during the daytime do you understand? So if you feel like you've eaten enough sugars or just something you know what I mean (.) you yourself would-if you know you're diagnosed with it then you know how much to eat (.) how you gonna feel during the day but (.) still I don't know I don't know the dangers (lines 74-81 FG2)

These participants speculated the effects fasting has on diabetes and whether it is compulsory for Pakistanis with diabetes to fast. They were clearly confused and lacked knowledge regarding this topic. They tried to make sense from what they knew and/or heard but were uncertain about the facts.

As mentioned before Eid is one of the main events that Pakistanis celebrate involving food. The food consists mostly of carbohydrates and sweet dishes. Again this is universal among all Pakistanis.

K: you kind of eat and it's mostly sweet dishes as well (line 117 FG2)

D: Yellow rice, brown rice, but we go out more on Eid days to others' houses

Group laugh and agree

B: Eid day is mitie and full of sugar. We don't do kebabs, we don't do samosas, we do pilau and the meat chops are in the oven so they're ok so it's just the sweets I think. They have the halwa, they have the mitie, they have the glam jaman. But it's not just the one day it's like three days (lines 1082-1089 FG1)

Participants explained how Eid is celebrated less with greasy fattening food and more with sweet and glucose rich foods. The savoury main dishes are not as unhealthy as meat is roasted and less frying takes place. As all the food is prepared at home it is fresh and better than unhealthy restaurant food. However there are a lot of sweet dishes and desserts that are enjoyed. Participants admitted enjoying these. Unfortunately things are starting to change for the worse as some Pakistanis are changing from making fresh home-cooked food to catered food on Eid.

A: ... Eid is changing you don't always have to cook you can get food in

INT: So you're going from cooking it fresh yourself to quick and convenient food

A: Yeah and it's really bad that is... Its just lifestyle our lifestyles have changed. All of us are more busy, we're so busy we can't even cook for Eid. We've got to get food in (lines 1107-1117 FG1)

Only one non-T2DM participant admitted to ordering catered food on Eid suggesting that it is not the norm among Pakistanis to do this. However as the option is available it could be possible that more people start to do this. Some of the participants also pointed out that catered food is also used at community events and functions. These gatherings are full of traditional Pakistani catered food.

A: They do the diabetes annual thing and there's food there

D: Yeah there was samosas and food there

A: Its run by Asian people so what do they give them Asians? Naans and food and rice (lines 1260-1263 FG1)

D: They're basically contradicting themselves cuz you're not allowed to eat this, you're not allowed to eat that, so why have they got it on the table?

B: They're lucky people don't have attacks while they are there (lines 1271-1275 FG1)

The participants highlighted how the wrong traditional Pakistani foods are offered at health promoting events. Asian naan breads are made from white flour and butter therefore they are not very healthy. These foods are the wrong example of foods to promote at a health promotion day. Participants also voiced pressure from others to produce unhealthy snacks at social gatherings, events and school parties. Healthier traditional Pakistani foods and dishes should be promoted and catered. Many factors contribute to a healthy Pakistani lifestyle; diet being one of the crucial components. Traditional food is the main element of Pakistani gatherings and celebrations and is culturally significant. The main problem whilst celebrating is the lack of control participants have.

4.4.6.3 Lack of exercise

When it comes to exercise all the participants in this study acknowledged they did not get enough exercise but that's one thing they find hard to do, nearly impossible.

D: ... I think (.) I don't get enough exercise (line 878-879 FG1)

N: I'm overweight, and I know that. I need to do more exercise but it's just finding the time

Q: Yeah

N: literally (.) I work full-time three children (.) so at the moment I'm trying to go to the gym at night but just having the motivation to do it

O: Definitely (lines 538-534 FG3)

M: ... I mean especially where physical activity is concerned I don't do any of it (lines 551-552 FG3)

P: I feel ok but I'm trying to do improve my diet you know don't eat too much oily foods and things like that but I don't do exercise at all. I really want to do it but I haven't got any time at home and everything (lines 557-560 FG3)

Participants realised that they do not partake in any physical activity or exercise. They shared similar excuses for them lacking in exercise mainly the lack of time and motivation. However as participants need to take control of their diet they also need to take control of their exercise. Participants suggested that exercising as a family is a good idea and that way they can encourage each other.

D: So we were in the park we went to feed the ducks with the kids and play football, and we got into teams, and my husband was encouraging me to run with him and sprint alongside him, and I end up getting a stitch but I stop for a bit and then like I started up again (lines 1229-1233 FG1)

M: I agree with that that we've got control but again it's again what you eat and how much you know cuz we all know that we should be eating healthily we all know that we should be doing exercise (.) but it's a case of if you do it (lines 649-652 FG3)

Participants emphasised the importance of exercising and the benefits of exercising as a family. They encourage each other to do their best and enjoy each others company. Participants believed that they need to take control of their exercise as well as their diets and maintain good habits.

4.5 Discussion

4.5.1 Summary

There are many internal and external factors contributing towards T2DM onset in British-Pakistani mothers. Non-T2DM participants were more careless with their lifestyle and struggled to live healthy lifestyles due to hindrances which they felt were out of their control. T2DM participants were more aware of the disease and its complications thus did their best to try and prevent it in their families. They also administered control over themselves. Overall participants from both groups admitted to not doing enough or any exercise. They all believed that the health service provided resources and care although the support they were offered was ineffective. They also voiced the opinion that the media played a part in luring them into unhealthy habits yet on the other hand it also helped to promote healthy living campaigns and T2DM awareness.

4.5.2 Comparing and contrasting British-Pakistani women with and without a diagnosis of T2DM

Five main themes emerged from the T2DM mothers and the non-T2DM mothers groups. Both participant groups discussed causal factors of T2DM. They discussed biological factors, gestational diabetes, symptoms of T2DM, genetics, bad diet and lifestyle factors. The T2DM mothers also discussed how they believed that T2DM had no single cause, the impact of other illnesses and vice versa, and impact of psychological factors. Pain was not discussed as a primary symptom of T2DM but T2DM mothers did discuss it as a result of their diabetes. This pain can be a symptom of which is one of the long-term complications of diabetes (Diabetes UK, 2006). It is not clear how diabetes causes nerve damage however research demonstrates that high blood glucose levels harms the nerves' ability to send

signals which damages the blood vessels carrying oxygen and nutrients to nerves (Diabetes UK, 2006).

Non-T2DM mothers in contrast discussed how being overweight has an impact on the onset of T2DM in their opinion. Another theme that emerged in both groups was moral support and social influence. All participants discussed moral support from family regarding T2DM diagnosis as well as hindrances from family and friends, and beliefs regarding support from the health service. Non-T2DM mothers also discussed issues around junk food and the need to increase awareness of T2DM.

Both participant groups also discussed issues around Pakistani lifestyle. They discussed Pakistani food and about consuming the right food at the right time. They perceived traditional Pakistani food as a pivotal part of celebrations. However in this theme T2DM mothers elaborated further by discussing their perceptions of T2DM as a chronic illness which is better managed in Pakistan and T2DM prevention in their children. The fourth theme which emerged was negative emotions. T2DM mothers discussed how they perceived their diabetes as being part of the norm. They went on to discuss their perceptions of severity of the disease, negative emotions towards T2DM and concerns for their children developing T2DM. Non-T2DM also discussed disease severity concerns and distress regarding the disease especially if their children were diagnosed with it. However they did not discuss the normality of living with the disease perhaps as they did not have it.

Finally the fifth theme that emerged in the T2DM participant group was management/control of T2DM where they discussed food and herbal remedies as well as family control of diet to manage their diabetes and to try and prevent it in their families. Lay beliefs and attitudes was the fifth theme that emerged among the non-T2DM mothers where they raised issues regarding misconceptions of T2DM and better living in Pakistan for individuals with T2DM overlapping with some of the issues raised in the management/control theme raised by T2DM mothers. However this theme differed as non-T2DM mothers also discussed their

perceptions and beliefs of T2DM being a common and a disease of old age which they will deal with when it happens. They also believed that British-Pakistanis with T2DM worsen their own health.

One of the main differences between the groups was that one out of the two T2DM focus groups one was conducted in Urdu however the participants in this group raised similar issues to the other T2DM focus group. There were no main differences in the themes and sub-themes that emerged nor in the conversations that took place. They also did not differ to the non-T2DM groups when similar issues were raised and discussed. Another difference was regarding the age range of participants. The non-T2DM mothers were younger than the T2DM mothers which may help to explain why they perceive T2DM as being an old age disease and that they will deal with it when it happens.

4.5.3 Pakistani Lifestyle

4.5.3.1 Lifestyle

This study illustrated that British-Pakistani mothers believed that lifestyle factors are crucial to maintaining good health and diabetes control. This is supported by the systematic review conducted in chapter 2, that lifestyle plays a crucial role in T2DM prevention. There was some understanding of blood sugar levels and biological factors among both groups with T2DM participants illustrating more knowledge. The knowledge regarding causal and explanatory factors were mostly based on experience rather than medical knowledge, which has been previously documented among British Bangladeshis who reflect on illness causes through personal experience and the experience of friends and family (Greenhalgh, Helman & Chowdhury, 1998). British-Pakistani mothers believed that hereditary and genetic factors play an influential role supported by previous research (Chesla et al., 2000; Grill et al. 1999) and that many people have experiences of close relatives suffering from T2DM thus this recognition influences their own view of the disease (Hornsten et al., 2004).

4.5.3.2 Lack of exercise

In this study British-Pakistani mothers did not exercise. Participants stated that they run around after children, move about a lot at home whilst doing housework and chores and some enjoyed walking, but they did not make a conscious effort to increase their physical activity. Hjelm, Bard, Nyberg and Apelqvist (2003) reported similar findings as they found that the importance of exercise was only mentioned by a few participants. Lai et al. (2004) reported that Chinese participants acknowledged that exercise does more good than harm and that it can treat any disease as well as enhancing physical strength, which was also voiced by participants in the current study. In contrast some British South-Asian women refrain from doing physical activity in fear of provoking or exacerbating their illness, and due to a lack of support and guidance from health professionals on suitable physical activities (Srisantharajah and Kai, 2006).

4.5.3.3 T2DM labelled as sugar

Bad diet was one of the main causes of diabetes in this study especially sugar intake thus explaining why the Pakistani community label T2DM as '*sugar*' disease. Lai et al. (2004) in their study regarding T2DM found that Chinese participants focused on 'sugar-control'. This misconception made them miss the importance of managing other risk factors. Lai et al. reported that the reason why lay Chinese focus their attention on sugar-control is related to the name. T2DM in Chinese is 'Tang Niao Bing' meaning 'sugar-in-urine disorder'. Hjelm, Bard, Nyberg and Apelqvist (2003) reported similar findings that Yugoslavians described enjoyment of life and emphasised freedom and security in life, enjoying food and retaining previous habits (e.g. eating too much fat and sweets) as the important factors for health much like the non-T2DM participants in this study

4.5.3.4 Bad diet and habits

British-Pakistani mothers understood why Pakistanis are at a high-risk of developing T2DM as being because junk food is readily available in homes and it is these unhealthy foods that are used as treats. Therefore parents are felt to be to blame for their children's bad eating habits. Participants acknowledged the need to take control of their family's eating habits and to be more assertive in their food choices. Participants from both groups went on to also place some blame on the media and local businesses. On the other hand participants appreciated media billboards and posters being used to raise public awareness of T2DM and they do seem to be having an impact (Hawthorne & Tomlinson, 1999). They believed that TV advertisements should be utilised as well to raise T2DM awareness as they too are effective. This supports a previous study which recommended raising public awareness through Asian radio and satellite television (Hawthorne & Tomlinson, 1999). Another suggestion made by some participants was using the internet especially to raise awareness among youngsters. Advertisements and site links should be on commonly used sites by British-Pakistanis so they can be drawn into find out more. Non-T2DM participants also emphasised how the government and schools can do more to help promote awareness of this disease especially with children.

4.5.4 Food and culture

A significant finding of this study was regarding the significance of food within the Pakistani culture. Lai et al. (2004) found that food is also important among the Chinese culture. Chinese food highlights an important aspect of Chinese culture. A freedom to enjoy food plays a critical role in improving quality of life (Yao, Chung, Yu & Wang, 2002). British Bangladeshis also centre occasions and festivals around food, and view it as culturally important (Greenhalgh, Helman & Chowdhury, 1998). Hjelm et al. (2003) found that participants discussed dietary recommendations and expensive food as consequences of their diabetes. Many Yugoslavians and Swedes, on the other hand, talked about the

importance of celebrating feasts to retain social networks with relatives and friends. Some Arabs also mentioned that their T2DM was a barrier to celebrating Ramadan as they need to take their medication and food several times a day even during Ramadan. Among many Yugoslavians Ramadan and the celebration of the Bajram feast were considered to cause problems in following good dietary advice. Bajram is celebrated in a similar way to Christmas in Sweden when people eat a lot of food throughout the day which is rich in fat and sugar and made following old recipes.

From this study analysis one can see that a good Pakistani diet can be achieved as the food is fresh and home-made, and Pakistanis need to ensure that they eat healthy, on time, take care of their portion sizes (also supported by Lawton, Ahmad, Hanna et al., 2008) and the key to being successful is to lead by example. British-Pakistani mothers discussed the impact celebrations have on their health as all celebrations are centred on food. Food helps to create a welcoming and celebratory atmosphere. This is also the case for social parties and gatherings. Participants illustrated that at these events unhealthy foods are shared and enjoyed. Even for school parties Pakistani children especially are encouraged to bring unhealthy traditional foods mainly samosas and pakoras all of which are deep-fried.

Traditional food is the main element of Pakistani gatherings and celebrations and is culturally significant. The main problem whilst celebrating is the lack of control participants have. T2DM participants do control themselves but only because they already have a diagnosis of diabetes and will suffer the effects if they do not. As stated by Hawthorne and Tomlinson (1999) Pakistanis find it hard to refuse food at social events and regularly eat rice and sweet dishes, this is supported by this study. Finucane and McMullen (2008) reported many participants expressed a strong desire not to burden their family or offend their hosts with special dietary needs and that sharing a meal is a way for people to connect and to remember their roots. They are expected to eat something when they visit someone's house, yet being offered food at every visit makes it difficult to adhere to a low caloric intake.

Research also supports that while many South-Asians accept the importance of a healthy diet, they believe it is rude to straying away from traditional methods of preparing food for guests (Lawton, Ahmad, Hanna et al., 2006; Stone, Pound, Pancholi, Farooqi & Khunti, 2005). Finucane and McMullen also reported that low risk perception and motivation was a mixture of feelings of low environmental control (such as when facing high-carbohydrate dishes at parties) and high personal control (such as taking medication to control blood sugar levels).

4.5.5 Gestational diabetes

GD is another significant risk factor for many British-Pakistani mothers developing T2DM. This is an emerging problem not just in western societies but everywhere even in Pakistan (Akhter, Qureshi, Rahim et al., 1996; Dornhorst, Paterson, Nicholas et al., 1992). By targeting pregnant women especially at the early stages of pregnancy health professionals can raise their awareness of T2DM and link it with the pregnancy and the effects on the babies. It can help to prevent the onset of the disease and educate them. The education can be carried on throughout the pregnancy and even after birth. This will tackle a significant portion of the Pakistani community and may lead to a ripple effect on to others.

4.5.6 Psychological factors

4.5.6.1 Psychological factors

Participants with T2DM believed that stress and worrying is another causal factor of diabetes as they recalled being highly stressed before being diagnosed. Seeking explanations and remembering salient events before diagnosis is common in most conditions (Kleinman, 1988). This study supports previous research regarding beliefs about the consequences of T2DM particularly the importance of taking care of oneself (Hunt et al., 1998), worry, anxiety and depression (Hampson et al., 1990), damage to the body (Gregory et al., 1999); and dramatic change in lifestyle and relationships leading to social problems (Cohen et al., 1994).

Hjelm and colleagues (2003) reported various factors relating to T2DM in women in Sweden. They found that Arab women expressed sorrow and mental pressure due to migratory experiences and thoughts about relatives left behind as well as general mental problems, genetic factors, excess food consumption and anaemia. Ex-Yugoslavians demonstrated feelings of anxiety, worries, fear, agony and dread related to difficult experiences in the home country and adaptation to life in Sweden, and genetic factors. The general picture was that Swedes showed a healthy and controlled lifestyle, Yugoslavians expressed enjoyment of life and Arabs emphasised feelings of mental well-being, adaptation to T2DM in particularly diet change. Whether these factors particularly psychological factors are the causes of T2DM or not many British-Pakistani mothers believe that they play a significant role in the control of T2DM.

4.5.6.2 Use of fear appeals

Previous research on fear appeals identifies three key independent variables which are fear, perceived threat and perceived efficacy (Witte & Allen, 2000). Witte and Allen conducted a meta-analysis on the fear appeal literature and reported that strong fear appeals produce high levels of perceived severity and susceptibility, and these are more persuasive than low or weak fear appeals. Their findings demonstrated that fear appeals encourage adaptive danger control actions i.e. message acceptance, and maladaptive fear control actions i.e. defensive avoidance or reactance. They also reported that strong fear appeals and high-efficacy messages produce the greatest behaviour change whereas strong fear appeals with low-efficacy messages produce the greatest levels of defensive responses. Therefore using strong fear appeals and high-efficacy messages can help to change British-Pakistani mothers' behaviours in preventing the onset of T2DM in themselves and their families.

It would be a good idea to use fear appeals with reference to children in prevention materials as the current study indicates that British-Pakistani mothers will be more forthcoming with

information impacting on their children's lives and health rather than just themselves. Being a happy child to these mothers means that children don't have to worry about food or health, it is their responsibility. If they were diagnosed with T2DM participants expressed they would feel extra pressure and stress, it would make them anxious regarding looking after their family, would make them change their ways which they seem reluctant to do, and would add extra responsibilities to their daily routines like extra cooking which they would resent. However this was not reflected among T2DM participants in fact their families were adhering to the same eating styles as them which was beneficial for the whole family. This was because they were the main cooks in their families. Finucane and McMullen (2008) also reported that many mothers put the health of the family before their own. They stated that as part of Filipino-American culture participants emphasised the importance of family and respecting one's elders.

4.5.7 Misconceptions

4.5.7.1 Lay beliefs

It is a suggestion of this study that lay beliefs should be tackled as part of a T2DM prevention especially myths and misconceptions as they lead to incorrect information or unnecessary anxiety. This is also supported by Chowdhury and King (2007) who list the main misconceptions among South-Asian people in the UK (as discussed in chapter 1). Traditional medicine is a very effective and popular strategy implemented among the British-Pakistani community which includes herbal and food remedies. According to British-Pakistanis many natural ingredients have homeopathic qualities and are very good organic resources for your body. This is supported by a recent study conducted by Pieroni and colleagues (2008) who found that their Pakistani participants affirmed that traditional medicine is still being used in local traditional healer places. Both this study and Pieroni et al.'s study support the notion that Pakistanis in the UK have their own strategies for dealing

with diabetes using traditional and herbal medicine. Furthermore detailed knowledge of these practices is essential to understand and incorporate in public health interventions especially as it is widely recognised that more culturally sensitive approaches are required. Hjelm, Bard, Nyberg and Apelqvist (2003) also reported that traditional remedies were used by Swede, Arabs and ex-Yugoslavians. Many Yugoslavians used natural remedies such as teas, cider vinegar, herbs, chromium, walnuts, etc. to a higher extent than Swedes. They also said that they perceived a higher confidence in physicians in providing treatment and thus used natural remedies as a complement.

There is no evidence to suggest that British-Pakistanis with T2DM worsen their own health yet this is a very common lay belief among the participants in this study. Finucane and McMullen (2008) also noted this in their study. Some of their participants suggested that one reason given for this internal locus of control maybe that it helps people cope. Reluctance to accept personal responsibility for their diabetes was perceived to be a way of avoiding the shame and embarrassment that many participants associate with sickness. An external locus of control is problematic for self-management in that if patients believe that their efforts will be ineffective they will not attempt lifestyle changes. It is evident that other health illnesses exist as a result of diabetes and vice versa such as cardiovascular and renal diseases (Chowdhury & King, 2007; Hawthorne & Tomlinson, 1999). They also believe that living in Pakistan rather than England is better especially for one's health, and the rates of T2DM are lower in Pakistan than England. T2DM is also a problem in Pakistan with many people being diagnosed and at high risk of developing it along with the same complications and health problems (Habib & Aslam, 2003). The prevalence of non-communicable disease will continue to rise especially due to epidemiological, nutritional and demographic changes occurring in Pakistan (Shah, Nanan, Rahbar et al., 2004).

4.5.7.2 Common beliefs

This study emphasised that a common belief amongst British-Pakistani mothers is that T2DM is an older person's disease. In previous decades this may have been the case however it is now very common for British-Pakistanis as young as 40 years old to develop it (Diabetes UK, 2006). Chowdhury and King (2007) report the onset age as young as 25 years of age. T2DM is so common among Pakistanis that many view it as an inevitable old age disease and it would be more dramatic if a young person was to be diagnosed with it compared to an older person. The British-Pakistani mothers in this study did not perceive themselves as being old yet they knew of some individuals with a diagnosis of T2DM younger than them. They found this unusual, but if an individual only few years older than them was to be diagnosed then they did not find this unusual. Greenhalgh and colleagues (1998) reported that British Bangladeshis view health and youth as synonymous, and that physical health deterioration and weakness are inevitable signs of ageing. In a study by Gregory et al. (1999) urban aboriginal people in Canada expressed diabetes as being all around. Hornsten, Sandstrom and Lundman (2004) stated that T2DM is something natural in life and that it is connected with ageing and excess body-use.

Health professionals have a hard job in trying to encourage British-Pakistanis to adhere to preventative behaviours (Chowdhury & King, 2007) as this study supports the idea that many Pakistanis would rather deal with the problem later rather than sooner as they do not believe it is of relevance yet. Hornsten, Sandstrom and Lundman (2004) found T2DM as a challenge for health professionals to empower patients to view diabetes as a condition that can be managed and lived with. They demonstrated that patients' personal understanding of illness is important. In this study some feared T2DM as they perceived it to be a very serious disease and they would be more concerned if their children developed it rather than them. Hornsten et al. stated that individuals with diabetes deal with both cognitive and emotional aspects. Previous studies have documented perceptions of the disease as serious (Gregory et al. 1999) and lasting throughout life (Hjelm et al., 1999; Cohen et al. 1994).

4.5.8 T2DM epidemic in Pakistan

Participants in this study did not realise there is also an epidemic problem in Pakistan, because they signify Pakistan as a warm hot country with fresh food whereas England portrays an image of cold wet weather and junk food culture. Participants believed that people can burn off a lot more energy because of the weather as well as being more active in Pakistan than England, and eat differently. Mellin-Olsen and Wandel (2005) reported that the meal pattern in Pakistan is a result of the physiological need during the day due to hard manual labour and adapting to the climate. Pakistani women in this study voiced three major changes in the meal pattern after migration: fewer hot meals, a more irregular meal pattern and a concentration of the energy intake later in the day. Hjelm, Bard, Nyberg and Apelqvist (2003) reported that participants blamed the weather as being too bad to exercise and thus was perceived as a barrier for exercise. Hawthorne and Tomlinson (1999) also found that Pakistanis did not want to leave their house especially on their own in the dark and cold. Indeed many British-Pakistanis utilise going to Pakistan as part of their diabetes treatment/management regime. Yet there are many opportunities for British-Pakistani people that were acknowledged in this study to be more active here in England and this needs to be emphasised to them. The health service needs to encourage this sedentary group to venture out and lead healthier lifestyles.

4.5.9 Friends and family

The current study highlights that British-Pakistanis gain a lot of moral support from friends and family regarding T2DM even children encouraged T2DM mothers to eat healthily. However sometimes family input and influence can be a hindrance in promoting the healthy living process especially grandparents who just want to spoil their grandchildren, as well as a lack of spouse support and friends. Ellison and Raymon (1998) commented that an illness like T2DM involves the whole family as well as the individual and has clear influences on

social life. This is also supported by Finucane and McMullen (2008) who found that T2DM self-care was improved by encouraging a family member or close friend to participate with them. Other studies suggest that individuals often discuss with family the best course of action when making health decisions (McLaughlin & Braun, 1998; Ka'opua, 2003). Shah and Sonuga-Barke (1995) reported that British-Pakistani mothers living in extended families report more depressed and anxious feelings than those in nuclear families however their children are better adjusted. Therefore it would be a good idea to involve older generations and extended families into a T2DM prevention programme. As many Pakistanis live within an extended family it makes sense to include them in future programmes.

4.5.10 Improve the healthcare service

T2DM participants believed that the health service is committed in making sure individuals get the right information and plenty of contact but it is not being effective as they believed they were not getting the appropriate support from it. Kai and Hedges' (1999) study supports this as they reported that Pakistanis and Bangladeshis thought their GPs were helpful as listeners and signposts to others, but were unsuitable to deal with worry or stress. Services offered among T2DM British-Pakistani women in this study were inconsistent as this study found only one T2DM participant received regular home calls to discuss her diabetes. This is also supported by Hawthorne and Tomlinson (1999) who found that knowledge of services offered was poor among Pakistanis as they found that these individuals did not know about certain diabetes related services such as the chiropody service. In the current study participants expressed that they can go to visit their doctor or nurse whenever they needed, but participants would appreciate it if the health service came to them providing care in their homes. This suggestion is impractical and expensive even in a primary care led service and perhaps suggests an unwillingness to enter into the social contract implicit in NHS services. There is a need to research the various types of social support available and determine whether participants are receiving this support from the right sources. A support network

was a suggestion put forward by T2DM participants for Pakistani women to get together and socialise and discuss their diabetes. Kai and Hedges (1999) reported similar suggestions as the participants in their study expressed views that talking about distress or worry was useful. It also supports the notion that Pakistani British women see value in talking about their problems and that they would only seek help from within their own family or social circle. Vyas et al. (2003) also suggested less formal educational sessions in a relaxed group atmosphere to enable the exploration of issues important to the group, which would allow people to talk about topics they do not know much about freely which can be improved. On the other hand some Pakistanis are satisfied with the health service supported in this study and by Madhok, Hameed and Bhopal (1998).

4.5.11 Conclusion

British-Pakistani mothers are pivotal in planning and implementing future prevention interventions to combat the onset of T2DM among this community. Incorporating and understanding their perceptions, beliefs and experiences of the illness as well as cultural customs and values are essential to designing effective and culturally sensitive materials. Food is clearly a major element of Pakistani lifestyle and needs to be understood so that effective preventative strategies can be developed. There was a good mix of participants with T2DM discussing their experiences from various viewpoints i.e. GD, having other health problems and familial links and although one of the focus groups was conducted in Urdu, this was not seen as a limitation as it helped to collect rich data from a hard to reach audience as these were migrant illiterate women with T2DM. Thus their insight was invaluable. Overall rich valuable data was collected from all groups and provided priceless raw qualitative data and analysis. The next study will be conducted to explore the perceptions and beliefs of young British-Pakistani females to provide a younger viewpoint which will be used to provide a holistic view of British-Pakistani perceptions.

Chapter 5

Perceptions and prevention beliefs of T2DM among Young British-Pakistani Females

5.1.1 Introduction

South-Asian children and young people are at a higher risk of T2DM onset compared with White British young people and it is more common in females than males (Ehtisham, Crabtree, Clark et al., 2005; Ehtisham et al., 2004) hence there is a crucial need to prevent T2DM in this group. Therefore this study explores younger British-Pakistani females' T2DM perceptions which can aid the development of appropriate prevention.

5.1.2 Prevention

Prevention of T2DM is vital and should be the aim of health interventions especially among British-Pakistanis. Netto, McCloughan and Bhatnagar (2007) highlighted the need for effective Coronary Heart Disease (CHD) prevention initiatives for South-Asian communities (specifically Pakistanis, Indians and Bangladeshis). They conducted six focus groups to explore how their views can be used to develop effective culturally focused CHD prevention interventions addressing identified barriers, including deeply held cultural beliefs. Four themes were reported: knowledge of CHD and risk factors, knowledge of prevention measures, barriers to change and attitudes towards a prevention intervention. They found that participants had varying levels of knowledge relating to the nature, causes and symptoms of CHD, some participants reported trying to reduce or prevent CHD while others did not, and persistent barriers to change were identified. Similar results emerged from the previous study (chapter 4) in regards to T2DM and British Pakistani women.

Adults with T2DM develop complications later in their working lives but young people in their adolescent years are more likely to develop complications in early adulthood which is a very stressful and crucial time for establishing employment, reproducing and bringing up children (King, 2009; Yokoyama, Uchigata, Otani et al., 1997). Low prioritisation of health among young South-Asian people is a known barrier to achieving a healthy lifestyle especially as they are in their late teenage years and rebelling against authority (Khunti, Stone, Bankart et al., 2008).

5.1.3 T2DM and young people

The Ten Towns Heart Health studies (Whincup, Gilg, Papacosta et al., 2002) conducted in the UK with children of age 8-11 year olds found significant ethnic differences in CHD and diabetes risk factors. Out of 128 participants 51 were Pakistani. They found that South-Asian children were more insulin resistant than white children but could not link this to body fat, meaning that South-Asian children are fundamentally more insulin resistant which may contribute to their increased risk of developing T2DM. Ehtisham, Crabtree, Clark et al. (2005) found that of the adolescents in their study being overweight and obesity were higher in the South-Asian adolescents than in British whites, and it was also higher than the reported figures in the 1999 Health Survey for England (Saxena, Ambler, Cole & Majeed, 2004). Therefore interventions aimed at preventing T2DM should be targeted at high-risk young groups.

Ehtisham and colleagues stated that South-Asian adolescents are more likely to have a family history of T2DM with an affected parent, and have higher body fat levels with increased central fat deposition. Viswanathan, Mohan, Snehalatha and Ramachandran (1985) reported high prevalence rates of T2DM among the offspring of Indian diabetic parent(s). None of the parents were diagnosed younger than the age of 20years with T2DM but a few of their children of the recruited sample were. This shows the significance of family risk and how prone young people are to T2DM in the South-Asian community.

Pollard, Unwin, Fischbacher and Chamley (2008) examined 30 Pakistani migrants living in the UK, 30 British-born Pakistani women and 25 British-born women of European origin to explore whether risk factors for CHD and T2DM change from migrants to subsequent generations born in the UK. They found that British-Pakistani women were taller, had a lower waist to hip ratio and lower mean fasting glucose levels compared to migrant British-Pakistani women. Healthier levels of CHD and T2DM risk factors were found in British-Pakistani women than in migrant British-Pakistani women. They also reported that British-Pakistani women differed from British-born European women as they had more adverse body composition. They suggested that this may be due to the effects of early environment or to differences in health behaviours. The British-Pakistani women who participated in study 1 (chapter 3) were either migrant British-Pakistani women or first generation British born Pakistani women with a minority of the non-T2DM participants being second generation British born Pakistani women. However in this study the young British-Pakistani females are second generation British born Pakistanis. Thus it will be interesting to explore the difference and similarities in lifestyles and health beliefs between the different generations. Consulting young female British-Pakistani adults regarding their perceptions, beliefs and any preventative T2DM behaviours may give insight into what is effective in working with young people to prevent their risk of T2DM. Another reason why it is ideal to tackle and learn from this younger female generation group is because T2DM is growing problem with young people and as 'future' mothers it is important to try and embed healthy lifestyles now so that they can teach these to their future children.

5.1.4 Familial risk

Family studies have estimated that the risk of an individual developing T2DM increases two to fourfold when one or both parents have a diagnosis of the disease (Klein, Klein, Moss & Cruikshanks, 1996; Mitchell, Valdez, Hazuda et al., 1993). Meigs, Cupples and Wilson

(2000) found that the risk of T2DM in young people is the same whether both parents are affected or if either parent is affected. Fathers with T2DM pass on abnormal IGT which develops relatively quickly to children whereas mothers may transmit the risk for a mild slowly progressive form of abnormal glucose tolerance in addition to diabetes. Meigs et al. concluded that fathers could transmit unique paternal genetic factors of similar significance to maternal environmental factors.

Shaw and Hurst (2008) believed that misconceptions existed about basic genetic concepts and inheritance patterns, thus they investigated the understandings of genetics, illness causality and inheritance among British-Pakistanis. These are influenced by education, culture and ethnic background (Richards, 1998). Observation and interviews in Urdu or English were conducted to identify environmental, behavioural and spiritual understandings of the causes of medical and intellectual problems. Shaw and Hurst found misconceptions about the location of genetic information in the body and of genetic mechanisms of inheritance, and they found that many British-Pakistanis believe that a child receives more genetic material from his/her father than the mother. They also stated that British-Pakistanis may not easily give up their lay or personal theories about the causes of their own or their child's condition or their understandings of genetic risk. These lay or everyday explanations can sometimes clash with genetic research as genetic risk is overlooked or misunderstood (Richards, 1998; Davison, 1996). Cross-cultural differences in understandings of inheritance may also affect risk perception and the acceptance of genetic information (Meiser et al., 2001). Health professionals therefore may need to identify, work with and challenge patients' understandings of illness causality and inheritance.

5.1.5 Illness perceptions

Illness concepts have provided promising evidence with respect to the appropriation of the illness representation model (Leventhal, Nerenz & Steel, 1984) for use with young people as

well as adults (Paterson et al., 1999). This model characterises illness beliefs as being represented by concrete and abstract labels. Paterson and colleagues (1999) pointed out convincing evidence that people's illness perceptions follow Leventhal's five cognitive dimensions but little is known as to how these dimensions develop through childhood and the impact that specific disease experiences can produce. It has been suggested that there are no major differences in the way that youngsters think about illness as compared to adults and that we need to take into consideration young people's understanding and ability to learn about their illness when seeking to design an appropriate treatment intervention (Chi, Glaser & Rees, 1982).

Health beliefs are often formed during adolescence and are more likely to be embedded permanently thus their importance cannot be undervalued (Moss-Morris & Paterson, 1995; Paterson et al., 1999). Paterson and colleagues (1999) demonstrated that young people who had experienced asthma had a more sophisticated concept of their illness but that not all aspects of illness representations were equally affected by their experience. There is some evidence to illustrate that people without illnesses are quite knowledgeable about factors which may affect health and quality of life as well as preventive measures to avoid onsets of disease, as health behaviours are the product of rational appraisal processes (Ajzen, 1985; Rogers, 1975). Previously the majority of studies exploring illness perceptions of individuals with a chronic illness, however (Figueiras & Alves, 2007) adapted the IPQ-R to use with individuals without a chronic illness to see if the illness representations have the same structure and pattern of interrelationships. The illness representation dimensions: psychological attributions, consequences, timeline and coherence accounted for 11% of the explained variance in attitudes towards the preventive behaviour, and illness coherence, psychological attributions and emotional representation explained 8% in the intention to adopt preventive behaviours. The results of this study demonstrated that illness representations account for a significant proportion of variance in attitudes towards preventive behaviours and intention to adopt them. Therefore exploring the perceptions,

knowledge and beliefs of the young British-Pakistani females in this study will lead to understanding what influences their health-related behaviours.

5.1.6 Sources of knowledge

Neuman (2006) illustrated that people gain knowledge from parents, teachers, experts as well as books, television and other media. He also stated that people rely on tradition for knowledge meaning accepting something as being true because it is the way things have always been. Individuals learn about the social world from reasoning and common-sense (Ogden, 2004). They depend on what everyone knows and what makes sense. Common-sense is valuable but it can allow misconceptions to occur. Common-sense can originate in tradition. Therefore it will be important to find out the sources of knowledge the young British-Pakistani females have in this study regarding their perceptions and beliefs of T2DM. It will be interesting to learn where their knowledge and perceptions stem from and what they perceive to be true as what appears true may actually be due to an error or distortion in judgement (Ogden, 2004).

Television, movies, newspapers and magazines are important sources of information about social life. The media spreads the myths of a culture (Ogden, 2004). Chew, Palmer, Slonska and Subbiah (2002) examined the impact of a health promoting television programme series on health knowledge and the key components of the HBM. Their study provides strong support for self-efficacy, susceptibility, seriousness and salience (Burke & Dunbar-Jacob, 1995). Cues to action variable and health knowledge boosted efficacy amongst viewers. Chew et al. concluded that a health promoting television series can increase health knowledge and enhance health beliefs in turn contributing to healthy behaviours. An alternative to television is utilising the Internet. The Internet provides a new way for understanding how social realities get constructed and reproduced through discursive behaviours. It is used as an effective and efficient communication medium (Markham, 2004). Barlow and Ellard (2004) reported that cognitive-behavioural techniques

and innovative approaches such as ways of using the Internet and multimedia to provide support and as an educational tool can boost the effectiveness of psycho-educational interventions.

5.1.7 Food

Socio-cultural studies have focussed on the meanings of food and eating in a specific cultural and social context. Food and meals are culturally approved and have been shown to be important symbols for identity, worldview, and social and political relations (Lupton, 1996; Makela, 2000). Moens and Braet (2007) commented that at mealtime parents are usually present but when young people snack parents are often absent. This is supported by Bourcier, Bowen, Meischke and Moinpour (2003) who found that parents bring home healthy foods, make healthy foods and tried to set a good example. Therefore parental attitudes, perception and parenting have an influence on an individual's risk of diabetes. Lawton, Ahmad, Hanna et al. (2008) conducted a qualitative study with 23 Pakistanis and nine Indians with T2DM to explore food and eating practices, perceptions of the barriers and encouragers to dietary change, and the social and cultural factors. One of their recommendations was that information and advice should be targeted at those responsible for food preparation which is mainly women, not just the person with diabetes. These findings are very similar to those reported in study 1 (chapter 4). It will be very interesting to explore the eating practices of the younger British-Pakistani female population, whether they prefer traditional Pakistani cuisine or have they adopted a more western appetite.

5.1.8 Conclusion

There is a need to use qualitative methodology and the young British-Pakistani community to develop effective prevention strategies against T2DM. The purpose of this study was to conduct focus groups with young British-Pakistani females to explore and understand their

T2DM beliefs and perceptions and their barriers to adhering to healthy lifestyle to prevent onset.

2.1.8.1 Research Question

What are the beliefs and perceptions of T2DM among young British-Pakistani females and do they try to prevent onset in themselves?

5.2 Method

5.2.1 Design

The same focus group design was used in this study as in the previous study (chapter 4). The methodology was duplicated but this time using young British-Pakistani females, allowing the researchers to explore similar research questions and then compare the results from this study with the previous one (chapter six). Participants were given the same opportunities in these focus groups as previous ones to share, explore ideas and opinions, divulge into their beliefs and experiences freely and generate rich viable data. It also allows open conversation to develop providing reliable research and better understanding towards the young British-Pakistani women.

5.2.2 Materials

An aide memoire (see appendix 5.1, table 5.1) was developed similar to the ones used in the previous study (chapter 4). The aide memoire included questions such as *'what do you think causes diabetes?', 'has living in England instead of Pakistan affected Pakistanis getting diabetes? If yes how? If not why not?'* and *'what kind of support would you expect someone with diabetes to get from the health service?'* Resources from Diabetes UK were used to prompt and generate discussions during the focus groups and a digital voice recorder was used to record the focus groups. Participant information sheets (see appendix 5.2), consent forms (see appendix 5.3) and debrief sheets (see appendix 5.4) were also used.

Number	Question
1	Can you tell each other your ideas about what you think diabetes is?
2	What do you think causes diabetes?
3	How would you feel if you were diagnosed with diabetes?
4	How would your family feel if you were diagnosed with diabetes?
5	Has living in England instead of Pakistani, effected Pakistanis getting diabetes? If yes, how? If not, why not? Use prompt about high prevalence of diabetes amongst South-Asians
6	How do you think your diet affects you getting diabetes?
7	Tell me about how someone you know with diabetes has to change their diet? Discuss if you think they can eat traditional meals?
8	During Ramadan, how would their diet differ from their family's or friends' meals? Use prompts about healthy eating during Ramadan
9	During Eid, how would their diet differ from their family's or friends' meals?
10	How would it make you feel if someone with diabetes could not eat the traditional foods you like to eat? Prompts of traditional Asian (Pakistani) cuisine
11	Tell me how you think exercise effects someone getting diabetes?
12	What kind of support would you expect someone with diabetes to get from the health service?
13	What effects do you think diabetes would have on your life?
14	What effect would diabetes have on your family, your parents?
15	What things do you and your family do to try and stop getting diabetes? How? If nothing, why not?
16	What kind of things would you like to get from the health service to help you understand diabetes better?
17	Currently how do you feel about your health? How do you feel about your family's health?
18	Right now, how much control do you think you have over you getting diabetes?
19	How much control do you think you have over your family getting diabetes?
20	Is there anything you want to bring up which we haven't talked about?

Table 5.1 Aide memoire for focus groups with young British-Pakistani female participants

5.2.3 Participants

Fourteen individuals were recruited for this study, none of whom had a diagnosis of T2DM. Of the 14 three dropped out. Therefore 11 participants took part in this study. All participants were female and from a Pakistani ethnic background. An opportunistic sample was recruited from Aston University. The focus groups took place onsite in a focus group room situated in the Psychology laboratories. Four focus groups were conducted; three focus groups consisted of three participants and one focus group had only two participants (please refer to table 5.2 for details). All participants were home students studying an undergraduate degree course at Aston University and were living at home whilst studying.

The mean age of the participants was 20.72 years old, with the age range of 18-26 years old. Only three of the participants stated that one of their parents had a diagnosis of T2DM. Two of the participants' fathers had T2DM and one of the participant's mothers had the disease.

Focus group title	Participants
YFG1	P1* P2 P3
YFG2	P4 P5
YFG3	P6 P7* P8
TFG4	P9 P10* P11
	INT= Interviewer

Table 5.2 Young British-Pakistani females' focus group details

* Participant with a parent who has a T2DM diagnosis

5.2.4 Procedure

The same procedure was used in this study as in the previous study (chapter 3). Ethical approval was granted by the Aston University Ethics Committee. The study was advertised through email, flyers (see appendix 5.5) and Aston University's Psychology Research Participation Scheme. The number of participants in each focus group was determined by

who signed up for that date and time. Before the commencement of the focus group participants were briefed about the nature of the study and were given the opportunity to ask any questions or express any concerns they had. They were given the participant information sheet to read and then asked to complete the consent form. Each focus group lasted between 30 and 67 minutes. At the end of the focus group participants were debriefed about the nature of the study and reminded about what would happen to their data. The focus groups were the same format of the focus groups in study 1 (chapter 4) with T2DM and non-T2DM mothers. This was done to allow for consistency between the studies so they can be compared in the next chapter (chapter 6).

5.2.5 Analysis

The focus groups were transcribed verbatim and thematic analysis was conducted (same as in chapter 4).

5.3 Results – Perceptions and experiences of young

British-Pakistani females

5.3.1 Introduction

Thematic analysis was used to analyse the focus group data. Six superordinate themes were identified: *Illness Representations of Type2 Diabetes, Student Lifestyle, Older Generation, Traditional Foods, Knowledge and Emotions, and England v Pakistan*. These themes are discussed in turn using data extracts from the four focus groups.

5.3.2. Illness Representations of Type2 Diabetes

5.3.2.1 Multiple causes

Participants highlighted various causes of T2DM and understood that it is not down to a single factor but several in conjunction with one another.

P1: If you're born with it then I think it's your genes, it's in your genes and it's probably hereditary or there's some sort of (.) erm I'm not really sure

P2: It does run in family though doesn't it?

P3: Type 1?

P1: Type 2 also runs in the family cuz all of my aunties have it and you've got some on your side as well (.) an:d type 2

P3: It's something to do with obesity

P2: yeah

P3: and your sugar

P2: and your diet but that's probably the same thing

P3: and social factors

P1: yeah like lack of exercise and becoming overweight and you're predisposed to it I think if you are Asian (lines 31-44 YPFG1)

P4: dietary requirements (.) erm I don't know maybe if they eat too much like (.) erm

P5: sugars

P4: sugary stuff, fatty stuff, it depends I don't know

INT: ok

- P4: it could [be genetics]
- P5: [I think genetics] genetic like so many people like (.) have it and it [runs in families you can see it] (lines 21-28 YPFG2)
- P6: Erm is it environmental factors like erm the way you eat so if you know erm you're constantly bingeing on like high sugar high sugar foods
- P8: yeah
- P6: or really fatty stuff, don't look after yourself, don't exercise properly, that can cause it and then (.) I think there's a diabetic erm there's one form which is genetic I think as well like genetic factors (lines 16-23 YPFG3)
- P4: I think it depends on the person like everyone's different so some people it's genetics, for others it's exercise, for others its food so it just really depends on the household and how they're brought up. (lines 413-416 YPFG2)

It is clear that the participants in this study recognised different factors contributing to the onset of T2DM and there is no single answer. In the extract above P4 commented that she thinks it is a result of the families way of life and behaviours and all families are different so the diagnosis of T2DM will vary between individuals. P1 commented that South Asians are predisposed to T2DM making Pakistanis more susceptible to the disease. A minority of participants did not classify genetics as a causal factor in their own family as nobody in their immediate or close family had a T2DM diagnosis. Yet they still acknowledged the importance of lifestyle and the environment.

- P3: For me I reckon it would be diet and exercise, not genetic (line 1183 YPFG1)

The common assumption of the majority of the participants however did include genetics as a significant predictor. Participants were able to identify links between their own personal risk and what they believed was a risk of the general population. They judged their own risk as being down to lifestyle but recognised that genetics is a possible factor for other British-Pakistanis.

- P10: I kind of thing it sort of passes down I think like if you have a family history
- P11: I think it is genetic yeah genetic-wise yeah (lines 71-73 YPFG4)

P6: the whole of my mum's family has it (line 83 YPFG3)

Many participants recognised blood glucose and insulin as significant biological components for identifying individuals with T2DM.

P9: ...all I know it's something to do with sugar levels

P10: I think it's like sort of like a lack of glucose in the blood (lines 5-7 YPFG4)

P4: it's something to do with insulin

P5: they can't eat certain foods or [they have to eat]

P4: [no you can't develop] can't develop insulin properly I think (lines 8-11 YPFG2)

P6: ...I think it's when your you get elevated glucose levels or low glucose levels to the normal level you should have in your blood

INT: right

P6: and

P7: is it when the body doesn't produce enough insulin so you have to inject it and stuff

INT: ok

P8: yeah and I know like people who have like (.) who are diabetic normally have like a lot of tablets to take (lines 5-14 YPFG3)

P9: is it cuz the glucose doesn't produce like produce in the body or something?

P10: She has regular insulin injections (lines 41-43 YPFG4)

Participants demonstrated a lack of knowledge and understanding to the properties and roles of blood glucose and insulin. It is most likely that they have heard and/or witnessed testing or treatment rather than learning about them specifically or experiencing them directly. P2 describes how she does not understand diabetes therefore does not know about it:

P2: I do not (.) see I understand what you do if you have diabetes but I don't understand what diabetes actually is and I'm sure that if I understood what diabetes is I'd understand (.) why (lines 1289-1291 YPFG1)

This could be true for many British-Pakistanis, especially the young generation.

5.3.2.2 Sugar

Participants went on to highlight the generic understanding of T2DM from a Pakistani point of view. It centred around sugar.

P4: Diabetes is just like erm (.) don't know sugar problems innit?

P5: Hmmm yeah

- P4: no when you diabetes like someone like (.) I don't know my granddad had diabetes and it was like 'oh he has sugar'
- P5: yeah that's what they call it sugar (lines 3-7 YPFG2)
- P1: ...if I actually sat down and said 'mum what is diabetes?' she'd probably just say one word which is 'sugar' (lines 1329-1330 YPFG1)
- P7: Is it when you have sugar?
- P6: Oh yeah everyone says that (lines 4-5 YPFG3)
- P6: I think that's erm that's (.) I don't know whether it's like er not right concept or anything but I think the concept that they've got in their heads is eat less sugar (lines 393-395 YPFG4)

Older generations refer to T2DM as sugar therefore subsequent generations also recognise T2DM as sugar. It's a universal term used among Pakistanis. As mentioned earlier participants believed diabetes had something to do with blood sugar levels which they probably heard from the older generation. This may explain why Pakistanis assume that reducing their sugar intake causes diabetes and will help with its management. As a result many participants reported that diabetics are not allowed sugar in their tea.

- P2: The only thing is that they put a lot a lot of sugar in their tea a lot (.) a lot
- P3: I do that
- P2: and they don't just have one or two cups of tea a day they have seven or eight cups of tea a day and it all accumulates probably the same amount to how much we have in our chocolate
- P1: Yeah well my mum when she was first diagnosed they said you need to give up, start with giving up sugar in your tea she did that
- P2: can't they can't do that (lines 321-330 YPFG1)
- P7: Erm just my mum she just like you know started eating differently and stuff like (.) like er without sugar in her tea (lines 340-341 YPFG3)
- P3: With my grandma I don't I don't think she has diabetes but they have told her that she's at risk so I have noticed myself like when she comes round with tea (.) she'll (.) I think it was really difficult for her to cut off the sugar so I think she has like half a spoon or something like that (lines 541-545 YPFG1)
- P4: granddad puts three sugars in his tea and my grandma's always fighting with him 'no you're only allowed one!' He's like 'I want three!' 'but no you're only allowed one' (lines 163-165 YPFG2)

P9: It has calmed down cuz like with his tea he doesn't have sugar in it anymore because he used to have too much sugar in his tea (lines 413-414 YPFG4)

Participants believed that the volume of sugar Pakistanis take in their tea is the equivalent to the amount that can be found in a chocolate bar. Therefore to control diabetes they try to quit taking sugar in their tea. Participants believed that many of the older generation diabetics struggle to give up sugar as they are use to it but they do try to reduce the amount, and those who try to sneak more in their tea are encouraged to have less by loved ones.

5.3.2.3 Exercise

These young female participants went on to discuss the value of exercise.

P2: I think it would be in sort of conjunction with diet as well it wouldn't just be not having enough exercise in itself erm (.) but I think if you're not I think being overweight does effect it so pos- maybe not as much as diet but probably does affect it

INT: right

P2: and it probably doesn't-once you've got it, it probably doesn't help if you are not getting enough exercise (lines 715-721 YPFG1)

P5: I think exercise would help prevent it

INT: right

P5: I think if you're sort of more fit and stuff when you're younger it probably helps when you're older (lines 383-386 YPFG2)

P1: ...exercise does help you not to not get diabetes because all that fat around there is sort of around your pancreas and it is one of the reasons why you don't produce the insulin (lines 747-750 YPFG1)

P9: Well as for any illness exercise is good

Group laughs

P9: I mean it's good to exercise I mean if especially you can get heart attacks from it it's good to like obviously do exercise

P11: keeping fit is one thing you should always do (lines 762-766 YPFG4)

The consensus of the group was that of exercise being a preventative measure not only to developing T2DM but other health problems too. They believed that the younger you start doing exercise the more benefits you will reap as you get older. They went on to express that it should be routinely performed as a basis to having not only a healthy lifestyle but a good quality of life.

5.3.2.4 Stress

In general a clear pattern can be seen identifying the key causes of T2DM ranging from environmental, lifestyle to biological factors. A key psychological concept credited as a causal factor by participants was stress.

P1: erm so say of you are always taking things in cuz ... when you're stressed out as well you do crave sugar and you crave like short energy bursts so I find that I'm always snacking on something that's sweet (YPPG1 lines 287-290)

P6: ...she gets quite stressed and (.) you know it takes a lot of pressure on her on little things that she gets really worried about people and stuff, and then that will affect her as well you know (.) her glucose levels will completely drop as well so I just think just little things like that (lines 294-289 YPPG3)

P9: yeah it is a lot of stress (.) I mean any health problem is like really stressful

P11: hmmm

P9: especially because it is a long term illness as well isn't it so (lines 196-200 YPPG4)

Participants illustrated that stress can affect blood glucose levels by causing them to change due to a hormone imbalance caused by worry and pressure. However it was also seen as having an indirect effect by causing cravings of sweet glucose rich snacks therefore increasing the risk of T2DM. Therefore the impression participants were giving is that stress can be one of many causal factors as well as it being a product of T2DM.

5.3.2.5 T2DM & other illnesses

Participants believed that diabetes can be both a by-product of another disease and that it be the cause of another illness.

P3: ...erm it decreases the risk of so many other diseases that might be a precursor to diabetes or diabetes maybe a result of those diseases kind of thing so exercise is generally (lines 730-733 YPPG1)

P2: ...she's like 'oh why me' type thing cuz she's got quite a lot of illnesses it's not just the diabetes but yeah (lines 91-93 YPPG1)

P4: [I think I think its linked with other things if you get diabetes] then you know you're gonna get something else or you must have something else to have got diabetes

P5: I think diabetes and heart disease are quite linked because I mean don't I don't you know obviously I don't know if there's any like actually link (.) but I know a lot of people who have diabetes and then also have heart disease and stuff like that (lines 623-630 YPFG2)

P6: You're more prone to getting obesity and God knows what else-or all other like heart disease and all them not just diabetes you'd (.) you'd get you know making yourself more susceptible to getting loads of other illness as well but (lines 566-569 YPFG3)

Participants believed that T2DM can either occur due to developing another illness or is part of a ripple effect contributing towards other diseases. The main disease T2DM is thought to be in conjunction with is heart disease. Participants may be under this impression as many of their close relatives suffer from a number of health diseases not just T2DM which are clearly highlighted in the extracts above.

5.3.3 Student Lifestyle

5.3.3.1 Chocolate and other sugary snacks as part of diet

Participants expressed their desire for chocolate as being an essential part of their daily diet.

P1: I can eat both (.) and like in my bag today I've got a packet of crisps and two chocolate bars (lines 124-125 YPFG1)

P10: there's not a lot of binge eating so that's all like chocolates (line 327 YPFG4)

P1: I think it would just be the chocolates I think cuz (.) I know it sounds really horrible but I have about two chocolate bars a day (lines 973-975 YPFG1)

P8: ...I've got a chocolate in my bag right now (line 146 YPFG3)

Participants demonstrated that they indulged in chocolate. They make the conscious decision to have at least one bar a day and to make sure they carry one on their person at all time. They went on to express that if they were diagnosed with T2DM it would mean they would have to give up chocolate.

P2: Not allowed chocolate
Group laughs and agrees

P3: Yeah that's how I would feel (lines 46-48 YPFG1)

They were clearly not happy about this. They were under the impression that they would have to give up chocolate from witnessing it from their immediate family members, from the way they once were to the way they are at present.

P10: like my dad he was a chocoholic, he every single day he use to have like a snickers or a mars bar now he has not touched chocolate for the past four five years (lines 368-370 YPFG4)

Giving up chocolate to manage T2DM seems to be a requirement which many of the participants found distressing when discussing. However they go on to explain that the older generation are contradicting their ways by giving up chocolate but encouraging the younger generation to enjoy it.

P10: like yeah that's like we (.) like my dad he loads us like with chocolates and biscuits, he'll bring it all for us but he's not having a single one out of it (lines 561-563 YPFG4)

Participants reported that parents are feeding the younger generation's junk culture with treats and snacks which can contribute to the onset of diabetes, especially as they are already at risk. On one hand they are setting an example of refraining from these types of food and on the other hand they are promoting this unhealthy snack eating. Participants acknowledged that the diabetic family member wanted them to enjoy what they can't have.

They also admitted to an unhealthy intake of sugars.

P1: I think it's just our lifestyle it will be like when you're running around and you snack on sweet things (lines 291-293 YPFG4)

P2: She hates hates it when I drink coke (line 93 YPFG1)

P11: I go through four cans a day of coke (line 355 YPFG4)

P11: cuz I know no-one with diabetes and I'm not (.) I haven't (.) I don't that's why I think it hasn't had an impact on me because I have coke as much I have about three sugars in my tea, I have tea all the time, the amount of sugar I have in my tea yeah so I don't think it's had an impact on me (lines 468-472 YPFG4)

P6: if my mum knew what I was eating outside the house I'd think she'd like kill me like 'what are you eating?' and the amount of junk that I eat like yeah so I know I'd probably (lines 176-179 YPFG3)

Just like eating chocolate, it is the norm for participants to intake high quantities of sugary snacks and drinks which is encouraged by some family members (see above) but is frowned upon by others especially mothers. As they seem not to be affected by the high volumes of sugar intake they perceived nothing to be wrong with it.

5.3.3.2 Mother's role

Participants continued to give an insight into the student ethos by explaining how they did not eat regular meals during the day. They were home students living at home with their parents whilst studying. Instead they snacked a lot especially during the day and then when they went home they would eat a home-cooked meal.

P1: and then I'll [probably go home and have dinner] (lines 133 YPFG1)

P2: ...I don't sit there and eat a meal I just pick up a chocolate bar from the shop, eat that, and then go home and maybe have one cooked proper cooked meal a day (lines 958-960 YPFG1)

P10: yeah I think that's just like yeah more put off but here here yeah it's just the junk food that we eat (.) like most people like like most of our age sort of people that's what we live on, we just live on that sort of junk food and our eating times are really like awkward it's like we'll eat one proper meal a day like I eat one proper meal a day and then all the rest is either I've got like a chocolate in my bag or something and that's just it or something

P11: yeah you always have something sugary

P10: yeah it's just one of those things (lines 340-349 YPFG4)

One proper meal seems to be the trend within this group which they have in the evening once they return home from University. The snack eating habit derives not only from the fact that it is perceived as normal for students but also because they do not have any set eating pattern. They snack whenever they want or feel the craving for something sugary. All the participants in this study behaved this way providing an outlook into the female Pakistani university student lifestyle. After conversing with each other participants highlighted the main reason to their unhealthy snack eating lifestyle as simply being too busy:

P3: For me timing would be the biggest issue I (.) sometimes even if I'm hungry if I don't have time I won't bother to eat (lines 1007-1008 YPFG1)

P2: [I could go days] without food I don't feel it you know you said you felt like really dizzy (.) I don't feel it I could go the whole day without food and not feel it (lines 1066-1069 YPFG1)

P2: But it's like she said about lifestyle like (.) our lifestyle is very stressed out, very busy, hardly find time to eat and when you do find time you pick up whatever literally

P3: Yeah

P2: you don't have time to think 'oh what shall I eat? Shall I eat this? Shall I make something proper? No no no' just grab something, anything. (lines 249-256 YPFG1)

Participants explained that they do not have the time to eat or think about proper meals, they feel they are too busy and stressed with their workload therefore they can go without decent food. Snacking is quick and convenient for their perceived busy lives. Participants only have one proper meal which is in the evening cooked by their mothers.

P2: what she gives me to eat >my mum bless her she cooks for me and everything< and (.) and even if I don't like what she's making she'll make me something else, she'll make something else for my dad and she'll make something else for me... and she'd just be really careful and she she doesn't put that much salt in and she doesn't put that much fat in anyway and we don't eat a lot of rubbish so really for me it is:n't it would be about the things that I eat myself not what's cooked-home cooked what I get in the evening (lines 1037-1045 YPFG1)

P4: I mean we hardly have like takeaways unless it's like you know one off (.) every few weeks or something

INT: uhmmm

P4: my mum doesn't really like it she's like you know

P5: yeah

P4: better off [having home cooked] (lines 539-544 YPFG2)

Participants are exposed to 'proper' meals at home. Their mothers make sure the meal is healthy, fresh and home-cooked. One reason for this could be that mothers do not know whether the participants have eaten during the day and want to make sure they have a full nutritious meal when they come home. However this is not the case for all young British-Pakistani women as some of them are expected to come home and help with the preparation of the evening family meal. Participants who had female non-students living with them i.e.

older sisters, sister-in-laws, etc, helped with the cooking and home chores so these participants were not expected to help after their day at University. Also participants knowing that they will have a proper meal when they get home may be another reason why they snack a lot. Snacking a lot during the day but eating properly in the evening balances their diet a little. Participants also conveyed that it is the mother figures of the household who cater for the family members with diabetes.

P4: it's different with my granddad like he I don't think he's er (.) you know like he's got a sweet tooth, he just likes a lot of sugar in his tea but he's not erm but my grandma she has like er like (.) she puts like less oil when she's cooking and stuff just for him and he's like put more oil in cuz it's not proper but she-it has changed the way that they prepare food in the whole house

INT: right ok

P4: so it does affect the whole family (lines 194-202 YPFG2)

P9: yeah (.) so we cuz we (.) we can't my mum's like I'm not making two separate so if we'll do it we'll just gonna do it thing and it will help like us as well so I think my mum's quite good at it (lines 1520-1523 YPFG4)

P5: Erm my grandma doesn't have have it so I think it's mainly cooking for people like most people in my family that have diabetes are actually male (lines 207-209 YPFG2)

For many of the participants it was the males in the family who have diabetes. Nevertheless it is the responsibility of the older women in the house to cook and look after the health of the family members with diabetes as well as everybody else's thereby emphasising British-Pakistani women being at the forefront of familial responsibilities. This has encouraged them to cook healthily for the whole family rather than making several dishes. Using less salt, less fat and less sugar is beneficial for all and this is appreciated by the participants. From this study participants explained that whether or not there is an immediate family member with diabetes, mothers cooked healthily and they do so mainly to maintain general good health or to lose weight. Not to prevent diabetes in the household.

P3: I don't think they have diabetes in their mind, when my mum tries to cook healthy food I don't think it's to prevent diabetes but (.) do we (.) no-one in our family's even overweight but my mum does have a fear

of fatness (*laughs*) it's just like that erm so they try to (.) it's more of a social thing really, it's kind of cool to eat healthy now

INT: yeah

P3: especially with the aunties when they get together swapping recipes and erm (.) but I don't think diabetes is their main concern right now. (lines 1238-1247 YPFG1)

P4: I think (.) you know what it is you know with the younger generation now like I watch what I eat

INT: uhmmm

P4: my sister watches what she eats so I think (.) I think I don't know if that's to do-it's not really to do with that it's just because you wanna be healthy and look after yourself (lines 522-527 YPFG2)

P6: cut it out and I think it's more to do with like we don't want to get fat now that

P8: yeah

P6: cuz like I've got three sisters and e:r (.) at the age that they don't wanna be fat anymore and like my mum's trying to loose weight as well and

INT: yeah

P6: I think it's more to do with that

INT: right ok

P6: cuz we don't think about diabetes you think more about 'oh I'm gonna get fat I won't be able to fit into my Eid suit'

P8: yeah that's true that'd be why yeah... I don't think it has anything to do with diabetes at all (lines 491-511 YPFG3)

P9: I mean my dad always says to me 'watch what you eat' that's just general like your parent's thinking (lines 404-405 YPFG4)

From the extracts above one can clearly see that participants believed that healthy eating is adhered to not with diabetes prevention in mind but for weight control purposes. It is mainly the females in the family who are concerned about their weight and losing weight hence they eat healthily at home, and as they cook the food they enforce it on the whole family.

5.3.3.3 Friendship/group culture

Participants placed some of the blame on their social life emphasising that their lifestyle is different to that of the older generation.

P6: our social lives are completely different to theirs (lines 219 YPFG3)

P4: it's quite hard like when you're at Uni and stuff like if you're gonna go out to eat with friends and stuff and they're eating something and

you can't have it you've got to be really careful about you know what kind of stuff you have (lines 485-488 YPFG2)

P9: influences around you as well obviously you're out with friends and stuff in our generation we're not gonna stop having chocolate cake or something sweet cus we've got problems (lines 500-502 YPFG4)

P6: Yeah especially with like our diet as well I don't really think I don't really exercise much as either so I'm just and I eat loads of crap (lines 98-100 YPFG3)

Participants explained that they are influenced by others around them and encouraged to eat unhealthy. They all do it together as a group and will find it hard to change as it is expected from them. They lead unhealthily lifestyles in general from lack of exercise to poor diets. They believed this is down to their social lives which the older generation were not exposed to. Therefore they believe that if they were diagnosed with T2DM it would have a huge impact on their behaviour as they not only like to indulge themselves but also regularly treat others.

P8: and it's just you know how like (.) when I'm meeting a friend up or something I'll just surprise them with a bar of chocolate or something just a lit (.) you couldn't do that you understand?

P7: Yeah

P6: or if we went to restaurant like you said like we go out like for lunch here and there and like 'oh I can't have dessert' and then you'd just do that (lines 725-730 YPFG3)

P6: and like yesterday and I feel really bad now I took her home like a twanger like one of those like (.) like sweet things and obviously if I didn't spoil her as much then she probably get less chance of doing it and probably have less to speak to us about as well

P8: yeah but you don't think of it you just think of it as 'oh I bought you a surprise' like thing and it's just something normal and you don't think of it as (lines 949-956 YPFG3)

P6: a spoonful of sugar yeah but you just don't think about it when it's in a form of a sweet

P7: because it's a treat you think you know I'm just being nice

P6: yeah

P7: you don't think it's something that's gonna effect a problem (lines 980-985 YPFG3)

Participants would find it really hard to refrain from having sweet indulgences around friends as it is the norm for them. Contemplating saying no to a dessert seems to be distressing.

They also enjoyed giving gifts and surprises in the form of sugary goods as they see nothing wrong with it. They are simply being nice and amiable. Although when discussing this in regards to diabetes participants realised that they are not setting a good example and are fuelling the problem. It is normal to give sugary junk rather than healthy alternatives. They mentioned earlier that the amount of sugar in sweets and confectionary is equivalent to the amount older people consume in their tea. P1 raised a good point:

P1: [but isn't] it your lifestyle that controls your diet or is it you?
Like making the conscious choice that I want a chocolate bar? (lines
1192-1194 YPFG1)

P1 realised during the discussions that female Pakistani university students are not in control of their diet rather they let their lifestyle dictate the way they eat. This was apparent from all the participants that they were not in control of their diet. They are living what they think is the normal student lifestyle depriving themselves of proper meals. All of the young women interviewed were living at home and therefore may have a different perspective on the student lifestyle from the majority of students.

5.3.3.4 Being healthy is expensive

Participants voiced the belief that being diagnosed with T2DM will not only affect their behaviours but also impact on them financially as they believed that it is expensive to be healthy.

P3: 99p just buy chicken and chips why cook?

P1: It's probably cheaper than cooking

P3: yeah definitely

INT: Yeah

P2: easier and less hassle

P1: if you're a student (lines 267-272 YPFG1)

P1: ...I just have to buy more expensive food because cheap food is obviously widely accessible, it's got high sugar in it (.) very refined sugars bit I probably have to sort of (.) shop in Sainsburys' and get all the alternatives get this really-actually very expensive to be a diabetic sometimes it's just like erm (.) I don't know I mean if you start buying org:anic I don't know (.) low-hmmm do you know what I mean? Like

INT: it's just more expensive to be healthy isn't it?

P1: It is a lot more expensive to be healthy and also like for me I don't like stuff like going for walks so I'd have to get-I think a better gym membership (lines 981-991 YPFG1)

Participants are exposed to cheap 'junk' deals when they go out therefore it is more financially viable and convenient for them. They perceived that being healthy is time-consuming and problematic especially for people with diabetes. Even when supermarket shopping, the cheap food options are not healthy as they are high in refined sugar. Healthy alternatives are perceived as expensive like organic or fresh foods. Financially it is not only their diet which would tighten the purse strings but also being active. A cheap or regular gym membership is not good enough or appropriate, it seems a good expensive gym membership is seen to be the only way to go for these participants to live healthy lifestyles.

5.3.4 Older generation

5.3.4.1 Old age disease

Participants believed that T2DM is a very common disease among the older Pakistani generation. It is an old age disease which most Pakistani's develop.

P4: it's just seen as common yeah 'yeah you've just got diabetes' (line 64 YPFG2)

P5: but when you're older they just think 'ok she's got diabetes'

P4: 'she's getting old [she'll eventually get it anyway]'

P5: [yeah it's inevitable anyway] (lines 87-89 YPFG2)

P5: Well yeah cuz like so many people have it

INT: yeah

P5: that's like 'oh you've got diabetes' and I'd be like 'yeah fine'...so I think everyone get's it and I don't know it's just I think in our people like I know in my family a lot of people have it so I would be just like oh well (lines 51-60 YPFG2)

Participants expressed that T2DM is so widespread in the Pakistani community that it is foreseeable that as the younger generation grow older and age they will develop the disease too. From the extracts above participants illustrated the lack of significance of the disease as

responses to finding out that people have diabetes are likely to be very casual; 'yeah fine' and 'yeah you've just got diabetes'. However even though the disease is perceived as being common it is upsetting for participants if they learn a younger person was to be diagnosed with T2DM.

P8: I >really don't know< but I know he got really scared when he got diagnosed because he was just well like you know 'I I never thought of myself as an old man before' (lines 445-447 YPFG3)

P9: when you're quite older it's not like common in young age groups (lines 14-15 YPFG4)

P9: I would be worried thinking that it's something for the older generation and if I'm gonna get it at this age it must be (.) something (lines 127-129 YPFG4)

P8 discussed how her uncle felt when diagnosed with T2DM. He was a 40 year old Pakistani man who initially was very scared and shocked to find out that he had developed an old person's disease. It made him feel like an old man. These emotions are also reflected in participants' feelings as they also believed that it is not common in younger generations, and that if it does occur they must be doing something seriously wrong to get it at such a young age. The impression the participants have of people with diabetes is that they are mainly older and overweight.

P1: ...I just don't assume that he's diabetic because I've got this image in my mind of like like older Asian women who are overweight but he's like erm (lines 687-700 YPFG1)

P4: ...I don't know you think of diabetes as you know old people having it (lines 44-45 YPFG2)

P1 believed Pakistani women are more prone to T2DM as most of her relatives who have the disease are females such as her mum, aunties and grandmothers. Most of the other participants have a father, uncles and/or grandfathers and grandmothers with T2DM. However the principal notion is the same that many older Pakistani overweight individuals have the disease hence why participants labelled obesity and being overweight as one of the

causal factors of T2DM. This may explain why younger female Pakistanis are choosing to live and indulge in carefree student lifestyles as they do not believe they are old enough to develop this disease. Due to the disease being so common among the older generation some participants did not initially realise close relatives had T2DM as they had good control and awareness over it.

P2: A lot of people in my family have got diabetes but because it's so common it kind of goes over your head but (.) also because they're so good in looking after themselves-no I mean really and properly only aware of what they suppose to be eating and what they should be eating and what they shouldn't be eating (.) I mean her mum but the rest of them are so careful (lines 473-479 YPFG1)

P1: ...you get a lot of people who are diagnosed with diabetes but they have the abil:ity (.) like even though they are angry they have the ability and they feel like they have the power to do something (lines 815-818 YPFG1)

Therefore it is most likely that many more of the participants' close relatives have this disease especially among the older generation but the participants do not know. Participants go on discussing diabetic family members, illustrating that not all of them are good at controlling their diabetes. It is a case of some do and some don't; there are those who look after themselves and those who rebel.

P1: ...my mum she's got depression as well (.) so it depends on if you've always played the victim or it depends on what stage you are at as to what-how much you can help yourself (lines 783-785 YPFG1)

P6: It makes you feel a bit bad cuz like sometimes like my mum will make a few things and my gran's like 'oh I can't have that, oh I don't want it' and my mum's like 'oh go on have some' and I just like feel bad cuz she can't eat it but then you understand that I don't want her to get ill or whatever so I feel a bit bad for her but then she needs to do that, that like you don't really want her to get ill cuz of it so

P8: it's the other way round in our household like my granddad whose got diabetes will be like 'oh can I just have a bit' and my mum will be like 'look you really can't' (lines 365-374 YPFG3)

P9: but the thing is people with diabetes it's like ok they know they've got a problem and they should be looking after themselves and cutting down these things but it's like (.) like they don't bother some do but

P10: some do and some don't yeah (lines 350-354 YPFG4)

P10: yeah yeah but we feel 'oh dad we're enjoying this dessert and you're having it with either without sugar or you're not having it at all' kind of thing and we feel-I do feel a bit like oh God you know I never-I'd just take it into the kitchen or something I won't eat it in front of him

P9: see with my dad he'll be eating it himself but he always wants us to say 'you shouldn't have too much sugar' this and that (lines 583-589 YPFG4)

Participants expressed their feelings towards older relatives who cannot enjoy the sweet dishes they like. They felt sad for them but understood that it is for their own health and benefit. Participants would rather family members with diabetes did not harm their health and some even refrained from eating in front of them. However participants did not sympathise with relatives who did not look after themselves and who expected others to stop them. Participants understood that some do control and manage their diabetes and others do not, and in a few extreme cases a minority do nothing at all to look after their diabetes.

P5: yeah well like my granddad had quite bad diabetes and (.) he'd wanna eat stuff and my grandma would be really really strict

P4: same here (lines 159-161 YPFG2)

P1: ...She doesn't see why she has to go to the gym whereas you'll get some people who have the cultural capital to be able to do something about [their own illness] (lines 792-794 YPFG1)

Participants acknowledged that in the extreme cases there are other factors to consider such as mental health issues and breaking old habits for those who are very old. Participants also found that those who controlled their diabetes were open to suggestions

P1: ...but she'll go out for walks, she'll look after herself, she'll go out of her way to make sure she eats fish three times a week now erm and if I make a suggestion like she'll take it on board (lines 1147-1149 YPFG1)

P2: I think yeah because when my mum if you tell her something's good for you or if you tell her something's bad for you she'll change it, she'll I know she'll do that dramatic thing where if you tell her something's good for you she's eat it all day and everyday, you explain to her that you know you need to be having a bit of this as well and having a bit of that like she'll she'll listen to it and if she can get hold of it (lines 1408-1414 YPFG1)

P4: Erm (.) I think you know when you get older they start listening to you a bit more

P5: yeah they do

P4: but s (.)

P5: I think it's easier to get round our mums (lines 819-823 YPFG2)

However some were not.

P5: yeah because they're really stuck in their ways

P4: there's a language barrier as well obviously I speak my own language at home but it's quite difficult to put across what you're saying to them in the right way because they take it offensively

P5: yeah no no I think if like

INT: it like telling them

P5: you tell them something and they're like 'oh it will be fine, don't worry'

INT: it's like they take it as in your telling them what to do rather than

P5: yeah yeah

P4: yeah it's like 'I should be telling you what to do not the other way round'

P5: they don't take it constructively anyway (lines 826-840 YPFG2)

P9: they think we're old now it doesn't matter like

INT: yeah

P9: like she was saying before we're young and we think ok we've got well most of us we've got our whole life ahead of us so we should look after it but like the older generation it's like you know like my grandma would say 'oh it doesn't matter now you know I'm this old'

P10: yeah

P9: they come out with 'we're use to it now' (lines 1295-1304 YPFG4)

Participants revealed they felt that the older generation are very unpredictable. There are some who are keen to control their diabetes and as a result are open to suggestions. Then there are those who whether they control their diabetes or not do not want to be told how to live their lives and take advice lightly given from those much younger than them. They have lived a certain way for a very long time and now to change their ways is a very difficult concept. Habits are very hard to change especially in old age therefore they feel justified to carry on the way they always have been. Participants believed that it is easier for older people to try and change their ways as they are not part of junk culture youngsters are exposed to today.

P3: ...but it's true all this stuff that we eat I think it's easier for (.) elders who haven't been raised in this junk culture

P1: Yeah my mum doesn't eat anything sweet

P3: and also [it would be easier for them to adapt kind of] (lines 81-85 YPFG1)

- P1: erm and when the dietician looked at her diet to be honest there wasn't that much wrong. (lines 383-385 YPFG1)
- P5: yeah I think also if you look at the different generations like our grandparents were bought up back home so they don't really eat like pizzas and all the kind of stuff like pasta and that kind of stuff that we would eat-we were bought up here (lines 298-301 YPFG2)
- P11: [I think you've mentioned it now diet] in Pakistan I think probably yeah it's much better than here (.) I don't know if the old people especially I think they'd prefer the natural ingredients and the erm yeah erm (.) but I think especially here with all the junk food don't we (lines 320-324 YPFG4)
- P10: I wouldn't be able to hack it (.) I think I (.) plus (.) I don't know I know it probably sounds a bit like thingy but back in the days they probably weren't eating as much junk food as we are we just binge eat a lot you know whatever we're munching on it's always chocolate (.) like sort of thing during the day to kind of keep us going and (.) busy lives and whatever which we fit in whenever, they had like sort of you know (.) set out meals and stuff like dad has he's tea and like toast whatever before he goes to work, has his lunch at work and then comes back and has his roti in the evening. He'll have tea and like whatever but roti in the evening (lines 728-738 YPFG4)

Participants expressed that they would find it harder due to the amount of junk and binge eating they do, however the older generation prefer organic and fresh meals. Participants also implied that the older generation have been bought up in a different culture and society back in Pakistan, and as they have been bought up in England they have been exposed to unhealthy habits from childhood. The older generation have not given up eating their set traditional meals indeed neither have the participants' parents who are second generation immigrants. Thus as stated by P1 the diet of the older generation is actually perceived to be good except for the high consumption of sugar as expressed by the young female participants earlier on.

5.3.4.2 Lack of exercise in older people

Participants recognised that the main problem for the older generation is lack of exercise.

- P6: Yeah it is cuz when you're running around here there everywhere then (.) yeah and I think in the older generation their lifesty-they are

pretty much just sitting down all day, their lives aren't as active as ours are so that probably impacts as well (lines 899-903 YPFG3)

P1: So what she needed to do was exercise and Asians don't (.) like Asians from my mum's generation don't believe in exercise. She laughs at me when I go to the gym. She's like if you did the housework properly you wouldn't need to go the gym (lines 455-459 YPFG1)

P2: the only thing she point blank refuses is to go to the gym because she doesn't like the idea of it (lines 1227-1228)

Participants discussed that lack of exercise is the main problem for the older generation as they are not being active. They are spending their time in their homes mostly on their own whilst the rest of the family are out at work, studying or socialising. Participants believed that the older generation did not approve of exercising especially if it entails one going to a gym or sports centre. They didn't have to do that in Pakistan or in their youth so why should they have to do it now. Also as they are older and are living with their kin they did not do any of the housework or any other kind of activity. But some participants believed that things are slowly changing and improving:

P6: I think things are changing though (.) like people are getting a bit more active like maybe like in 10 20 years ago there just was no no mention of it but like these days like I said I see so many older men and women like running with their joggers on and walking around so I think people are getting more conscious of it (.) so I don't think (.) it's getting there (lines 661-665 YPFG3)

P9: my dad's joined the gym recently because of this >whole thing he's been to the doctor's and the doctor's said you need to exercise< (.) I don't know he's been motivated these last-like actually yeah let's go and join the gym and he's really good and he feels a lot more healthier like coming back from the gym

P11: hmmm

P9: I mean he goes swimming every weekend like he takes my little brother I mean it's better because he's taking my little brother who's also helping him as well (lines 777-785 YPFG4)

P10: my dad hasn't actually thought about joining the gym but he walks a lot

INT: hmmm

P10: and stuff and plus he's always at work and it's always at a machine work and stuff anyway so he's really active in other senses at home DIY and stuff as well plus your dad's really active in DIY and stuff (lines 788-794 YPFG4)

Participants demonstrated the different ways older generations are starting to become more active. Many are walking or jogging in their local parks, some have joined the gym and others are active in their job and home lives. They are also motivating and encourage others to join them as people tend to go for walks in groups or involve their children in recreational activities. This is seen as very promising.

5.3.4.3 No fasting

Participants also noted something else about the older diabetic Pakistani generation. They don't keep fasts during Ramadan.

P1: but for my mum she'll you know she doesn't fast

INT: yeah

P1: because she can't erm she found it really difficult. Every year she tries erm and every year she fails^o but it's something that she has to try (lines 605-609 YPFG1)

P8: Well my granddad doesn't do it because of his diabetes

INT: yeah

P6: yeah most of my grandparents they don't actually fast cuz they're just too old and ill to so I don't know

P8: cus like if you have like medication you need to take at certain intervals of the day then you can't really do that while you're fasting and I know some people take it like before the fast and like over the fast (lines 412-419 YPFG3)

P7: it would be so hard for them

INT: hmmm

P7: because like they've already got like diabetes

P6: I think they would try but I think it would be more of a trial- trial and error like they'd do it once and if they thought they couldn't do it then they probably wouldn't

P8: I think it's more to do with their age isn't it once they get (.) that (.) even if it isn't diabetes just general fatigue at that age isn't it like they just physically can't

P6: yeah but even if it was a young person they would be- what if their diabetes was so low that you know they literally didn't have the energy to move anymore (lines 428-439 YPFG3)

P9: but mind you our grandma she tries to fast but she can't last long cuz she needs her food during the day and ends up breaking it so we say to her 'don't keep it' (lines 631-633 YPFG4)

P11: I don't (.) are diabetics allowed to keep fasts?

P9: They don't I'm not sure (lines 635-636 YPFG4)

Participants expressed the belief that it is best for their health if older diabetic family members do not fast. They need to adhere to their treatment routine and their diabetes does not allow them to go for a significant length of time without any food for functional purposes. Although many try to fast they are not successful. Thus participants encourage older family members not to fast but as discussed earlier those in control of their diabetes may listen to youngsters but otherwise they do not. Also Ramadan is a very religious and significant time so it is not surprising that the older generation try to partake in this spiritual practice.

5.3.5 Traditional Foods

5.3.5.1 Pakistani cuisine

According to the participants traditional Pakistani cuisine is a vital part of the Pakistani culture. Pakistanis have always eaten traditional foods and prefer it.

P1: look at the way you eat and the way that I eat and you know we only make roti and like (lines 89-90 YPFG1)

P3: ...all they know is butter and ghee and that's all they eat (lines 211-212 YPFG1)

P2: yeah I think she's always eaten like that yeah (lines 641 YPFG1)

P3: It's out culture-I had a friend who went from Pakistan she came from Muway I think it was or somewhere like that and they were like so shocked about the number of restaurants here, the number of takeaways, they were like we don't have that there it's you know we have to have a proper home-cooked meal everyday. It's part of their culture to but here we have access to everything just go out and buy

P1: chips (lines 259-266 YPFG1)

P4: it'd be really hard I know cuz you-as Asians you know

P5: that's what you're bought up by (.) it's quite comforting eating sort of home food so to not be able to eat home food (.) I think for a few days you could go without it but after a while you would just (lines 283-287 YPFG2)

Participants believed that traditional cuisine is an essential part of not only Pakistani's diet but also their lives. They gave the impression that this is true for all generations as P3 stated

'it's our culture'. The older generation are used to eating chapattis and ghee and find it comforting. Since living in England life is different hence maintaining their traditional Pakistani diet could be a way of preserving some culture. As mentioned earlier a lot of the older generation being old have become accustomed to certain ways and to change their diet from something traditional and enjoyable is not feasible. Participants go on stating that the older generations cannot live without their traditional Pakistani foods.

P10: they cannot cut out out of that no way

P9: as we said we Pakistanis can't live without their food (lines 509-510 YPFG4)

P1: so cuz they-like my mum doesn't feel full until she's had her roti like her chapattis (lines 247-248 YPFG1)

P2: ...if I feel like having something a bit different I'll just make it and if they want one or two they will have one or two but they won't- they will still eat. For them it's just like a little starter, they'll have like one or two and then they will eat their roti anyway (lines 630-635 YPFG1)

P5: and she'll eat like erm (.) like we made pasta and she'll like have a little bit but she'll need some Asian food as well right she'll also eat that on the side (lines 355-357 YPFG2)

P4: Yeah that's what my granddad use to say too-we'd get like takeaway and he would eat that and then he'd be like 'oh go and make me one just one' >and you know what he'd do?< cuz he ate too much of the pizza or the takeaway he would sit on his feet (*laughs*) just to fit it in and we would just laugh at him and say 'what was the need?' and he'd be like 'I ain't full until I've eaten it'

P5: yeah my granddad is exactly the same he was like you know what he would eat like if you got him a takeaway like naan I don't know sheesh kebabs or whatever >he would eat that and be quite happy with it< but then he'll be like 'can't we just have some roti as well now'

P4: or even if you do make something English they want like a twist on it so Asians

P5: we have to put spices in it

P4: put spices in, put garam masallah in you know whatever and so even when we make pasta and stuff it's quite Asian with chillies and all that kind of stuff (lines 361-378 YPFG2)

Participants expressed the view that the older generations have to have their traditional meals at mealtimes in order to feel content with what they have eaten. Eating something non-traditional is not enough to satisfy their stomachs. Therefore they will eat traditional

meals alongside other dishes that are made. Even having an Indian takeaway like naan and kebabs would not be sufficient. Underpinning the traditional cuisine is that it has to be home-cooked. Although naan and kebab are Pakistani foods that Pakistanis enjoy, their appetites will not be fulfilled until they have something home-cooked like curry and chapattis. Participants illustrated that the non-Pakistani cuisines made at home transformed into Pakistani style cuisine as they use many of the spices and ingredients found in traditional Pakistani cooking but not other cultures. Chillies and spices are often not used in Italian or English cuisines to the extent that they are in Pakistani households, allowing the whole family to enjoy the meal. Ultimately participants agreed that even they would miss traditional Pakistani cuisine if they had to stop eating it as they have been exposed to it from a young age and it is their culture too.

P3: With me you kind of (.) you know if you haven't had chapattis for a while you do crave it because it's our food it's our stable diet, if you don't have it for a while I'd (.) I'd feel like having it (lines 579-582 YPGF1)

P4: I think it's because we're so use to it

P5: yeah I know

P4: this is the way we cook

P5: I think that we can erm like ok we make a lot of non-Asian food but we still have all the Asian stuff in it so we can say that it's Mexican or its Italian or whatever but it's like Italian-Asian (lines 774-780 YPGF2)

P11: I wouldn't be able to do it either I love my salan and my chilli food and my oily food

P10: it's like one of those chapattis that you know rotis roti kind of thing and you know there's noway

P11: can't live without my roti

P10: you can have like your takeaway food but you have to have (.) I think it's a lot more common amongst erm guys like my brothers if they have takeaway they will still have their roti no matter what

P9: yeah

P10: it's one of those things they they just love it kind of thing (lines 523-533 YPGF4)

Traditional Pakistani cuisine is a part of culture that has been passed down through generations and is still being preserved. Participants demonstrated that even youngsters their age enjoy their traditional foods and crave them, and that especially the males in the

family will behave like some older generation people by wanting to eat traditional Pakistani food alongside other cuisine. It is part of their lifestyle to consume and enjoy traditional foods hence they have also learned to cook in a traditional Pakistani style, which they use to adapt other dishes from different cultures.

5.3.5.2 Food & Celebrations

Another reason traditional Pakistani food is pivotal to the Pakistani culture is because participants believed that it is a significant part of their celebrations.

- P10: [it's the] atmosphere [I think the atmosphere helps like you know]
- P11: [it's still Eid so you have to eat]
- P10: it kind of makes you want to go to people's houses [and eat so yeah]
- P11: [even though you've had] it the whole month the food
- INT: yeah
- P11: I always eat it it's a way of celebrating isn't it (lines 673-681 YPFG4)
- P6: Yeah well like P8 touched on being like Pakistani and how we eat all these mities and stuff like our family's not really like that... but I just think it's just things like you know when you have like celebrations and things like >that and you've got oh it's Eid or something and you've got all this fatty food on the plate< (lines 280-288 YPFG3)
- P3: Yeah definitely (.) it's like parantee in the morning which is just like butter basically and in the evenings we erm this Ramadan we didn't even have chappatis at all (.) it was just erm (.) fried food
- INT: right
- P3: samosas, pakoras, you know rice even but no-one really likes rice in my family to be fair. It was just chips and stuff like that, pizzas, garlic bread
- INT: yeah
- P3: it was really bad
- INT: and Eid? The same thing?
- P3: Yep (lines 561-572 YPFG1)

Participants explained that celebrations are associated with food which entails rich spicy greasy traditional food. It is a crucial part of celebrating. They want traditional Pakistani '*junk*' food like samosas and pakoras that are deep fried; all home-cooked but very fattening.

Celebrations such as Eid and Ramadan create a special atmosphere of bringing together

family and friends and enjoying each others company with food. As P11 stated '*I always eat it it's a way of celebrating*' which all the participants agreed with. Celebrations aid retention of the Pakistani culture along with traditional Pakistani foods. Participants acknowledged that they freely enjoyed themselves and over indulged during celebrations yet diabetic family members still needed to show restraint and were encouraged to do so by loved ones.

P5: On Eid we are kind of like 'oh it's Eid just let him have what he wants' cuz it's Eid and you're just like aww and we make like for Eid we make loads of biscuits and stuff and cakes and loads of stuff like and he'd really want to eat it so (.) we let him eat more than what we normally let him eat but not as much as he'd want to have (lines 265-270 YPFG2)

P4: Erm (.) I think obviously you know like in Ramadan you have like a lot of fried stuff

INT: yeah

P5: yeah

P4: I think it's limited to that because (.) my grandma she doesn't let my granddad like have too much of it, she gives him and he has to eat only a little but but erm (.) the rest of the family they eat like however they want to like cuz it's there, it's just limited on how much he can eat

P5: and also like in Ramadan we have like lassi and falooda and stuff like that (.) cuz because obviously it's really sweet, it has sugar and stuff erm erm sometimes my grandma will put like (.) you know those sweeteners

INT: yeah

P5: stuff like that because he'd really want it and obviously it doesn't taste nice if it's not sweet (.) erm and stuff like that (lines 225-241 YPFG2)

Participants realised that it must be hard for the older generation who have T2DM however family members did accommodate for them. They are not as restrained with food as they want them to be part of the celebration but at the same time do not allow them to indulge. They also make sugar-free sweet dishes for the T2DM sufferers to enjoy. Another big celebration recognised by participants was weddings.

P8: and she said that one of the like main things that she like she is on her review sheet that she has to talk to them about is like many cultures you only have like one or two weddings a year whereas when Asian wedding season comes around you have like 7 or 8

Group laughs

P8: and the dishes there are really sugar so she has to like say to them erm ok when we say stuff like oh you can have the odd treat on a wedding, Asian weddings you get 7 in like a months time yeah so just like balance it out (lines 310-319 YPFG3)

As P8 mentioned the wedding season is a big part of the Pakistani culture. So many occur simultaneously promoting a marathon of eating and indulging. This is especially bad for individuals with T2DM therefore it is important to implement a balance strategy to manage and maintain diabetes care. Participants also commented on how traditional food is used to socialise with guests.

P1: but (.) I don't know I think in Ramadan you do make it more often but again we tend to make it more often when we've got guests

INT: right

P1: so if we know someone's coming down or like somebody turns up we'll just put some samosas out from the freezer and then fry them (lines 595-601 YPFG1)

P6: ...like we won't actually go and make the effort it's only on the weekends when we're expecting guests and all the parties we'll do it but there's a lot more parties in Ramadan so (lines 468-471 YPFG3)

Traditional food is again used to create a welcoming and friendly environment allowing guests to relax and mingle with the hosts and other family members. Many participants found that people have started to accommodate guests with T2DM.

P1: because yeah like a lot of people go out of their way now to accommodate my mum's diabetes so they will make things separately for her but she still wants her samosas, she still wants the pakoras and it's a special occasion and it really annoys her like when people are looking at what she's eating (lines 156-160 YPFG1)

P2: I think it depends. I think if it is someone who has had diabetes for years and years and years and years and is use to it then you know it wouldn't stop me from eating it and if they came to my house to eat then obviously I would try to accommodate for that but I wouldn't necessary feel bad about it as opposed to someone who had just been diagnosed

INT: hmmm

P2: and they were just trying to get use to it then I probably would try to be a bit more careful and a bit more weary of what I eat as well (lines 648-657 YPFG1)

Above are two extracts one an example of how others accommodate and the latter an example of how participants accommodate guests with T2DM. Feeding guests is a way of making them feel comfortable and at ease hence it makes sense that people are trying to do the same for their guests with diabetes. Participants clearly felt that this is a good step forward however not all older generation T2DM sufferers fully appreciate it. From the extract

above the impression given by P2 is that it would be easier to feed a long-term sufferer than an individual newly diagnosed. An explanation for this is that the participant does not know how the sufferer feels about their newly diagnosed diabetes therefore she would be more cautious with the food she offered them. Participants highlighted that society has also started to provide food for individuals with diabetes.

- P8: [yeah I know there] are a lot of stuff from the market now like erm (.) diabetic chocolate and diabetic mitie and stuff like that
- P6: (*laughs*) is there really?
- P8: yeah there is like in Boots they've got like a whole section for diabetic like people with diabetes and stuff and it's like they're trying to cater for it because it's like such a like (.) big problem now (lines 58-65 YPG3)

Participants expressed that there are a lot of alternative choices for people with diabetes to enjoy. Food is being marketed and being made readily available as the T2DM disease is becoming more common according to participants. Everyone seems to be doing their bit to help aid diabetes care and management.

5.3.6 Knowledge and Emotions

5.3.6.1 Severity & risk

Participants discussed the seriousness of T2DM.

- P1: the one yeah like basically my auntie's husband on my mum's side he was diabetic but he never controlled his diet and he lead a very sort of wayward lifestyle he just travelled so he lived in Belgium most of his life on his own erm (.) he had to have like several toes amputated and stuff like that and eventually his kidneys gave up (.) and that's what can happen
- P2: [Erm doesn't it have something to do with your eyes as well?]
- P1: [but that's like when you really don't do anything] for yourself yeah you can [go blind]
- P2: [eyes get affected]
- P1: erm yeah (.) so basically all you extremities eyes erm (.) it's really really important if you're diabetic if you get ill or if you get a cut or something you really need to look after it (.) and to look after your feet and that kind of thing and people who aren't aware of this that's a problem
- INT: hmmm

P1: so (.) there is a serious more serious side to it like you know but I think people who don't understand (.) that's when you're really gonna hit a wall with them (lines 930-948 YPFG1)

P9: it's quite a lot of the you know like (.) if you don't look after it you can get like a heart attack call

P11: hmmm

P10: yeah

P9: <what else can you get?> (.) like it's something to do with the kidney or something is it?

P10: There are a lot of side effects like

P9: side effects to it (.) as [Asians they don't look after themselves] (lines 47-55 TPF4)

P10: Like my dad's older brother he's got very severe erm like case of diabetes he's sort of like he's toes have started falling off and (coughs)

P11: ooooo

P10: it's really bad and he's partially losing his sight and stuff (lines 224-228 YPFG4)

Many participants were aware of the seriousness of this disease. They stated the severe implications T2DM can have on an individual who does not look after themselves or who has a severe case of the disease. Participants believed that Pakistanis do not look after themselves and as a result it can lead to severe health consequences ultimately death. Although T2DM is very common and participants acknowledged the severity of the disease, participants did not seem to be affected by this. As a result the young generation has become desensitised towards this disease.

P4: it's not seen as a major thing because so many people do have it... we don't really see it as a big problem

P5: or as a big disease

P4: like a big issue kind of thing. (lines 61-68 YPFG2)

P7: at least it's not life threatening [I see it as] (line 57 YPFG3)

P8: it's not made out to be kind of erm like an illness like some illnesses you'll think twice before doing something or saying whatever but I don't think diabetes is considered to be so er (.) you [know 'oh my God']

P6: [you know it probably is] you know how like when someone gets like diagnosed with cancer everyone's just like 'oh my gosh' like it's the end of the world type of thing but with diabetes even though it can be a serious illness it probably impacts your life a lot more

P8: ye::ah everyone's like ok

- P6: everyone's like ok like maybe because it's becoming so normal
P8: yeah it's becoming-yeah I think that's what it is (lines 543-554 YPFG3)

Participants clearly do not classify T2DM as a serious disease though they are aware of the severe side to it. They have a very blasé attitude towards the illness which stems from it being so widespread in the older Pakistani community. They perceived the onset of the disease as inevitable in the older generation and so they were aware of the disease. They also understood that the way the Pakistani community live their lives has an impact on T2DM but the participants did not actually know what the disease was.

- P8: and stuff it's like what we eat these days and I think (.) we've increased the level of fat and sugar stuff that we eat and we've decreased the amount of exercise you do
P6: exercise yeah
P8: so it's going to result in high diabetes levels especially in our community because we do eat a lot of fatty food (lines 239-244 YPFG3)
- P1: ...so I would feel really like (.) angry I think at myself more than anyone else that I didn't do anything about it and I would feel really thick as well cuz like I'm always telling my mum what not to eat but I eat it myself like in abundance (.) very frequently.
P2: I: I think I would have to change everything cuz [like I] (lines 58-63 YPFG1)
- P11: hmmm (.) I think people who don't have it and have no (.) er idea of what diabetes is they don't really care (lines 383-384 YPFG4)
- P11: but people who were grown up with families and diabetes I think they're more wary of stuff (lines 390-391 YPFG4)
- P2: I do not (.) see I understand what you do if you have diabetes but I don't understand what diabetes actually is and I'm sure that if I understood what diabetes is I'd understand (.) why (lines 1289-1291 YPFG1)
- P5: yeah I think it's all the carbs and I don't know I don't know what goes into diabetes actually (lines 142-143 YPFG2)
- P11: [I personally don't know much about it] personally (lines 56-57 YPFG4)
- P9: The thing is cuz (.) not too sure exactly what it is (.) and like we don't know the symptoms or (lines 96-97 YPFG4)

Participants understood their unhealthy diets and lack of exercise are the main problems that contribute to the high T2DM rates in Pakistanis. They are at fault for being so laid back about their health. P1 stated that she would feel '*stupid*' if she was diagnosed with the disease as she is constantly battling with her mother to be careful with the foods she eats yet P1 herself is just as bad if not worse. She feels like she needs to take her own advice. Most participants did not actually know what diabetes was therefore they did not have a clear understanding of it. The general assumption among the participants was that if they had an immediate family member with a diagnosis of T2DM they would be more aware of the disease however if participants did not have an immediate family member with T2DM than they were not aware and less concerned about it. The participants who did have a family member with T2DM understood that they were at risk of it.

P1: I'd hate it because I've I've been like erm told to be really careful already and I eat way too much sweet stuff it's like I crave it as well so it panics me like when I crave it and like if I was diagnosed with diabetes I would feel really stupid because I know that I'm at high risk and I know that right now I can do something about it whereas if I got pregnant and then I got older (.) like the chances of what I can do about it slim down (lines 49-56 YPFG1)

P2: But I was saying my sister-in-law's mum has got diabetes and like my sister-in-law has been told that she needs to be careful with her diet and (.) I think you must do then if they're telling her that cuz

P1: Well I've been told and I still find it hard (lines 356-360 YPFG1)

P6: it kind of runs through my mum's family, my gran's got it, like I think two of my uncles have got it, erm and because of that my mum obviously knows she's at high risk because obviously so many people in the family have got it which is why she takes like (.) extra care cuz she doesn't want to get diabetes even so she won't have sugar in her tea, and just like little things like that, she's trying to already kind of like combat it like as much as she can but (.) yeah then I think as well 'maybe I'll get it as well' so I think I mean I don't bother with it now I don't really think about it but sometimes when I think about of my mum does that then maybe I should be a bit careful as well (.) seen as it runs in the family I don't really wanna like (lines 85-96 YPFG3)

P10: so there is a lot of family issues

P9: so does that mean that we've got a risk of getting it as well?

P11: It depends how severe it is I think doesn't it?

P9: But if it's common in our family cuz in our family we know quite a few people so (lines 80-84 YPFG4)

Some participants appreciated the difficulty of trying to live healthy lifestyles especially as they are at risk of developing the disease. It is hard to give up comforts and not to give into cravings. Although they are aware of the risk through their unhealthy diets and also family links participants are unflustered about the illness. They do not want to concern or worry themselves yet. A reason for this mentality was that they perceived themselves as too young to develop T2DM.

5.3.6.2 Negative feelings

Participants expressed how they would feel if they were diagnosed with T2DM at this age:

P5: It's sort of like standard

P4: no I'd feel really like upset it would make me think that I wasn't healthy or (lines 39-41 YPFG2)

P1: ...like if you develop diabetes like if I developed it I think I (.) I would eventually adjust to it but I would really be annoyed as well (lines 113-116 YPFG1)

P6: I wouldn't be heartbroken but I'd just be a bit like (.) you have to really control and really look after the way you're eating because I know my gran has it and like (.) the (.) obviously with her being quite old as well and the minute she eats a bit of mite or something she has like you know blood sugar levels go through the roof so I'd be a bit like (.) like you know like (.) have to erm watch what I'm eating and start to take all these tablets, checking my blood sugar levels all the time, I'd just be a bit annoyed I guess but

P8: I'd be really upset because I think it like really like (.) like downgrades your level of like life and it's like always have to be like 'can I have this, can I not' like instinctive like when you're at a restaurant you don't think twice you'll just have dessert (lines 38-51 YPFG3)

P6: ...I don't know I think you'd feel it I don't know like I think being at this age as well you know like going out like say if you're out with your friends and (.) you know

P8: I'd feel a bit like a freak to be honest

P6: not a freak

P8: no but it's weird do you understand like erm when you go to a restaurant and you're gonna be like the one constantly thinking 'oh can I have this can I not?' (lines 697-704 YPFG3)

- P11: it becomes hard work
 P9: is not that unheard of for old-but if I got it at this age I would be
 (.) I would be worried because wait a minute
 P10: yeah I'd be really gutted
 P11: it becomes part of your life doesn't it? You're anxious about
 everything, you have to be on the ball, and injecting everything
 everyday can be really heart bearing on you, it's stressful and stuff
 yeah so (lines 108-115 YPG4)

There were mixed reactions from participants regarding being diagnosed with T2DM. Some felt that it would not be as shocking as it is so common and inevitable but they would feel annoyed because they would have to take medication and change their behaviours. Most participants expressed feelings of being upset and worried to be diagnosed with the disease at such a young age. It would make them feel unhealthy, distressed and anxious. They felt that it would downgrade their quality of life making them feel '*like a freak*', inferior to other female Pakistanis their age. It would force them to change their lifestyle and behaviours which would be stressful and tough. Participants believed that their immediate family members would be very distressed too.

- P3: They'd be so upset because they (.) don't know how it is they don't
 know anybody who's had-got it and I think it'd open up their eyes and
 make everyone more aware definitely because we're quite a close family
 even with cousins and relatives >we're quite close< so definitely it
 would change the way they think (.) for sure (.) I don't know how they
 would take it actually I don't know how I would take it (lines 177-183
 YPG1)

- P3: [My dad] would just be like 'oh bejari' give me like sad looks 'ahhhh'
Group laugh

- P3: my brothers would be like you know waving crisps in my face 24/7,
 having pizza in my face, but my mum I think she'd take like an active
 role she's really good like that she's been encouraging us to eat more
 healthy anyway and erm with cooking and that she can cook, she can do
 all of this, this is (.) I don't know (.) she'd probably take it to
 the next level (lines 1081-1089 YPG1)

- P8: so yeah she's like that so she'd be gutted

- P6: my mum's a bit the same actually she'd like (.) she really erm you
 know my mum she really monitors what we eat like make sure we eat
 properly kind of stuff so (.) I don't I don't know how they'd feel if
 we got it I don't know

P8: they'd probably feel it was their fault also like cus like to some extent your parents control what you eat (lines 166-172 YPFG3)

P6: yeah I think they'd realise, I've got like loads of younger brother and sisters so I think for them it would-my mum would definitely be like ok look if it's happened to me and they're not that much younger like my brother is two years younger than me so he might just think 'ok we'll if she can get it'

INT: yeah

P6: and we pretty much have the same kind of lifestyle, he doesn't eat differently -much from mine, so I think he'd be a bit more like conscious about like 'oh hang on I could get it as well' so it might give him a shock to the system and maybe make them change their ways as well (lines 757-767 YPFG3)

P10: I (.) initially I think my mum would start crying her eyes out

P11: hmmm

P10: dad would be really really worried

P11: yeah definitely

P10: he'd just make me really really control it kind of thing and [especially keep on eye on us] (lines 133-138 YPFG4)

P10: plus it's like one of those things that parents kind of (.) they kind of expect to outdo their kids

P11: yeah they only think that they

P10: do you know what I mean it's like they (.) they think that they have to go through it first before the kids to go through it

P9: yeah

P10: and it would be a bit of a shock like 'oh my God the kids have kind of'

P11: I think not only your parents but your aunties and your uncles

P9: yeah

P10: [yeah and grandparents]

P11: [and your siblings] as well it's not only your parents that would actually

INT: erm

P11: it's the out bit-especially in Asian families in Pakistani families you have erm big family don't you surrounded around you definitely

P10: yeah

P9: and if they find out it will be like 'oh God'

P11: yes

P9: 'oh my God she's so young' you know like 'we haven't got it'

P10: yeah it's just one of those things (lines 165-186 YPFG4)

Participants believed that their parents would be very upset and shocked. It would make the whole family realise how vulnerable they are. The consensus in the group was that mothers would take an active role in caring for them as well as the whole family. Fathers would be more sympathetic and nurturing and siblings would enjoy teasing and tormenting them. Parents would become more aware and try to prevent it occurring in their other children.

Some participants thought their parents may feel guilty as they are responsible for the diet in the household. However earlier they admitted that the food provided at home by mothers is healthy (except celebration foods) and freshly home-cooked and that it is the snacking they do during the day that is unhealthy for them. Furthermore many participants expressed that parents would rather carry the burden of having diabetes than their kin having to do it. They just want to protect their young. Being diagnosed with T2DM would not only affect their parents but the whole family including siblings, grandparents, cousins, aunties and uncles. As P11 stated above Pakistani families are large and include close family members outside their immediate family. They would all offer support and sympathy. The biggest shock to all these individuals would be the age at which the participants would hypothetically be diagnosed with T2DM. If they were diagnosed when they were a lot older the reactions would most likely be different.

P5: I think it depends what age like if I got diagnosed with it now I know that my mum and dad would be really upset

INT: hmmm

P5: erm but I think if I was older (.) like say 40 or something like that and I got diagnosed with it (.) I don't know not that they expect it but I think it would be easier for them to deal with (lines 73-79)

It is more acceptable for older people to be diagnosed with T2DM and is almost natural.

Moreover participants discussed how T2DM would change their lives.

P3: yeah it would force you to reconsider your position because diet and exercise its not (.) its you have to look at everything your working lifestyle and timing and take that all into account to you know establish (.) erm a routine where you can you know you have the time to cook a proper meal where you have somebody there to cook a proper meal there for you, you taking time out to go to the gym, (.) and it would do-it would change everything. (lines 962-969 YPFG1)

P4: It would change it dramatically cuz like obviously

P5: everything we eat will change

P4: change yeah hmmm (.) you're gonna have to

P5: and I think I would really really keep on eye on your intake of sugar and you know all those things (lines 480-484 YPFG2)

P8: but then you'll have to be like 'ok well I had this yesterday maybe I shouldn't have this today' that type of thing, I think it really impacts on your life (lines 54-56 YPFG3)

P8: because it just impacts on everything like in diabetic people like don't they get like really tired really easily, they get black outs and stuff like if they don't control it properly and I think that really lowers you like

P6: and obviously if it goes like too too high then it can be fatal for them as well so they really have got to be careful and stuff as well (lines 69-75 YPFG3)

P10: I think diet-wise I would change, your lifestyle what you do and sort of thing

P11: yeah

P10: I think cuz men just like-it have like a sort of not just a physical sort of effect but mental impact as well

P11: mental yeah (lines 1136-1141 YPFG4)

The participants believed T2DM would have a huge impact on their lives. They would be forced to lead healthier lifestyles; eat healthily, increase exercise, have a daily routine, consume proper meals not snacks which would help to reduce their sugar intake. They felt that everything in their lives will be impacted and consequently change. They would need to worry about becoming either hypoglycaemic or hyperglycaemic as this would have drastic implications for their health. Participants also identified the impact T2DM would have on them psychologically. P10 mentioned that men are more prone to the psychological effects however this could be universal. Participants went on to illustrate that although there is a need to be consistent with your lifestyle to control T2DM they would probably be back to their old ways in no time.

P4: I think it would die down after a bit because obviously when you [hear something first]

P5: [shock it's the shock of it]

P4: yeah it's the emotional shock and everything but w-w (.) when you become use to it you think that yeah you know 'it's ok back to my old ways' (lines 507-512 YPFG2)

P10: yeah we've kind of like not got that sort of motivation to kind of think oh you know this can happen or we should watch what we eat, what we're doing kind of thing, it's like we'll cut it straight we'll maybe do it like to sort of please the parents for a bit but where I probably will do it for a few months just to keep them happy but then I'll probably go to my own back to my own ways again (lines 489-495 YPFG4)

P10: ...but there's no way I'd be able to cut it out to that-I'd cut down a lot I think cuz I think I'd be like mum and dad on my head and like kind of watch myself but erm (.) not all together no

P9: I think I'm the opposite I think if I found out that-because of the shock and the whole stress of it I'd be like I don't give a shit like you know what I mean whatever's meant to happen its happened and I'd just carry on eating it (lines 458-465 YPFG4)

Participants agreed that after the shock of their hypothetical T2DM news had worn off and some time had passed they would go back to their old unhealthy ways. They would try to maintain a healthy diet in front of their parents to not worry them but they would not be able to completely lead a healthy life. They felt they would still need to indulge but not to an extreme extent. They would however do their best to reduce the amount as much as possible on unhealthy living but it would be too hard to quit the luxuries that they enjoy. P9 stated that she may not change at all as what was meant to be has happened therefore she would still maintain her carefree lifestyle. Participants also identified that among the emotions and distress of being diagnosed with T2DM some parents would also be inclined to say *'serves you right'*.

P2: My mum would be like serves you right
Group laughs

P1: I'm sure she wouldn't

P2: She would >she'd say 'I told you so I can tell your diets so bad'
(lines 140-144 YPFG1)

P1: ...I think if I got diabetes (.) erm everybody would sort of in my family because we are so aware of it just sort of look at me and think well we did try to warn you (lines 1155-1157 YPFG1)

P8: My mum would be really annoyed
P6: annoyed? (*laughs*) (lines 142-143 YPFG3)

P10: my dad would be like 'I told you to cut down I told you to cut out' and stuff but then he'll be huffing and puffing and really upset but then he'll still be like that I told you so kind of thing (lines 1201-1204 YPFG4)

Participants had already previously discussed how their family diet is healthy and how some of their older family members were active therefore it is predictable that some parents will frown on their children for being so reckless. They will be supportive and concerned but also vent as it is the participant's own fault. Parents would believe that it is the junk consumed by the participant that would inevitably cause the onset of T2DM. However all the participants did not want to burden themselves with the worry and stress of preventing T2DM. Again they simply felt they were too young to think about it.

P2: ...I think if you don't know anyone and if you don't have it yourself you kind of just try to ignore it because you don't want to be thinking about your diet you just want to pick up what you can when you can (lines 952-955 YPFG1)

P4: I don't [think]

P5: [I think] we don't do anything right now

P4: no preventive measures

P5: yeah we kind of just eat whatever we want like (lines 515-518 YPFG2)

P5: I don't really pay attention to (.) am I eating healthy or not?

INT: right

P5: I just think I'm too young to bother (lines 654-656 YPFG2)

P8: Cuz like I said it's completely-complete laziness

P7: we have everything on the plate

P6: it's true (lines 248-251 YPFG3)

P8: No honestly I was just thinking I've never thought about it like (.) I kind of do what I want when I want

INT: hmmm

P8: and it's never done me any harm like so I guess like that's the views that most people have before they get it like 'it's not done me any harm so why stop now' but (lines 916-921 YPFG3)

P10: I don't know it's like you think I mean I would I think like you know the amount of cases that we've got in the family like (.) erm heart attacks and diabetes and stuff you know it sort of impacts us on to that extent watch what we're eating ourselves but it hasn't

P9: yeah

P10: to be honest I had like I haven't changed my diet

P9: see that's what I mean cuz even though it's like in our own house I don't-it still hasn't effect me (lines 825-833 YPFG4)

Throughout the focus groups participants made it clear that they were too young to be concerned about developing T2DM. If they did not have an immediate family member who suffered from the disease then they simply chose to ignore it. Yet those who did have an immediate family member diagnosed with the disease were just as blasé about it. It did not have an impact on their behaviour. The consensus of the participants was that they will deal with it if/when it happens.

P6: probably to be honestly I know it sounds really bad like we should prevent it before it happens but you just don't think about it and you just think we'll live life to the max now and we'll worry about it tomorrow

Group laughs

P6: when we actually get it (lines 924-927 YPFG3)

P11: we wouldn't do anything to prevent it right now because it hasn't really happened so far now (lines 1242-1243 YPFG4)

P9: so I'm still like yeah ok I'll worry about it when

P11: if it happens then probably

P9: if it happens then that's when I'll deal with it

P10: yeah

P9: cuz it hasn't happened we'd be like ok whatever let's hope it doesn't happened but (.) you're not gonna really do much about it (lines 1252-1258 YPFG4)

Participants were more concerned about living their carefree student lifestyle. They did not want to think about the potential harm they are causing themselves. From the extracts above participants were not suggesting they would not get T2DM rather when they do they will deal with it. Therefore they probably assumed they would get it in their old age regardless of their lifestyle now. They are not concerned about trying to prevent the onset as they are not experiencing any negative side-effects from their cavalier lifestyle. Participants believed that a young person being diagnosed with T2DM especially from within their friendship circles would be more tragic and have more of an influence on them.

P4: so when a young person is diagnosed with it obviously you feel

P5: yeah that's true insecure

P4: yeah insecure about it about yourself and stuff (lines 47-49 YPFG2)

P4: Erm (.) it would change the whole like it would change everybody in the house because

P5: yeah I think if like say one of us got it diab-even if it was one of my brothers or sisters everyone else would be like 'oh my gosh'

P4: watching them (.) it's like [erm you know]

P5: [it it would] be kind of like erm like a wake-up call almost

P4: yeah

P5: it's like 'oh my gosh she's got it! Ok we all have to look after ourselves now' cuz it just makes you take more notice (lines 491-501 YPFG1)

P6: like with my granddad [I don't think twice]

P8: [I'd think twice]

P6: but if someone like close to me like in my friends circle then I probably wouldn't I'd feel a bit more bad, that sounds really bad but (lines 719-722 YPFG3)

Participants clarified that young people of their own age being diagnosed with T2DM would make them feel insecure and vulnerable. They would become anxious and distressed as they would feel that if it can happen to their friend it can happen to them especially as they lead similar lifestyles. It would be a *'wake up call'* for them prompting them to be more aware and careful. Participants realised that this may sound appalling as they would feel more of an impact if a close friend was diagnosed rather than an immediate older family member but this is due to them being the same age. As emphasised before participants know their lifestyles are unhealthy especially their diets but they were not disturbed by this.

5.3.6.3 Self-control

Many participants believed they did have some control over their health and preventing the onset of T2DM.

P6: yeah you just think that at the end of the day you know they're old enough to know like what's gonna effect them you know it's not even like you need your parents to tell you, you know yourself what you should be doing and it is up to you to do it or not (.) you've only got yourself to blame really so

P8: and we're kind of past the force feeding stage so if we do not want to do it there's nothing that can make us do it now

P7: yeah that's true (lines 934-941 YPFG3)

P10: but I don't think I'm helping myself in that sense to kind of prevent it kind if I know it can just happen and you know what like I could try as hard as I want kind of thing and it could still happen but

P11: I always like get shouted at by (friend's name) the amount of sugars that I have in my tea she goes 'what you doing?' I always (.) these lot go on about it but I need to have that much sugars worth in my tea I don't control it therefore I don't control it do I (lines 1478-1486 YPFG4)

Some participants were in accord regarding having control over being healthy to try and prevent the onset of T2DM yet they did not demonstrate this control. They acknowledged that it was not their parents' fault if something was to happen as ultimately it was their decision to eat what they wanted and behave the way they did. Participants acknowledged that they should be doing more to try and prevent this disease but their attitude of *'if it*

happens it will happen' takes over. They displayed that they did not want to enforce any prevention strategies rather they would deal with the disease when it happens and it was more important to manage it.

P1: I feel like I've got a bit less control than you because I know so many people in family who are diabetic (lines 1393-1394 YPFG1)

P2: I think I think I have got a lot of control if I sorted my diet out (.) I mean obviously if it's gonna happen it's gonna happen not really (.) not necessarily just diet but I think (.) I think the more important thing if you did get diabetes it's what you do about it (lines 1378-1382 YPFG1)

P4: I don't think there's anything

P5: I think right now we do have-I do think we have a bit of control because we are [still at that age that we can change it]

P4: [I don't think we do because (.) you can] get it all of a sudden cuz it just depends really (.) on

P5: I think it is genetic as well so (.) your control is only limited

INT: yeah

P5: but because we are at that age that you can still change what you're eating, your diet, and exercise, and your routines, all that kind of stuff we still do have quite a bit of control over it

P4: you could do but even the most healthiest people the ones who exercise you know (.) a lot they get it as well so (.) obviously there are things that you could do to try and prevent it but I don't think there's anything you could do that will actually prevent it (lines 783-799 YPFG2)

Those with a family history of the disease felt less control however also felt it is still up to every individual to try and enforce their control. Most participants did believe that the control was in their hands however there was a few who felt that they had no control. These individuals felt that sometime there is no explanation for it or it is simply down to genetics. P4 was very cynical as she accepted that Pakistanis can try and prevent the onset of this disease but she is not convinced that there is anything that will actually prevent it. It is because of her cynicism that she is reluctant to try and lead a healthy lifestyle. This stems from her already experiencing health problems but in general participants did acknowledge control.

Participants were however more troubled about the diets of younger siblings and younger generation children to them especially young boys.

- P1: Er:r I'd be worried about the diets of my younger brothers cuz they're a bit extreme on the junk side erm with my dad I'm kind of his very aware and he just looks after himself and he's doing fine erm and my older brothers they're I think they're doing ok you know because they're older they know they need to look after themselves now (lines 1370-1375 YPFG1)
- P8: she was trying to work and he was annoying her so she got a spoonful of sugar and put it in his mouth
- P7: o:h
- P8: I was like 'I know Mary Poppins says it good to help medicine go down and all that but seriously what are you doing' and she was like 'yeah but he was annoying me', she can't speak English and I was like seriously you know just if he's gonna like he calls like (.) erm coke milk and he's at that stage you know you need to like stop him because it's his father who's just been diagnosed with it (lines 961-969)
- P4: I think my little brother's very unhealthy like he loves cakes, you know sugary stuff, anything like that but (.) um everyone else you know as as you get older you realise because I was like that when I was smaller as well cuz (.) but when you get older you understand that you know I need to eat moderately and
- INT: yeah
- P4: so I think if he get's older he'll understand for himself but it's just (lines 718-725 YPFG2)

Participants explained that older siblings and family members should be looking after themselves as they were older and therefore wiser. They were less anxious regarding their health and diets. Yet they felt inclined to be more responsible and apprehensive for younger siblings and children. As the participants were older they could advise the youngsters to look after themselves. It's almost like their right as an older sister. Some participants felt that this was a phase youngsters go through and as they grow up they will become less unhealthy.

5.3.7 England v Pakistan

5.3.7.1 Pakistan living better

The majority of the young participants believed that it is better for your health to live in Pakistan. The first reason given for this was that in Pakistan the diet was better.

P5: I think I think it could do because obviously there's er (.) they kind of the kind of food intake in Pakistan or in India is a lot different to what you have here (lines 102-104 YPFG2)

P5: even if you go there now they have like pizza hut and they have [all those kind of things]

P4: [they do yeah they do]

P5: its just not as erm

P4: common

P5: as it is common it is here

P4: but here you go shopping and you think oh I'm hungry let's just go and pop into I don't know erm

P5: takeaways yeah you just think oh yeah

P4: and then you just get it but with Pakistan or whatever it's like we live in a village so you're gonna have to go further out

INT: yeah

P4: because of the distance as well it's a lot more difficult to get(.) the access to these places whereas they are easily available here yeah (lines 326-341 YPFG2)

P3: Yeah there's obesity

P2: Yeah

P3: there's the food that we eat.

P1: My aunties in Pakistan are a lot slimmer (lines 192-195 YPFG1)

P11: I think their diet changes as well when they're there (line 306 YPFG4)

The second explanation given for this was more activity and exercise.

P8: yeah but I think it's er (.) the stuff we eat hasn't changed like my mum still makes a curry and roti and stuff and dinner but I think like over there you work it off (lines 225-227 YPFG3)

P11: they're working in fields and working in the mills and

P9: chopping the crops up

P11: no they were really well my grandma

P10: yeah they use to say that 'you're lucky that you've got all these erm like sort of machines, machinery and technology and what not' and I think to be honest that has kind of affected how active we are, people are, because we sit back and let the machine do the work sort of thing

INT: hmmm

P10: back then obviously they were like really active everything was done by hand

P9: yeah

P11: yeah and the elders they don't get their illness until their 60 70 but now like our parents when they came here (.) they didn't spend most their lives

Group talk over each other inaudible

P10: like loads kids are getting like loads are like little kids have started getting diabetes

P11: and they're getting illnesses in their 20s early 30s (lines 863-881 YPFG4)

Lastly participants believed that Pakistan's lifestyle was better due to the weather.

P1: whereas like in Pakistan it's sunnier, it's hotter, she did like-my
aunty like she doesn't sit at home she wanders around, it's very
chilled out lifestyle (lines 253-225 YPFG1)

P10: yeah I think it's the warm sun cuz she feels a lot better either it's
Saudi or it's Pakistan she feels really a lot better (.) but

P9: hmmm for some reason (.) it's strange (lines 288-291 YPFG4)

Participants believed there are so many reasons for why it is better to live in Pakistan than England for your health. They assumed that the food was better and healthier. Although takeaways and fast food franchises exist in Pakistan they are more common in England. In Pakistan it is more of an effort to eat out especially the need to travel from villages into big cities whereas in England it is more easily accessible. Participants were under the impression that there was more obesity here as relatives in Pakistan were slimmer and fitter. They also believed that diet changes when people come from Pakistan to England. Participants believed people are more physically active in Pakistan than in England. People walked more in Pakistan, they did more manual work and more chores as they did not have modern technology to rely on. Participants expressed the view that Pakistanis living in England rely on machinery to do most of the strenuous housework e.g. Hoover and washing machine. Individuals who have diabetes much later on in life in general seemed to have lived healthier and more active lifestyles in Pakistan, yet in England Pakistanis are lazier and unhealthy causing T2DM along with other diseases to occur at a younger age. The consensus of the participants was that more diseases occur in England because of poorer lifestyles.

Moreover the weather seemed to be a big contributing factor to a better life in Pakistan than in England according to the participants. Participants believe that people went out more, were happier and more relaxed. In England Pakistanis are reluctant to leave the house especially if the cold weather will have an effect on their health or body. The hot weather in Pakistan is believed to be exhilarating and has a positive effect on people's outlook.

Participants had witnessed for themselves the improved attitudes, behaviours and lifestyles of people travelling from England to Pakistan. They supported the notion that when family members went back to Pakistan their diabetes improved.

P9: it's like my grandma she's got diabetes (.) she's when she's here she's always ill but when she goes Pakistan she feels a lot better

P10: hmmm

P9: so that I've heard a few people in those cases

P10: yeah that's so true (lines 276-281 YPFG4)

P1: but she's the youngest out of all her sisters and like you know (.) her sister in Pakistan she will get up in the morning, she'll have a bath, change her clothes, go out for her walks, erm talk to people, my mum is socially withdrawn as well so with her there's a lot of other factors whereas if I look at my aunties (.) even though they don't have English and they don't have loads of education they still feel like you know I can go for a walk and feel good today

INT: So do you think if she was in Pakistan your mum, do you think she would be like your auntie? Or do you think she would be the same?

P1: I think she would be more like my auntie if she was in Pakistan because whenever she even dreams its set in Pakistan (lines 831-843 YPFG1)

P1: erm (.) and I think like when she does go over there (.) erm (.) she stops taking like she's not suppose to stop taking her medication but she stops taking her medication and for a couple of months she's fine

INT: hmmm because she's probably more active there

P1: yeah

INT: probably more [happier yeah]

P1: [happier yeah] just happier (lines 852-858 YPFG1)

Whether this is possible or not, the participants clearly felt that older people live better quality of lives in Pakistan compared to England. As their health improved so did their diabetes.

However a minority of participants disagreed:

P11: I wouldn't think so

P10: I don't think it makes a difference

INT: ok

P9: it doesn't matter where you are (lines 214-217 YPFG4)

These few participants believed that it didn't matter where you lived. You can get diabetes wherever you are. But the participants did agree that the lifestyles of Pakistanis in England are more highly stressed than those in Pakistan.

P1: yeah in this country I think the lifestyle here is pretty highly stressed (lines 1210-1211 YPFG1)

P4: I think you're exposed to a lot more pressures (line 106 YPFG2)

Participants may be generalising their own personal views on other Pakistanis and generations. Previously participants mentioned that the older generations try to preserve culture. Another example of this given by participants was how individuals try to adapt their lifestyle here according to the way they lived it in Pakistan. The Pakistani lifestyle is not only familiar to them but was part of a time when their health was at its prime.

P1: ...she's diabetic, she goes for walks, she's got erm she's basically tried to make her lifestyle as much like Pakistan as she can

INT: hmmm

P1: because there they use to work the land, they grew up working the land erm so here she's got an allotment (lines 1106-1111 YPFG1)

P8: ...but she thinks it's because ,like they're envir-environment they were brought up in was like completely different different like they use to have fresh vegetables and stuff, live in the fields

All agree: yeah

P8: erm it's a completely different scenario that we live in Birmingham city centre, the air is not exactly

P6: yeah

P8: treat yourself clean yeah so she just thinks because she's like use to being grown up in an open country village and stuff she thinks that you know you should live like that still live like a pure natural like and anything you eat like everything with additives in it and stuff is gonna add up (lines 152-164 YPFG3)

It is hard to try and adopt the Pakistani lifestyle in England but as proven by participants it is not impossible. Family members are trying by being more active and cooking in the traditional Pakistani way. Another reason why participants believed that living in Pakistan is better was because they cannot afford the luxuries that they indulge in England.

P2: Yeah and it's because in Pakistan where we live you can't afford the things we can afford here you know we can buy anything whatever go to the shop 20p, 30p, 40p

P1: Yeah and then

P2: and we can afford it but they can't so much afford things there I think we put a lot of salt and a lot of fat in our food but although they make the same food there they put so much less in because they haven't got as much which is why their diet although is exactly the same as what they eat the names of it, what they actually put in it is different (.) I think anyway (lines 196-205 YPFG1)

P5: people living in India and Pakistan can't (.) they can't really afford (.) even if they wanted it they wouldn't be able to go out and get chocolate or biscuits or stuff like that hmmm here it's like

everyone's shelves are like stocked with loads of sugary food and all the [fat stuff so I think it's easier] (lines 111-115 YPFG2)

- P11: especially like the people who live in the small villages and stuff
P10: [yeah]
P9: [yeah]
P11: it's gonna depend
P9: even if it's not in the villages its Pakistan at the end of the day
P11: that's how I see it
P10: it's like erm like money-wise and stuff they're sort of stranded for like
P11: and it can be
P10: medication
P11: yeah the big hospitals especially in Islamabad or the big cities it's kind of a distance to go all the way (lines 246-259 YPFG4)

Everything from food to medication costs in Pakistan and getting necessities from the big cities to the small villages can be problematic according to some participants. As mentioned earlier the traditional foods consumed in England and Pakistan are the same in name but the quality of ingredients are different. The presumption was that foods are fresher and not as readily available in Pakistan. Older generations would have eaten healthier versions of the traditional meals made today in the UK because of the quality of the ingredients and their usage. However a few participants disagree:

- P4: I don't think diabetes is linked with the poor issue, with the biscuits and stuff because I know quite a few people in Pakistan like they are quite poor and they have diabetes and it's not e:r I don't think that's due to dietary requirements so I don't think its necessarily (.) you get it more if you live in this country or whatever (lines 122-127 YPFG2)
- P3: With the type 2 diabetes it probably is more common here but I think that things are changing (lines 206-207 YPFG1)

This minority of participants expressed their opinion that T2DM is not linked with the poverty issue. T2DM can occur in anyone anywhere. They expressed that although diabetes is perceived as more common here in England this may no longer be the case. There are individuals in Pakistan who also have T2DM and the developments in the country may prompt a significant change.

5.3.7.2 Herbal remedies

As a result of maintaining Pakistani culture many Pakistanis explore herbal alternatives to managing many illnesses including diabetes.

P11: oh yeah you've heard of herbal treatments

P9: you know what herbal treatments are the best I love my herbal treatments

Group laugh

P10: my mum does read up on a lot of like herbal treatments but I don't think we've actually sort of like practiced any I mean we've read up on them definitely (lines 1052-1058 YPFG4)

P10: my mum here went to a hakeem like you know for cholesterol and like he gave her some tablets and she like some sort of tea thing to make and stuff and she's been taking that regularly now so (.) and she does do like this ginger and cinnamon kawa thing at home

Group laughs

P9: I was saying like when I've got like stomach pains or if or like er (.) time of the month or [stuff I'll get my mum to make it]

P10: [so for cholesterol she has but] (lines 1075-1085)

P9: [I think they're more natural so it's] not gonna harm you so I see it as ok it's not gonna harm you so there's

P10: if it works it works if it doesn't it's not doing you any harm sort of thing like with these sort of medications you know it's helping you once but it's the amount of side effects that come with it it's like cuz she was taking the tablets for cholesterol and she was like she absolutely hated it because she has no energy left at all and stuff and then she started this whole er (.) tea thing and she feels a lot better and she does it on a daily basis now (lines 1102-1112 YPFG4)

Some participants touched on how Pakistani culture promotes the effective use of herbal remedies as an alternative to western medication. Even some younger generation Pakistani females preferred to try it. Many Pakistanis living in England had at least researched herbal alternatives for illness even if they didn't try them. P10 gave an example of how herbal remedies aided her mother's health and wellbeing. Her mother preferred it to her prescribed cholesterol tablets as she felt more energetic and benefited as a result. Herbal remedies are perceived as containing 100% natural ingredients and not to have any adverse side-effects that many western medications do. This may explain why some Pakistanis do not take their

medication when they go to Pakistan. As well as the better lifestyle and weather they may opt to try herbal alternatives to their regular medication.

P9: actually my dad went—he went Pakistan last year or was it the year before? Er he bought some tablets from Pakistan and they were actually working a lot better (lines 1065–1067 YPFG4)

5.3.7.3 Healthcare better in England

Participants agreed that although the lifestyle in Pakistan is better the healthcare provided in England is more enhanced.

P10: Yeah (.) yeah so he's sort of like (.) like (.) I always think Pakistan obviously with the medication the problem with that as well he's not getting the full sort of treatment that he should could get here (lines 236–239 YPFG4)

P9: but I see it even if it is Islamabad it's still Pakistan at the end of the day (.) treatment

P11: yeah obviously

P9: there's a different between the treatment we get here (lines 263–266 YPFG4)

P11: see I'm still wary now I'm still quite wary about that I just like to have your normal prescriptions and your normal medicines (lines 1096–1098 YPFG4)

Some participants supposed that the medical treatment offered in England is better as there are more options and choices, and medication is prescribed and certified. There is a stigma that Pakistan is a poor developing country therefore cannot afford nor provide the best treatments available. Diabetes care and management may not be a result of the country's financial situation rather the poor lifestyle behaviours adhered to by T2DM suffers. Participants expressed that one of the biggest obstacles that the healthcare service faces with the Pakistani community is poor attendance rates.

P1: and what she hates more than the diet is having to go to the doctors to have her blood test taken, to have her weight done, to you know for all of this medication, and the side effects from the medication. (lines 448–451 YPFG1)

P10: Hmmm to be honest with you my dad really sort of avoids his appointments and stuff

P9: yeah

P10: I think he (.) I mean it's there cus they're constantly ringing and saying you know 'he needs to come in and see you' and stuff and we're like 'dad you need to go in' but he really sort of avoids it as much as he can (lines 963-969 YPFG4)

Participants emphasised that older Pakistanis do not like going to visit their GP surgery. In general many people do not like to go to the doctor however this is an added pressure on the NHS when it comes to promoting diabetes care and management among Pakistani sufferers. There are a lot of expectations on the healthcare system in England.

5.3.7.4 Role of the NHS in prevention and management

Participants believed that there is a lot that can be done to provide adequate information and care for diabetes.

P3: to educate them about why they've got it, or what they should be doing, and if they need help if (.) like your mum she's quite dependent on you lot but if there's nobody for them to depend on the health service should be providing that kind of care. (lines 866-870 YPFG1)

P2: Dieticians (.) erm like maybe erm people that (.) personal trainers and things, you know like they have that prescribed exercise places-I know my mum got offered a place on one of them ages ago [for free]

P3: [even
in]conjunction with the cohorts maybe

INT: ok

P2: maybe if they haven't got anyone to be dependent on some kind of nurse or care worker comes into help them with injections if they need injections and things (lines 874-882 YPFG1)

P4: Erm (.) obviously like because erm you know a lot of people even though who are older generation-they don't know English properly so it would be helpful if they got the help that they needed so more explanations

INT: uhmmm

P4: erm on like on what to do to help them stop cuz with my granddad and my grandma because they don't know English I don't know I think they skip corners sometimes like you know she'll let him have it but I think if she knew more about it like you know what kind of effects it could have in the long run then she would obviously be more careful (lines 425-435 YPFG2)

P5: ...obviously my grandma didn't understand full erm you know everything all the details but most of it you know they'd understand and I think they just need to know like-ok you read the leaflet >and it's like don't eat this, don't eat this, don't eat this< but li:ke (.) Asian

people need it you can't especially my granddad he couldn't live without all those things so I think to know how to limit it and like

INT: right

P5: erm say 'ok (.) this is how much of I don't know sugar you can have everyday' or 'this is how much you need', I think if you have it broken down for the individuals differently because obviously everyone's different and everyone has different levels of diabetes and stuff (lines 442-455 YPFG2)

P4: j-just someone to talk to like counsellors and stuff

P5: yeah

P4: they'd be very helpful because who know Asian people they don't really like to talk to other people they don't know it's just in the family and it becomes quite difficult so (.) er counsellors probably, more help

P5: I think yeah Asian people just don't talk to people about anything

P4: they don't (lines 465-473 YPFG2)

P5: erm (.) and also if like (.) I think when you when you're first diagnosed with it like I'm not being racist but it's when it's someone who's not your own sort of-if it's an Asian person being diagnosed, if it's not an Asian doctor I think like my grandparents would find it harder to talk to them to explain our lifestyle and I think think other people don't get it

INT: yeah

P5: so if it was like someone who understands you it would be easier and you would feel more free and open to talk to them about stuff like that (lines 576-586 YPFG2)

Participants expected healthcare services to provide better education for Pakistanis to highlight how and why they need to change their behaviours and habits as well as explaining the direct benefits and potential risks. They need to provide support for T2DM individuals who are not independent and do not have any immediate family to rely on. Some participants believed that the healthcare service should have multidisciplinary teams involved in T2DM care and management especially for older illiterate British-Pakistani women and offer all services available such as '*exercise on prescription*'.

One of the main obstacles for the health service to overcome is the language barrier especially between health professionals and the older Pakistani generation. Participants expected efficient support from bilingual medical staff that are competent in providing effective information in the different community languages for Pakistani diabetics and

tailoring programmes to individuals as people are different. This would also aid effective communication between the health service and Pakistani patients as the patients will feel more comfortable conversing in their own language and helping them to fully understand the care being provided. Participants assumed that it will also encourage the older generation to talk freely and confidentially to an outsider who is not a member of their family or friend. Participants went on to illustrate their dissatisfaction for the NHS in England.

P9: but I don't think we get enough support from the NHS (.) it's like ok they take into consideration the illness but I don't these nurses, the NHS secretaries, I don't think our support is what it should be (lines 915-918 YPFG4)

P9: I like I mean I've got personally a long term illness and I don't feel as if I've been supported enough to help me with my health

INT: hmmm

P9: it's like ok you come in for your check ups and that's it go home

INT: that's it yeah

P9: what you gonna help me with think-well oh (,) 'take your tablets and you'll be fine' and then but at the same time 'don't take your tablets because in the long term it's gonna affect you'

INT: yeah

P9: so if I can't take them when I am suppose to take them what am I suppose to do? (lines 923-936 YPFG4)

P10: I don't know sometimes I think it's on the day sometime you think you know they're there for you but you know what they're not doing anything (lines 982-984 YPFG4)

P8: diabetes informa-like thinking about it cuz you're asking me these questions you know how like the governments like released these campaign posters and stuff like get fit initia-you know be more active like (.) erm don't drive to work walk

P6: yeah

P8: cuz you don't wanna get fat or reduces your risk of CVD's and stuff like that, they don't actually talk about diabetes much considering it effects such a large portion of the population (lines 570-577 YPFG3)

P2: if I wanted to go and find out just me avoiding the topic that I know is quite-its gonna tell me to change my diet but if I wanted to find out about diabetes it wouldn't be hard for me to go and find out about it, go on the internet, leaflets, books, I could go speak to someone, I could call NHS service up or whatever I could find out very easily but if my mum wanted to know what diabetes is it would be ten time harder for her because she doesn't speak a word of English (lines 1338-1345 YPFG1)

Participants stated that there is a lack of support from the NHS. Health care professionals are available medically but do not offer the moral nor psychological support to cope with illnesses. Specific to diabetes they felt that it is under-publicised though it is a huge national problem. The support is missing to enhance T2DM's profile. Participants felt that there is a need for clarity especially regarding medication for chronic illnesses, and the need for consistency in support that should be on hand. Again participants emphasised the lack of support available for an older Pakistani with a language barrier issue. Participants suggested the need to utilise the internet more especially to reach out to youngsters.

P2: I was gonna say the language barrier not for doctors and for leaflets and [something on the internet because if I wanted to find out what diabetes is I could do that easily] (lines 1332-1334 YPFG1)

P4: Ah the best place I'd look is [the internet]

P5: [the internet] yeah

INT: yeah

P5: it's the first place I'd look-go (lines 591-594 YPFG2)

These comments suggest that the internet is a very powerful and effective tool of which the NHS should take full advantage. Participants also go on to make other suggestions for improving the support and care provided to T2DM Pakistanis.

P6: I don't know you know like they have like blood drives and stuff and how like they get people standing in town and stuff and just like (.) not preaching you but kind of like like telling you about it

P7: yeah

P6: advantages and disadvantages, how it can help, and (.) I think if they did more stuff like that like just actually raise public awareness like (.) they're doing it but it's not hitting home (lines 810-818 YPFG3)

P4: No no I was just about to say that you know with smoking and strokes and stuff

P5: y:eah

P4: there's advertisements but there's nothing to do with diabetes so I think erm for young people there should be more things out there especially Asian people

INT: so raising awareness?

P5: yeah yeah

P4: yeah like cancer and stuff I mean its (.) I know it's not the same but they're still you know

P5: yeah (.) yeah but there's so much more awareness and so much more research in that you know cancer research and all those things and erm (.) you don't really see anything for diabetes I think (lines 601-614 YPFG2)

P8: maybe like going to the younger generation like we are here like you said about diabetes a lot more younger people are getting it
INT: uhmmm
P8: so I don't know I mean in Unis and schools and things like that but then (.) I don't know to do an actually general get fit like why aim at obesity? Why aim at diabetes? Because then technically they come from this but the root is exactly the same so just to make it into general you know we all claim about how we are all getting fat and we're all whatever, just make it into a general get fit campaign and then use those 2 for 1 deals and free memberships and whatever just make it into a general (.) you know like a healthy
P6: and if they wanted to target like specifically like South-Asian communities they could they could like put erm (.) like a national campaign advert to one of like the most watched Asian TV channels like STARPLUS
P7: yeah that's it
P6: if they just put it between like (.) two series at 8 o'clock I guarantee you half the Asian women in our community will watch it
P8: but they do that I've seen quite a few debuts and they have it in Urdu and everything (lines 832-854 YPFG3)

All the participants across the focus groups made similar remarks regarding raising awareness. Participants suggested improving public awareness through health campaigns, in academic institutions and advertising it on television. Participants suggested getting people more involved in explaining the implications and benefits. Incorporating it in with existing health campaigns as T2DM is linked with other health conditions. There is also a need for specific T2DM campaigns for Pakistanis being affected by T2DM in order to target the prevalence and implement prevention strategies. More research is also needed and the dissemination of this research is vital to demonstrate that T2DM is a serious disease. Again the language barrier was emphasised for the older generation and suggestions were made on advertising on popular Asian television networks as well as other popular channels in general. For the younger generations participants thought it would be a good idea to incorporate it into schools and universities either as awareness topics or as part of the curriculum. There was great enthusiasm generated regarding ideas on how to promote T2DM awareness and how the NHS can be improved. However there were a minority of participants who voiced support for the NHS.

P2: Well I think if you're at risk the doctors and things do try and tell you right but if you're not really at risk (.) they don't really like

(.) te:ll I don't know I don't I think we rely a bit too much on the health service sometimes I mean we should just know these things really but erm (lines 1298-1302 YPFG1)

P1: I think the health service has so many constraints at the moment but with my mum they did play a big role... I think sometimes the onus is as much on you as it is on somebody else but it terms of raising awareness it is the (.) you not knowing you know what diabetes is (lines 1308-1325 YPFG1)

P8: To be honest I just think a pamphlet (.) cuz I know they send out like erm like my aunt's a nurse so I know she like like they'll talk to you about altering your lifestyle but at the end of the day they can't really make you do it

P6: yeah it's true

P7: hmmm

P8: it's just providing information I think (lines 591-597 YPFG3)

P6: yeah I don't think there's that much out there but then it's that kind of like (.) like where you can't (.) like what can you really give someone who's got diabetes? All you can do is advise them on how to change their lifestyle and then ultimately it's up to them to do that you can't like (.) you know (lines 605-610 YPFG3)

P11: I think we can be negative but I do think they are they can help

P9: they are there but

P11: I do you know we always like all negative on the NHS

P9: but it's up to you kind of thing (lines 977-981 YPFG4)

P11: imagine if they weren't there at all what would you do? Do you know what I mean (lines 988-989 YPFG4)

P9: I'm quite comfortable with my GP, I don't think I would go to my parents I would go to my doctor and say like 'doctor this thing' yeah I would definitely go to my doctor

P11: I would actually go and talk to my family as well my-me and my dad are really close so I would actually tell my mum and dad

P9: I'm really close to my dad and I would tell him but instead of like worrying them first I'd go to my doctor, get the advise, and then come home and say 'dad look this is' (lines 994-1001 YPFG4)

P11: you do go to you GP and see the leaflets lying around and you can pick the leaflet up

P10: you can do it yourself and read up on it and stuff (lines 1009-1011 YPFG4)

These participants felt that society is too pessimistic and negative on the health service in England. Participants acknowledged earlier that they had control therefore ultimately it is up to the individual to change their unhealthy ways. The NHS needs to support this and there are current campaigns available but more can be done. However there is only so much that

the NHS can do to raise awareness and implement prevention strategies. It is the people who need to take responsibility and change. Participants admitted earlier that living unhealthy lifestyles is up to them and their parents were not at fault if the worse was to happen. Just as parents regularly encouraged them to be healthy so should the NHS. However it should not be perceived as the fault of the NHS if someone is diagnosed with T2DM. It rather maybe thought that younger Pakistani generations need to take control and find out about diabetes especially as it is so common in their community, and there are many national health campaigns that they can opt in to. However the decision is theirs but as participants had made clear earlier on they do not want to change. They want to carry on living '*life to the max*' and deal with the illness when they are faced with it.

5.4 Discussion

5.4.1 Introduction

Young British-Pakistani females believe that there are many T2DM causal factors and they perceive it to be a disease of old age which is inevitable among Pakistanis. They recognise that their lifestyles especially their diets are poor but they enjoy their carefree blasé lifestyles and will deal with T2DM development when/if it happens. They would be more concerned if a younger person developed the disease rather than an older person and are more inclined to be worried about the younger generation's health. These participants believed that food is a pivotal part of Pakistani culture preserved through celebrations, and that living in Pakistan rather than England is perceived to be better however the healthcare and diabetes campaigns are not.

5.4.2 Basic knowledge and awareness

This study found that young British-Pakistani females have basic knowledge regarding T2DM generated from what they have seen and heard from family and health campaigns. This supports Neuman's (2006) research that knowledge is gained from authority figures, tradition and media. Young British-Pakistani females highlighted various causes of T2DM and understood that this disease is due to several factors in conjunction with one another rather than a single cause. Genetics was a significant factor although a minority of participants did not identify genetics as a causal factor as nobody in their immediate or close family had a T2DM diagnosis. Participants were able to draw a distinction between their personal risk which they identified as lifestyle factors and genetics as a risk factor for the general British-Pakistani population. In general young British-Pakistani females identify the key causes of T2DM ranging from environmental, lifestyle to biological factors. A key psychological

concept credited as a causal factor as well as a product of T2DM was stress (Walker, 2006). Participants also believed that T2DM can either occur due to developing another illness or is part of a ripple effect contributing towards other diseases especially CHD, which is supported by previous research (Chowdhury & King, 2007; Whincup, Gilg, Papacosta et al., 2002).

5.4.3 Unhealthy diets

Chocolate was an essential part of young British-Pakistani females' diets as well as an unhealthy intake of sugars, which is frowned upon by some parents especially mothers. Participants explained how they did not eat regular meals instead they snacked a lot especially during the day and will then go home to eat a home-cooked meal. This is supported by Bourcier, Bowen, Meischke and Moinpour (2003) who found that parents bring home healthy foods, make healthy dishes and tried to set a good example. As the participants in this study seem not to be affected by the high volumes of sugar intake they perceived nothing wrong with their diet at their stage of life. Being diagnosed with T2DM would mean they would have to give up sweet sugary foods as their generic understanding of T2DM from a Pakistani point of view was that T2DM is about sugar. Older generations refer to T2DM as sugar therefore subsequent generations also recognise T2DM as sugar. It's a universal term used among Pakistanis (Luyas, 1991). Young British-Pakistani females blamed their lifestyle on a number of reasons such as being too busy and junk food being cheap and convenient.

5.4.4 T2DM responsibility of mothers

Participants conveyed that it is the mother figures of the household who cater for the diabetics in the family who are mainly male, as well as everybody else (supported by Lawton, Ahmad, Hanna et al., 2008). This has encouraged them to cook healthily for the whole family rather than making several dishes. However participants stated that mothers cooked

healthily to maintain general good health or to lose weight, not to prevent diabetes in the household. In accordance with the findings of the previous study (chapter 4) British-Pakistani mothers are at the forefront of familial responsibilities and it is up to them to control the diet of the family especially those with T2DM diagnosis.

5.4.5 Inevitable disease of old age

This study found that young British-Pakistani females believed that T2DM is a very common disease among the older Pakistani generation. It is an inevitable disease of old age for Pakistanis. Many older overweight Pakistanis develop the disease hence why participants labelled obesity and being overweight as one of the causal factors of T2DM. This may explain why younger female Pakistanis are choosing to live and indulge in carefree student lifestyles as they do not believe they are old enough to develop this disease. Participants believed that control of T2DM varies among the Pakistani community as there are some who look after themselves and those who rebel. Participants expressed that they would find it harder to change their dietary habits due to the amount of junk and binge eating they do however the older generation prefer organic and fresh meals. Participants also implied that the older generation have been brought up in a different culture and society back in Pakistan, and as they have been brought up here in England they have been exposed to unhealthy habits from childhood. Lawton, Ahmad, Hanna et al. (2008) support this as they found that South-Asians acknowledge their food can be detrimental for their T2DM. Participants recognised that the main problem for the older generation is lack of exercise.

5.4.6 Traditional Pakistani food

Traditional Pakistani cuisine is a vital part of the Pakistani culture for all generations. Participants believed that the older generations cannot live without their traditional Pakistani foods indeed neither could many young Pakistanis especially males. Another reason traditional Pakistani food is pivotal to the Pakistani culture is because participants believed

that it is a significant part of their celebrations (Lawton, Ahmad, Hanna et al., 2008; Hawthorne & Tomlinson, 1999). Participants acknowledged that they freely enjoyed themselves and over-indulged during celebrations yet diabetic family members still needed to show restraint and were encouraged to do so by loved ones. Participants expressed that there are a lot of alternative choices for people with diabetes to enjoy. Food is being marketed and being made readily available as the T2DM disease is becoming more common. Although celebrations and everyday life do differ there is an unclear boundary between everyday life and celebrations as there is unrestricted access to chocolate and junk food. Similar foods are eaten on a daily basis whether for celebrating or treating one self.

5.4.7 Ambivalence

Young British-Pakistani females are aware of the seriousness of this disease yet do not seem to be affected by this. As a result the young generation has become desensitised towards this disease. Most participants expressed feelings of being upset and worried to be diagnosed with the disease at such a young age. They felt that it would down grade their quality of life making them feel '*like a freak*'. Participants believed that their immediate family members would be very distressed too. Some participants thought their parents may feel guilty as they are responsible for the diet in the household. They acknowledged that it was not their parents fault if something was to happen as ultimately it was their decision to eat what they wanted and behave the way they did. Participants went on to illustrate that although there is a need to be consistent with lifestyles to control T2DM they would probably be back to their old ways in no time.

5.4.8 Healthier living in Pakistan

Young female Pakistanis believe that it is better for your health to live in Pakistan than the UK as diet is better, there is more activity and exercise, and Pakistan's lifestyle is better due

to the weather. This is a common misconception (Lawton, Ahmad, Hanna et al., 2008). In England Pakistanis are reluctant to leave the house especially if the cold weather will have an affect on their health or body. The hot weather in Pakistan is believed to be exhilarating and has a positive effect on people's outlook. Participants had witnessed for themselves the improved attitudes, behaviours and lifestyles of people travelling from England to Pakistan.

5.4.9 Healthcare service expectations

There are a lot of expectations on the healthcare system in England. Participants felt that T2DM is under-publicised although it is a huge national problem. Participants felt that there is a need for clarity especially regarding medication for chronic illnesses, and the need for consistency in support that should be to hand (supported by Diabetes UK, 2010). Participants suggested the need to utilise the internet more especially to reach out to youngsters, and improving public awareness through health campaigns in academic institutions and advertising it on television. Chew, Palmer, Slonska and Subbiah (2002) reported that a health promoting television series can increase health knowledge and enhance health beliefs in turn contributing to healthy behaviours. The internet is a very powerful resource which can be used by researchers to reach out to people (Markham, 2004). More research is also needed and the dissemination of this research is vital to demonstrate that T2DM is a serious disease. There were a minority of participants who voiced support for the NHS believing society is too pessimistic on the health service in England. There is only so much that the NHS can do to raise awareness and implement prevention strategies. It is the people who need to take responsibility and change.

5.4.10 Conclusion

Despite low recruitment numbers invaluable rich data was collected from the focus groups. They discussed and shared various beliefs and the analysis has led to vital exclusive

findings. The participants represented an educated group of young British-Pakistani women who were living at home while studying an undergraduate degree course. They may possess more knowledge regarding T2DM due to their level of education compared with similarly aged British-Pakistani females not in education. As they were all living at home their eating patterns may differ from undergraduate students who are living away from home. However this group clearly represented that many British-Pakistani females chose to live at home whilst studying whether this is due to cultural factors or personal choice.

The main findings of this study are similar to the previous study. Therefore it would be fair to say the British-Pakistanis in general recognised numerous causal factors of T2DM, believe it is a common and inevitable disease, have many lay beliefs regarding the disease and its treatment, believe food is a vital part of Pakistani culture and lifestyle, and there is a lot the health service can do regarding prevention of the disease but ultimately it is up to Pakistanis to live healthily and prevent it. British-Pakistani mothers need to encourage and enforce healthy living as they are the main cooks of the family and youngsters need to make the right choices to live healthier lifestyles. Dietary and physical activity patterns are changing between the generations as younger and middle-aged British-Pakistani females are being more active and healthier compared to the older generations although this is not to prevent illness but to be slim. The perceptions and beliefs of British-Pakistani women fit with the ideologies of the PMT and CSM. The next study conducted was a quantitative survey to generalise these results and the results of the previous study. However before this study, the next chapter will compare in depth the results of the two studies so far across the three participant groups highlighting the differences and similarities leading on to devising an appropriate survey tool for the final study.

Chapter 6

Synthesis of Qualitative Studies

6.1 Introduction

The purpose of this chapter is to bring together the findings from the previous two studies (in chapters 4 and 5). It is important to highlight the differences and similarities between the three different participant groups (British-Pakistani mothers with T2DM, British-Pakistani mothers without T2DM and the young British-Pakistani females) in order to understand British-Pakistani women's perceptions and behaviours towards T2DM and learn about any preventive measures enforced by them. The data will also be used to devise an effective and perception-specific survey tool. This tool was used in the final study (in chapter 7) with the IPQ-R to determine whether these groups' illness perceptions can be generalised.

6.2 Theme comparison

6.2.1 Overlapping themes

Table 6.1 illustrates the main themes which emerged from the qualitative studies. Themes that are lined together in the table represent overlap between themes from the different groups. These themes complement each other as the discussions were very similar and share similar findings. *Student lifestyle* theme from the young British-Pakistani focus groups was the only theme that was different from the British Pakistan mother groups. This is because they specifically discussed issues relating to their lifestyle of being a student which differs from the mothers in this project who are more responsible for the families.

T2DM mothers	Non-T2DM mothers	Young females
Causal factors and symptoms <ol style="list-style-type: none"> 1 Biological factors 2 Gestational diabetes 3 Symptoms 4 Genetics 5 Bad diet 6 Lifestyle factors 7 No single cause 8 Impact of other illnesses 9 Psychological factors 	Causal factors and symptoms <ol style="list-style-type: none"> 1 Biological factors 2 Gestational diabetes 3 Symptoms 4 Genetics 5 Bad diet 6 Lifestyle factors 7 Being overweight 	Illness representations <ul style="list-style-type: none"> • Sugar • Exercise • Multiple causes • T2DM and other illness • Stress
Management/control <ul style="list-style-type: none"> • Food and herbal remedies • Family control via diet 	Lay beliefs & attitudes <ul style="list-style-type: none"> • Misconceptions • Better living in Pakistan • Worsening one's own health • Old age disease • Common disease • Deal with it when it happens 	Older generation & *England v Pakistan <ul style="list-style-type: none"> • *Herbal remedies • *Pakistan living better <p>Old age disease</p> <ul style="list-style-type: none"> ○ Lack of exercise in old people ○ No fasting
Moral support & social influence <ul style="list-style-type: none"> • Moral support from family • Family hindrances • Hindrances from friends • Health service support 	Moral support & social influence <ul style="list-style-type: none"> • Moral support • Family hindrances • Hindrances in the form of friends • Healthcare service expectations • • Junk food • Increasing awareness 	*England v Pakistan <ul style="list-style-type: none"> • *Healthcare better in England • *Role of the NHS in prevention and management
Emotions <ul style="list-style-type: none"> • The norm • Negative emotions • Concern for their children • Disease severity 	Negative emotions <ul style="list-style-type: none"> • Concern and distress • T2DM diagnosis in children • Severity 	Knowledge & emotions <ul style="list-style-type: none"> ○ Negative feelings ○ Self-control ○ Severity and risk
Pakistani lifestyle <ul style="list-style-type: none"> • Chronic illness • Better management in Pakistan • Pakistani food • T2DM prevention in children • Lack of exercise • Traditional food pivotal part of celebrations 	Pakistani lifestyle <ul style="list-style-type: none"> • The right food at the right time • Lack of exercise • Celebrations and traditional foods 	Traditional food <ul style="list-style-type: none"> • Pakistani cuisine • Food and celebrations

T2DM mothers	Non-T2DM mothers	Young females
		Student lifestyle <ul style="list-style-type: none"> o Chocolate and other sugary snacks as part of diet o Mother's role o Friendship/group culture o Being healthy is expensive

Table 6.1 Comparing qualitative themes across the three different study participant groups
 *England v Pakistan subthemes overlapped with different subthemes from two super-ordinate themes from T2DM mothers and Non-T2DM mothers datasets

There is a generational difference between the three participant groups. Though there were overlaps, mothers with T2DM represented an older generation (age range 35-50 years), mothers without T2DM represented a younger generation group (age range 25-40 years), and the young women represented the youngest generation group of adults (age range 18-26 years).

6.2.2 Causal factors and symptoms and illness representations

British-Pakistani women believed there are many causal factors of T2DM and there was a consensus that lifestyle factors are crucial to maintaining good health and diabetes control. British-Pakistani mothers discussed single factors in turn whereas young British-Pakistani females highlighted various causes of T2DM and understood that this disease is due to several factors in conjunction with one another rather than a single cause. British-Pakistani mothers with T2DM's knowledge regarding causal and explanatory factors were mostly based on experience rather than medical knowledge. The knowledge of both British-Pakistani mothers without T2DM and young British-Pakistani females was also based on experiences not of their own but rather of family members suffering from the illness, complementing previous research that many people have experiences of close relatives suffering from T2DM and this recognition influences their own view of the disease (Hornsten, Sandstrom & Lundman, 2004). All three groups identified stress as a key psychological causal factor (supported by Walker, 2006). The three participant groups believed hereditary and genetic factors play an influential role. They also acknowledged that T2DM can either

occur due to developing another illness or can be part of a ripple effect contributing towards other diseases which is complemented by previous research (Chowdhury & King, 2007; Whincup, Gilg, Papacosta et al., 2002).

Being overweight was seen as a significant causal factor amongst non-T2DM mothers and the young females however this was not mentioned nor raised among T2DM mothers. Many of the females without T2DM pictured someone with T2DM as being an overweight older Pakistani woman. The majority of the T2DM mothers who took part in the focus group were not large and therefore may not class themselves as being overweight thus explaining why they did not discuss being overweight as a causal factor. This also reflects the research which has been conducted on Pakistani women having a diagnosis of T2DM at lower BMI rates compared with British white (Ehtisham, Crabtree, Clark et al., 2005, Banerji, Faridi, Atluri et al., 1999) and compared to older British-Pakistanis women who came into the UK after getting married (Pollard, Unwin, Fischbacher & Chamley, 2008).

All the participants emphasised their belief that sugar is detrimental for individuals with T2DM. They highlighted that the Pakistani community label T2DM as '*sugar*' disease rather than diabetes, as they too referred to diabetes as '*sugar*' to clarify the disease they were discussing during the focus groups. Both the non-T2DM mothers and young females also explained how they did not eat regular meals instead they snacked a lot. Therefore T2DM mothers exercised more control regarding diabetes care and prevention especially among themselves and their families, whereas non-T2DM mothers emphasised lack of control over themselves but firm control over their family especially their children. Young females acknowledged they had bad diets and should do better but they were not motivated to do so.

An interesting finding of this study was that Gestational Diabetes is seen as another significant cause for many British-Pakistani mothers developing this disease. However this was not mentioned among the young female group. A reason for this could be that none of

the young females were married nor been pregnant, therefore were unaware of pregnancy-related diabetes.

6.2.3 Management/control, lay beliefs and attitudes, older generation, England v Pakistan

All three groups acknowledged herbal remedies or certain foods which were believed to help reduce and control T2DM. Mothers discussed this in more detail whereas the young females discussed certain elders they knew who used these alternatives.

There is no evidence to suggest that British-Pakistanis with T2DM negatively affect their own health (Finucane & McMullen, 2008) yet this was a very common lay belief across the three participant groups. Participants believed that living in Pakistan rather than England is better especially for one's health and the rates of T2DM are lower in Pakistan than England even though this is not the case (Pappas, Akhtar, Gergen et al., 2001; WHO, 1999). Pakistan is seen as a hot country with fresh food whereas England is portrayed as having an image of cold wet weather and junk culture. The hot weather in Pakistan is believed to be exhilarating and has a positive effect on people's outlook. All groups supported the notion that when family members went back to Pakistan their diabetes improved. Some of the participants expressed the belief that they would find it harder to change their dietary habits due to the amount of junk and binge eating they do however the older generation prefer organic and fresh meals and therefore it would be easier for them. However some of the participants acknowledged that it may be harder for the older generation to change especially the very elderly as they are more set in their ways and it is harder for them to change their habits. Therefore younger generations should be encouraged to change as it would be more manageable for them.

There was a common belief among non-T2DM mothers and the young females that T2DM is an older person's disease. It is now very common for British-Pakistanis as young as 40 years old to develop it, which was recognised by some of the mothers with and without T2DM. Across all the groups T2DM was perceived to be so common among Pakistanis that many view it as an inevitable old age disease. This could explain why younger female Pakistanis are choosing to live and indulge in carefree student lifestyles as they do not believe they are old enough to develop this disease. Therefore health professionals have a hard job in trying to encourage British-Pakistanis to adhere to preventative behaviours as many Pakistanis would rather deal with the problem later rather than sooner as they do not believe it is of relevance yet (Hornsten, Sandstrom & Lundman, 2004).

6.2.4 Emotions, negative emotions, knowledge and emotions

Participants perceived it to be a very serious disease. They were especially fearful and would be more concerned if children or people younger than them developed it rather than them, as T2DM was perceived as a chronic life-long condition (supported by Hjelm et al., 1999; Cohen et al.; 1994). However some participants expressed that they would not be surprised if they were diagnosed later on in life with diabetes. Participants believed that a young person being diagnosed with T2DM especially from within their friendship circles or among younger generations would be more tragic and have a more of an influence on them. They were less anxious regarding their health and diets yet they felt inclined to be more responsible and apprehensive towards younger siblings and children. Therefore using fear appeals (Witte & Allen, 2000) with reference to children in prevention materials could be an effective method. Most non-T2DM and young females expressed feelings of sorrow if they were to be diagnosed with the disease at such a young age. However this was not reflected by the T2DM mothers. Some participants thought their parents may feel guilty especially among the young female group however they acknowledged that it was not their parents' fault if something were to happen as ultimately it was their decision to eat what they want

and behave the way they do. Participants stated although there is a need to be consistent with lifestyle to control T2DM they would probably be back to their old ways in no time.

British-Pakistani mothers without T2DM expressed that if they were diagnosed with T2DM they would feel extra pressure and stress, it would make them anxious regarding looking after their family, it would make them change their ways which they seem reluctant to do, and would add extra responsibilities to their daily routines like extra cooking which they would resent. However this was not reflected among T2DM participants in fact their families were adhering to the same eating styles as them which was beneficial for the whole family. This was because they were the main cooks in their families. In contrast a study by Peel, Parry, Douglas and Lawton (2005) reported that women change the diet of the whole family when a man in the family has a diagnosis of T2DM, whereas if a woman has a diagnosis of T2DM she deals with it on her own for herself. However this study group consisted of 19 women and 21 men all of whom were British white except for one British-Pakistani woman. This indicates a potential cultural and ethnic difference between dietary management for T2DM within the family existing in the UK.

6.2.5 Moral support and social influence, England v Pakistan

British-Pakistani mothers acknowledged that they would receive a lot of moral support if they were diagnosed with T2DM from friends and family. This was complemented by T2DM mothers who stated that they gained a lot of moral support from friends and family regarding T2DM even children encouraged them to eat healthily. However all groups believed that sometimes family input and influence could be a hindrance in promoting the healthy living process especially grandparents who just want to spoil their grandchildren, as well as lack of spouse support. They recognised that T2DM control and prevention involves the whole family and this has clear influences on social life (Finucane & McMullen, 2008; Ellison & Raymond, 1998). As many Pakistanis live with extended family it is appropriate to include them in future programmes (Smith, 1998).

British-Pakistani mothers understood why Pakistanis are at high-risk of developing T2DM, not only the genetic risk but because junk food is readily available in homes and it is these unhealthy foods that are used as treats. Therefore they believed that parents are to blame for children's bad eating habits. They should control them from a young age and not expose them to bad eating habits and unhealthy lifestyles. British-Pakistani mothers went on to place some blame on the media and local businesses too as they lure in parents and families to unhealthy ways of living. They went on to discuss using the media to promote and raise awareness. Young females agreed by stating that T2DM awareness campaigns should be aired on the Indian/Pakistani satellite channels to reach the Pakistani community. Another suggestion made by some of these young participants was using the internet especially to raise awareness among youngsters.

T2DM participants believed that the health service is clearly active providing support but it is not being effective. A support network was a suggestion put forward for Pakistani women to get together and discuss their diabetes. Young British-Pakistani females agreed the healthcare provided in England is enhanced compared to in Pakistan. These participants expressed that one of the biggest obstacles that the health service faces with the Pakistani community is poor attendance rates. In general many people do not like to go to the doctor however this is an added pressure on the NHS when it comes to promoting diabetes care among Pakistanis.

6.2.6 Pakistani lifestyle and traditional food

Participants across the three groups admitted to not doing any or not doing enough exercise. Some participants believed that Pakistani women refrain from doing physical activity in fear of provoking or exacerbating their illness (Sriskantharajah & Kai, 2006). Just as Pakistanis need to take control of their diet, they believed that they also need to take control of their exercise too.

A major significant finding which was consistent throughout all of the focus groups was regarding the significance of food within the Pakistani culture. A good Pakistani diet can be achieved as the food is fresh and home-made, and Pakistanis need to ensure that they eat on time and take care of their portion sizes (also supported by Lawton, Ahmad, Hanna et al., 2008). The key to being successful is for British-Pakistani women to lead by example e.g. British-Pakistani mothers making and eating healthy meals that are of a good portion size with other family members.

British-Pakistani women discussed the impact celebrations have on their health as all celebrations are centred on food. Participants illustrated that traditional foods are shared and enjoyed. Young females discussed how wedding celebrations are centred around rich traditional food, and non-T2DM mothers explained how at awareness and promotional events there are unhealthy foods. This was a significant finding of the qualitative focus groups across the three participant groups that the lifestyle of British-Pakistanis contributes to their higher risk of T2DM. For example the cultural significance of food was a clear theme among all participants illustrating that British-Pakistani women inherit not only susceptible T2DM genes but also Pakistani cultural lifestyle. Participants acknowledged that the main problem whilst celebrating is the lack of control participants have. T2DM participants do control themselves but only because they already have a diagnosis of diabetes and will suffer the effects if they do not. They had adhered to some changes and strategies implemented were cutting out or cutting down. Participants realised that it must be difficult for the older generation who have T2DM however family members did accommodate them. Participants expressed that there are a lot of alternative choices for people with diabetes to enjoy. Food is being marketed and being made readily available as the T2DM disease is becoming more common.

6.3 British-Pakistani Mothers are the key

This is a cross-cutting theme. The younger female participant group discussed this specifically whereas the mother participants both with and without T2DM discussed in general how they felt responsible for their children's health. British-Pakistani mothers acknowledged that mothers need to encourage and enforce healthy living as they are the main cooks of the family. Young British-Pakistani females also conveyed that it is the mother figures of the household who cater for the diabetics in the family supported by Lawton, Ahmad, Hanna et al. (2008). Therefore British-Pakistani mothers are pivotal in planning and implementing future prevention interventions to combat the onset of T2DM among the Pakistani community. Incorporating and understanding their perceptions, beliefs and experiences of the illness as well as cultural customs and values are essential to designing effective and culturally sensitive materials.

6.4 Illness and prevention perceptions

6.4.1 Prevention perception questionnaire

Using the main similarities from the qualitative data from the previous two studies, a prevention perception questionnaire was devised to be used in the final research study for this thesis. It was used to collect statistical data from British-Pakistani mothers and young females in order to validate and generalise the previous findings. The main limitation of using qualitative methodology is that data is derived from a small sample of participants so results and findings are hard to generalise (Ogden, 2004). Therefore the 12 item perception of preventable aspects of diabetes scale has been produced from the main findings of the qualitative studies to explore British-Pakistani female perceptions on a larger scale. Survey research is widely used and can be used in conjunction with qualitative research, which is ideal for this research.

This survey aimed to measure the beliefs, perceptions and preventative behaviours discussed in the qualitative studies. Nine out of the 12 items under investigation were classed as preventable variables which were:

- prevention control over child(ren)
- health service effectiveness
- effect of T2DM on child(ren)
- effect of illness on looking after your child(ren) and family
- T2DM is a sugar disease
- T2DM is affected by diet
- T2DM is affected by physical activity
- concern about child(ren) developing T2DM
- prevention of T2DM in children

The remaining three variables emerged from the qualitative data as important variables which were out of participants' control:

- T2DM commonness
- old age perception
- effect of living in England rather than Pakistan on T2DM

The 12 statements were based on the qualitative data which was in turn based on the constructs of the PMT and CSM. Participants were asked to score the 12 items in regards to how much they agreed with them, how they felt about the disease in regards to different situations and lay beliefs. From the '*causal factors*' theme from the mothers with and without T2DM groups and '*illness representation*' from the young female group the following items were derived: T2DM is a sugar disease, T2DM is affected by diet and T2DM is affected by physical activity. Effect of living in England rather than Pakistan on T2DM item was derived from the '*Pakistani lifestyle*' themes from the mothers with and without T2DM groups and '*England v Pakistan*' from the young female group. The health service effectiveness item

was taken from '*moral support and social influence*' themes from the mothers with and without T2DM groups and '*England v Pakistan*' from the young female group. From the '*lay beliefs and attitude*' and '*older generation*' themes from the T2DM mothers and young female groups respectively, the following items emerged: T2DM commonness and old age perception. Items regarding families and children emerged from the British-Pakistani mothers data. From the '*emotions*' and '*negative emotions*' themes the items for effect of T2DM on child(ren) and concern about child(ren) developing T2DM were derived, from '*Pakistani lifestyle*' themes emerged prevention control over child(ren) item and prevention of T2DM in children item, and the item of effect of illness on looking after your child(ren) and family derived from the '*moral support and social influence*' theme. These statements exploring British-Pakistani women's prevention perceptions may provide an explanation for their T2DM illness perceptions. If they believe that they have control over preventing the illness in themselves and their families then they should have strong illness perceptions of control/cure.

6.4.2 Illness perception questionnaire

In order to compare the prevention perceptions with illness perceptions the IPQ-R was also used for the next study. Comparing illness perceptions with prevention perceptions may provide an explanation for British-Pakistani women's T2DM illness behaviours. This will help to explain how and why British-Pakistani women think and act towards T2DM. Comparing prevention perceptions with illness perceptions may also lead to explanations of certain coping strategies which influence illness outcome and prevention. Therefore the British-Pakistani mothers who did look after their diabetes and adopted coping strategies to fit in their daily lives were coping better with their illness.

The Illness Perception Questionnaire Revised (IPQ-R) (Moss-Morris, Weinman, Petrie, et al., 2002) uses the five cognitive illness representations from the CSM and also deals with the minor psychometric problems and includes additional subscales. It provides a more thorough and psychometrically acceptable assessment of the key components of patients' perceptions of illness. The IPQ-R measures emotional representations affecting coping determining behaviour. For the non-T2DM and young female groups the survey was modified to ask participants to score the items according to if they were diagnosed with T2DM. There are limited studies focussing on how healthy people view and perceive health and illness, and how their ways of thinking relate to health-related behaviours (Figueiras & Alves, 2007). Weinman et al. (1996) expressed the opinion that adaptations can be made to the IPQ to test the psychometric status of it especially with different illness populations therefore in this study the IPQ-R is used with mothers with T2DM and an adapted version of the IPQ-R for mothers without T2DM and young females. The adapted version was produced by the author of this study and it asked participants for their perceptions if they had T2DM. Using the IPQ-R across the three groups encouraged consistency and reliability of the study. The IPQ-R can help to explain significant variance in attitudes and intentions towards the adoption of preventive behaviours (Figueiras & Alves, 2007)

6.5 Conclusion

There are many theme similarities across the three population groups, which help to explain the perceptions and beliefs of Pakistani women. There are also important differences which can help in the development of appropriate tailored prevention interventions. Using the 12-item prevention perception questionnaire derived from the focus group findings and the IPQ-R, the next step was to explore the perceptions and beliefs of young British-Pakistani females via a quantitative study to provide a holistic view of British-Pakistani perceptions.

Chapter 7

Illness perceptions and prevention beliefs of T2DM among British-Pakistani Females with and without T2DM

7.1.1 Introduction

Prevention of T2DM is an important objective (Pieroni et al., 2008). It is crucial to find out perceptions and beliefs of British South-Asians regarding the disease and its prevention to allow for the production of culturally appropriate resources. The purpose of the studies conducted earlier in this thesis (chapters 4 and 5) was to gain in-depth data on the perceptions, beliefs and knowledge of British-Pakistani women with and without T2DM and to ascertain any preventable behaviour they are aware of and perform. The quantitative study in this chapter explores this further by exploring the relationship between illness representations relevant to T2DM prevention perceptions and testing the generalisability of the qualitative findings to a larger sample of British-Pakistani women.

7.1.2 Dietary behaviours and T2DM

In Norway Pakistanis also constitute the largest ethnic minority group (Blom & Henriksen, 2008) and their diet tends to consist of low fibre intake, high consumption of animal fats and processed carbohydrates. Johansen and colleagues (2009) reported that Pakistani women in Norway have a high-risk of being overweight and developing T2DM therefore they examined the effect of a culturally adapted lifestyle education intervention on Pakistani women's intentions to changing dietary behaviours and intake. They found significant changes and reported that culturally adapted lifestyle education interventions have the potential to change Norwegian Pakistani women's intentions to make their diet healthier. Johansen et al. also reported that Pakistani women living in Pakistan have a good intake of

vegetables and fruits but this reduces when living in Norway. Some popular reasons for this are high costs, lower quality and freshness, and decreased availability in Norway (Karstad, 2008). This was a common belief among the British-Pakistani women from the previous two qualitative studies that Pakistanis eat fresher and wholesome food in Pakistan compared to when they are living in England.

Previously research has highlighted two universal challenges: low levels of education and poor language skills in the main language of the country they are living in (Hussain-Gambles, Atkin & Leese, 2004) as well as different health beliefs and behaviours from the rest of the general population (Johansen, Bjorge, Hjellset, et al., 2009). However these challenges are outdated. The majority of participants used in this thesis project did not have low levels of education nor poor language skills. Although a minority did these were older migrant citizens whereas the women without T2DM conversed and understood English, and it is this group that needs to be targeted from a prevention perspective. Also whether British-Pakistani women differ in their health beliefs and behaviours from the rest of the general population is debatable. There are cultural differences as documented in the previous qualitative studies (chapter 4 and 5) i.e. significance of traditional Pakistani food, and living in England versus Pakistan views, however many beliefs and behaviours mirror the rest of the UK population e.g. poor diet and lack of exercise (Alberti, Zimmet & Shaw, 2007).

Dietary behavioural change is a complex process and it is assumed that people's intentions are important in that process (Glanz, Patterson, Kristal, et al., 1994; Kristal, Hedderson, Patterson, et al., 2001). Change is also influenced by knowledge and awareness of diet (Curry, Kristal & Bowen, 1992) and motivation. Lovejoy and DiGirolamo (1992) reported that low dietary fibre intake along with increased dietary fat intake is consistent with reduced insulin sensitivity in obese participants compared to lean healthy individuals. Fukagawa and colleagues (1990) found that high-carbohydrate and high-fibre diets improve glucose disposal rates in young individuals although these diets are less effective in older individuals. Garg and colleagues (1988) reported that increasing monounsaturated fatty acids in diet

improves glycaemia control and blood lipids in individuals with T2DM more than a high-carbohydrate diet. In this study one of the prevention perceptions items is on diet and in the IPQ-R participants are asked to list the main T2DM causal factors in their opinion. By exploring any relationships between preventive perceptions and illness perceptions may help to develop strategies to motivate British-Pakistani women to change their behaviours and intentions towards leading healthier lives.

Rahman, Malik and Al Mubarak (1992) assessed glycaemic index for local staple foods in Lahore, Pakistan. The same weight of carbohydrates in different foods can produce a varied blood glucose response; thus emerged the concept of glycaemic index. Rahman et al. found that most of the research on glycaemia index has been carried out in western countries. In Pakistan there is a generic belief that rice aggravates T2DM and gram seed flour is good for it. Rahman and colleagues' study reported that gram seed flour is good for individuals with T2DM even better than wheat chapattis but they refuted the lay belief that rice is bad for diabetes. British-Pakistani women's prevention and illness perceptions are important across the different generations because we can learn from the older generation who already have the disease leading to the development of effective preventive strategies to be targeting at subsequent generations, especially around food as this is a pivotal part of Pakistani culture and lifestyle.

7.1.3 Physical activity among British-Pakistanis

Healthy diet and exercise are significant prevention factors but are not complied with by many individuals especially the British-Pakistani community. The increased prevalence of T2DM amongst South-Asians has been blamed on moving towards a more 'western lifestyle' (Abate and Chandalia, 2001) in that South-Asians do less physical activity in the west compared to when living in South-Asia. Although it is true that physical activity and exercise need to be promoted within South-Asians (Carroll et al., 2002), it is not accurate to blame the South-Asian group's lack of physical activity on 'western lifestyle' as there are lower levels of

physical activity amongst British South-Asians than in the general population especially in women and older people (Hayes et al., 2002; Fischbacher, Hunt & Alexander, 2004), and South-Asian adults with diabetes do less physical activity than South-Asian adults without diabetes (Thomas et al., 2004) Lack of exercise was highlighted as a main problem among British-Pakistanis by the different participant groups in this project in the qualitative studies. They too recognised that majority of Pakistanis living in the UK do not exercise whether they have a diagnosis of diabetes or not. Those who did do some exercise did it to look healthy and slim rather than to lower their risk of developing the disease.

7.1.4 Lay beliefs and misconceptions among British-Pakistanis

There are many lay beliefs, myths and misconceptions about diabetes among South-Asians as discussed in the previous chapters. Some people believe that diabetes is caused by eating too much sugar, by a western diet or stress. However Chowdhury and King (2007) reported that these can be contributing factors but not causal factors as consuming large amounts of western and sugary foods and drinks can lead to being overweight leading to T2DM. They also stated that stress releases hormones which also make the body need extra insulin and if the pancreas cannot deal with this then it can lead to T2DM. Many also believe that people with diabetes cannot exercise as they are too weak (Lawton, Ahmad, Hanna et al., 2006), which was supported by the qualitative studies with British-Pakistani women in this project. Another common misconception is that the diet for people with diabetes is strict and different to the rest of the family however this does not seem to be the case as British-Pakistani mothers with T2DM (in chapter 4) stated that as the main cooks of the family everyone was eating healthily and the same meals as them at home.

Another popular lay belief is that going to Pakistan reduces T2DM and the weather in the UK is bad for diabetes. It is more likely T2DM reduces for an individual when they go abroad as they become more active because the weather is warmer so they enjoy being more physically mobile and partake in physical activities (Chowdhury & King, 2007). Nanan (2001)

comments that Pakistan is also part of the overweight/obesity epidemic however from the previous qualitative studies conducted British-Pakistani females' lay beliefs are that it is more of a problem in the UK than Pakistan and that the problem is finite there. The T2DM prevention perception questionnaire identifies the main findings of the qualitative findings which includes some of the aforementioned lay beliefs and misconceptions. Participants have stated that the majority of items included in this questionnaire were in their personal control to change whereas three items were not (full details have been provided in the results section 7.3). The aim of the questionnaire was to see whether these twelve main beliefs can be generalised on a large British-Pakistani women group. If so this has many implications for future work in designing appropriate T2DM prevention interventions for this population group. The Illness Perception Questionnaire Revised (IPQ-R) (Moss-Morris, Weinman, Petrie et al., 2002) discussed in the chapter 6, has also been used for this study.

7.1.5 Conclusion

7.1.5.1 Current study

For this study a survey design was used to collect statistical data from British-Pakistani mothers and young females. A 12-item T2DM prevention perception scale has been produced to measure illness perceptions relevant to prevention. This scale will be referred to as the prevention perception scale for brevity, though it was recognised that it is not measuring perceptions of prevention per se. The Illness Perception Questionnaire Revised (IPQ-R) (Moss-Morris, Weinman, Petrie et al., 2002) was used to gain a more general understanding of British-Pakistani mothers and young females' illness perceptions regarding T2DM. Following on from the qualitative studies reported in chapters 4 and 5, the aim of this study was to generalise British-Pakistani women's T2DM illness and prevention perceptions and beliefs and explore the reliability and validity of the measure. The questionnaires were also used to explore any possible relationship between British-Pakistani women's T2DM prevention perceptions and their more general illness perceptions.

7.1.5.2 Research Question 1

Can the findings of the qualitative studies be generalised to a larger sample of Pakistani women, including similarities and differences between the illness and prevention perceptions of T2DM between British-Pakistani mothers with a diagnosis of T2DM, British-Pakistani mothers without a diagnosis of T2DM and young British-Pakistani females?

7.1.5.3 Research Question 2

What is the relationship, if any, between the perceptions of British-Pakistani women relevant to the prevention of T2DM and their perceptions of T2DM more generally?

7.2 Method

7.2.1 Design

Initially the T2DM prevention perception scores and the IPQ-R scores were compared across the three population groups descriptively and statistically; British-Pakistani mothers with T2DM, British-Pakistani mothers without T2DM and young British-Pakistani females without a diagnosis of T2DM. This was done to determine whether the main findings from the qualitative studies (chapters 4 and 5) could be generalised. Then the three participant groups were combined to form one population sample group and regression analysis was conducted to test whether there were any significant relationships between participants' illness perceptions and T2DM prevention perceptions. The variables of the study were T2DM illness perceptions and T2DM prevention perceptions.

7.2.2 Participants

British-Pakistani mothers were recruited into one of two groups depending on whether they had a diagnosis of T2DM or not. Participants without diabetes were recruited across four SureStart Centres in Birmingham (Adderley Children's Centre, Highfield Children's Centre, Centre 80 and Ward End Children's Centre). Participants with T2DM were recruited from Heart of England Foundation Trust (HEFT) and Birmingham East and North (BEN) Diabetes Community teams. The young British-Pakistani females were recruited from Aston University. This was done using flyers, posters and emails advertising the study and inviting potential participants to participate. On the basis of expecting a medium effect size (0.3) with high statistical power (0.8) and a significant alpha level of 0.05, recruitment of 30-40 participants were needed for each group (Cohen, 1988). Forty-seven participants without T2DM were recruited, 41 participants with T2DM and 42 young female participants were recruited. For the regression analysis there was a total sample size of 130 which is sufficient

for the 13 IVs for this study using the guidelines provided by Cohen & Cohen (1983). All of the participants were female and were of Pakistani ethnic origin. The young females did not have children, and the other two groups consisted of mothers with at least one child. Participants without T2DM verbally acknowledged that they were between the ages of 20-35 years, but specific age was not collected. Ages of the participants with T2DM were between 32-50 years with a mean age of 42 years. Ages of the young female participants were between 18-25 years with a mean age of 20 years, and were living at home whilst studying at Aston University. The majority of participants in the young female group did not have either parent with a diagnosis of T2DM (28), nine participants had a father only who had T2DM, four participants had a mother only with T2DM and 1 participant had both parents with T2DM.

7.2.3 Measures

Three questionnaire packs were administered one to the T2DM group, another to the non-T2DM group and third to the young female group. These consisted of participant information sheets (appendices 7.1, 7.2 and 7.3), a consent form to ask permission from each participant (appendices 7.4, 7.5 and 7.6) followed by the 12 item T2DM prevention perception survey derived from previously conducted qualitative data (chapters 4 and 5; appendices 7.9, 7.10 and 7.11), the IPQ-R (appendices 7.12, 7.13 and 7.14) and a debrief sheet (appendix 7.7 and 7.8).

Using the main similarities from the qualitative data from the previous two studies (chapter 4 & 5) the T2DM prevention perception questionnaire was devised. A main purpose of this study was to generalise the main qualitative findings on a larger British-Pakistani women group. The 12 item T2DM perception scale aimed to measure the beliefs, perceptions and preventative behaviours discussed in the qualitative studies. Four of the 12 items under investigation were classed as relating to aspects of T2DM which were preventable:

- Health service effectiveness

- T2DM is a sugar disease
- T2DM is affected by diet
- T2DM is affected by physical activity

Three items were on variables which emerged from the qualitative data as important but were out of participants' control:

- T2DM as a common condition
- Perception of T2DM as a condition of old age
- Effect of living in England rather than Pakistan on T2DM

Five items were on aspects of T2DM in relation to either the women's children or their family, depending on the participant group:

- Effect of T2DM on child(ren)
- Prevention control over child(ren)
- Effect of illness on looking after your child(ren) and family
- Concern about child(ren) developing T2DM
- Prevention of T2DM in children

Participants were asked to score the items in regards to how much they agreed with them, how they felt about the disease in regards to different situations and lay beliefs. From the '*causal factors*' theme from the mothers with and without T2DM groups and '*illness representation*' from the young female group the following items were derived: T2DM is a sugar disease, T2DM is affected by diet and T2DM is affected by physical activity. Effect of living in England rather than Pakistan on T2DM item was derived from the '*Pakistani lifestyle*' themes from the mothers with and without T2DM groups and '*England v Pakistan*' from the young female group. The health service effectiveness item was taken from '*moral support and social influence*' themes from the mothers with and without T2DM groups and '*England v Pakistan*' from the young female group. From the '*lay beliefs and attitude*' and '*older generation*' themes from the T2DM mothers and young female groups respectively two following items emerged: T2DM commonness and old age perception. Items regarding families and children emerged from the British-Pakistani mothers data. From the '*emotions*'

and 'negative emotions' themes the items for effect of T2DM on child(ren) and concern about child(ren) developing T2DM were derived, from '*Pakistani lifestyle*' themes emerged prevention control over child(ren) item and prevention of T2DM in children item, and the item of effect of illness on looking after your child(ren) and family derived from the '*moral support and social influence*' theme. These statements exploring British-Pakistani women's T2DM prevention perceptions may provide an explanation for their T2DM illness perceptions. If they believe that they have control over preventing the illness in themselves and their families then they should have strong illness perceptions of control/cure. For the non-T2DM and young female groups the survey was modified to ask participants to score the items according to if they were to be diagnosed with T2DM. For example T2DM mothers were asked to answer on a five point scale:

How much do you agree with this statement: Type2 diabetes is a very common illness?

How much do you think physical activity affects your illness?

Statements were modified where applicable to ask Non-T2DM mothers:

How much do you agree with this statement: Type2 diabetes is a very common illness?

How much do you think physical activity would affect this illness?

And again statements were modified appropriately for the young female groups:

How much do you agree with this statement: Type2 diabetes is a very common illness?

How much do you think physical activity would affect this illness?

For the full version of the 12 item questionnaires for the three different population groups please see appendices 7.9, 7.10 and 7.11.

The Revised Illness Perception Questionnaire (IPQ-R) provides a comprehensive and psychometrical assessment of the key components of a patient's perceptions of T2DM illness (Moss-Morris et al., 2002). For background information on the IPQ-R please refer to chapter 3. Changing patients' illness perceptions improves recovery, and improves patient outcomes for CSM interventions for illnesses as diverse as diabetes and coronary heart disease (Petrie, Broadbent & Meechan, 2003). The IPQ-R offers the potential for illness perceptions to be investigated in a wider range of patient groups and is therefore a relevant tool for this

study. In this study the data from the IPQ-R helped to demonstrate the wide scope of their illness representations. For the non-T2DM and young female groups the IPQ-R was modified to ask how participants would feel and be affected if they had T2DM. The column of experienced symptoms was omitted and participants were only asked which symptoms they thought were related to T2DM.

Participants were asked to identify symptoms they experienced and then to identify which of symptoms they specifically associated with their illness. For the T2DM mothers, participants were asked if they had experienced a symptom and then whether they thought it was related to their illness i.e.

	I have experienced this symptom <i>since my diabetes</i>			This symptom is <i>related to my diabetes</i>		
Pain	Yes	No	Don't know	Yes	No	Don't know
Sore Throat	Yes	No	Don't know	Yes	No	Don't know
Nausea	Yes	No	Don't know	Yes	No	Don't know

For the non-T2DM and young female group participants were asked whether they thought the symptoms were related to T2DM i.e.

	<i>This symptom is related to diabetes</i>		
Pain	Yes	No	Don't know
Sore Throat	Yes	No	Don't know
Nausea	Yes	No	Don't know

The main section of the questionnaire includes statements regarding perceived consequences, perceived timeline of illness, and control statements which can be divided into personal and treatment components. The last section measures the causal factor which can be divided into psychological attributions, risk factors, immune system factors and chance factors. One of the most beneficial sections of this questionnaire is the last question which asked participants to list the three main causes of T2DM in their opinion. Participants are free to write down whatever they think causes the disease rather than being influenced

by restricted options. For the full IPQ-R questionnaires used, please see appendices 7.12, 7.13 and 7.14.

7.2.4 Procedure

Participants with T2DM were recruited from the waiting areas of diabetes clinics run by either HEFT or BEN diabetes teams. The main researcher of this study was given a list of potential participants to approach during clinic hours by the clinic receptionist. The researcher would approach these individuals once they had signed in and were waiting to be seen by a health professional. In the absence of the researcher, the clinic receptionist approached potential participants and gave them information about the study. Participants without T2DM were recruited from parent and toddler groups in the four different SureStart children centres in Birmingham. Participants were asked if they were willing to participate in this study during the sessions. On consenting they were given either the diabetes or non-diabetes questionnaire pack depending on whether they had diabetes (41 participants) or not (47 participants). Young female participants were recruited from the School of Life and Health Sciences at Aston University. The study was advertised via email. They had a choice of either contacting the author to arrange a suitable time and place to meet or they could complete the questionnaire online via "*Survey Monkey*". All participant data was kept confidential. All the results collected were only seen by the authors of this study. Participants were made aware of the study and asked if they have any concerns, worries or queries. They were made fully aware that they could withdraw anytime before, during or after the study (up to one month after). Having taken part if they changed their mind their data would have been withdrawn.

All participants were required to read the participant information sheets containing information about the study and to explain what they would be required to do. They were then asked to give their consent and complete the questionnaires. On completion of the questionnaires, the participants kept the top sheets (a copy of the participant information

sheet and consent sheet) and the bottom sheet (the debrief sheet). Those who completed the questionnaire online were prompted to contact the author for a copy of the information sheet, consent form and debrief sheet. Questionnaire packs were available to take away if desired. Self-addressed envelopes were provided. Participants who took the questionnaire packs away with them were asked to keep the top sheet (a copy of the information and consent sheet) and the bottom sheet (the debrief sheet) and return the remaining questionnaire pack (a copy of the consent sheet and the completed questionnaires) in the envelope provided and to post it. Participants were also able to complete the questionnaire online via *Survey Monkey*. They were provided details on how to do this if they expressed a preference for this option.

7.2.5 Data analysis

All questionnaires were collated and scores were recorded on SPSS version 17 (see appendices 7.9, 7.10 and 7.11). A descriptive comparison of the IPQ-R scores and prevention perceptions scores was carried out between the three population groups: British-Pakistani mothers with a diagnosis of T2DM, British-Pakistani mothers without a diagnosis of T2DM and young British-Pakistani females without a diagnosis of T2DM. Five items from the perception questionnaire which differed between groups (items 3, 5, 6, 10, 12) were removed and compared separately as the items ask T2DM mothers and non-T2DM mothers to rate the items according to effects on their children whereas for the young females group the items ask about themselves and/or their families.

One-way ANOVAs were conducted on the remaining seven prevention perception items and the 12 IPQR domains to statistically compare the data across the three groups. Bonferroni-Holm correction was then applied to counteract family wise error arising from multiple comparisons of the same groups. The statistical analysis assesses differences between the groups on each different item which will test the validity and generalisability of the qualitative findings from the previous two studies in a larger sample of British Pakistani women.

The three groups were combined together to form one population group and an extra variable added to the dataset to reflect this (groups). The seven prevention perception items were combined to form one DV and the independent measures were the IPQ-R and groups variables. Regression analysis was conducted with a total of 130 participants and 13 IVs. This analysis will illustrate and relationships between T2DM illness perceptions and T2DM illness prevention perceptions in British-Pakistani women.

7.3 Results

7.3.1 T2DM Prevention perception scores

The twelve T2DM prevention perception items were individually scored between 1 (strongly disagree) to 5 (strongly agree) by each participant. Common, old age and England v Pakistan item scores were reversed for analysis purposes. Five items from the T2DM perception questionnaire which differed between groups (items 3, 5, 6, 10, 12) have been removed and reported separately. These items differed as they asked mothers with T2DM and non-T2DM mothers to rate the items according to effects on their children whereas for the young females group the items ask about themselves and/or their families.

Prevention perception items	T2DM		Non-T2DM		Young females	
	M	SD	M	SD	M	SD
Common	4.15	0.94	4.02	0.94	4.02	0.68
Old age	2.59	1.14	2.94	1.29	2.93	1.05
Health service	3.85	0.99	3.89	0.81	3.71	1.02
Sugar	2.93	1.29	3.74	1.07	3.36	1.16
Diet	3.71	1.10	4.17	0.90	4.17	0.91
Physical activity	2.93	1.02	3.70	1.20	3.83	0.91
England v Pakistan	3.37	1.22	3.60	1.01	3.48	0.97

Table 7.1 Mean scores and standard deviations of seven prevention perception items across the three participant groups (maximum score=5, minimum score=1)

One-way ANOVAs were also conducted to statistically compare the data across the groups.

Prevention perception items	f	P
Common	0.288	0.750
Old age	1.239	0.293
Health service	0.436	0.648
Sugar	5.304	0.006
Diet	3.187	0.045
Physical activity	0.612	0.544
England v Pakistan	0.508	0.603

Table 7.2 One-way ANOVA results for seven of the prevention perception items

Although several of these comparisons appear to be statistically significant there is a risk of family-wise error. Thus Bonferroni-Holm correction (P) was applied to the above data, using a significant α of 0.05 and the 7 prevention perception items $P=0.007$. In order of the lowest α sugar v prevention perception ($p=0.006$) is smaller than P therefore there is a significant

difference between the perception of sugar being related to prevention across the three groups. Diet prevention perception ($p=0.045$) is greater than P , therefore the null hypothesis could not be rejected for the remaining six T2DM prevention perception items across the three groups.

Sugar ($p=0.006$) item differed between the three population groups which supports the differences found in the qualitative studies data. Sugar was seen by many non-T2DM and young female participants as a T2DM causal factor due to its excessive intake, whereas mothers with T2DM did not discuss sugar on its own as a causal factor. They recognised other detrimental factors as well as sugar i.e. carbohydrates and fats. Sugar is clearly a very important factor to consider in terms of prevention for this population group.

From the statistical findings a non-significant difference between the groups for the common, health service and England v Pakistan items validate the findings from the focus group studies generalising the results on a larger British-Pakistani women group. Although descriptively there appears to be a difference for the physical activity item between the three groups, statistically there was no difference which is in accordance with the focus group data.

The old age item did not statistically differ between the groups which was surprising. From the qualitative data non-T2DM mothers and young females discussed their perceptions of T2DM as an old age disease however the mothers with T2DM did not. Thus a significant difference for this item would have been expected. Due to the non-significant result, differences in between-group perceptions of T2DM as an old age disease cannot be generalised on a Pakistani women sample.

The British-Pakistani mothers with and without T2DM scored similarly on the T2DM prevention perception items which referred to their children (see Table 7.3). The only two items in which there is a noticeable difference are family care and children prevention items. This means that mothers without the illness believed that family care responsibilities affect

T2DM (non-T2DM=3.2, T2DM=3.7) and that they try to prevent T2DM developing in their children more (non-T2DM=4.3, T2DM=3.6).

Prevention perception items	T2DM		Non-T2DM	
	M	SD	M	SD
Control over children	3.41	0.97	3.36	1.11
Effect on children	3.34	1.06	3.79	0.98
Family care	3.17	1.05	3.66	1.05
Concern for children	3.54	0.98	3.53	1.12
Children prevention	3.56	0.90	4.26	0.97

Table 7.3 Mean scores and standard deviations of five prevention perception items across the mother participant groups regarding their children (maximum score=5, minimum score=1)

7.3.2 Reliability

Internal consistency of the T2DM prevention perceptions measures was tested using Cronbach's alpha (α). The analysis illustrated that the seven T2DM prevention perceptions reached a moderate level of consistency ($\alpha=0.6$). Removing specific items did not yield a higher level. Although a higher level of internal consistency would be desirable (>0.7) (Clark-Carter, 1997) the combined seven item perceptions were used as the DV for further analysis (T2DM prevention perceptions) as this level of internal consistency is compatible with the assertion that the seven items are measuring a single construct, namely perceptions of whether T2DM is affected by preventable behaviours. The range of the overall score was 4 (out of 5). The T2DM prevention perceptions variable represented an individual participant's perceptions towards aspects of T2DM relevant to prevention.

7.3.3 IPQ-R

The IPQ-R uses the five cognitive illness representation of the CSM and provides a more thorough and psychometrically acceptable assessment of the key components of patients' perceptions of illness than the original IPQ. This questionnaire differs from the T2DM prevention perception questionnaire as it does not explore prevention perceptions of an illness whereas the latter does. Thus the IPQ-R was used as a generic T2DM illness perception measurement tool in this study and the T2DM prevention perception

questionnaire measured specific prevention perceptions of a larger British-Pakistani women sample.

7.3.4 IPQ-R scores

The identity items of the IPQ-R were scored according to how many symptoms they identified with T2DM. The remaining items were individually scored between 1 (strongly disagree) to 5 (strongly agree) by each participant. Thirteen items' scores were reversed before calculating the means and standard deviations of each IPQ-R domains. There were 12 constructs in total. The last question on the IPQ-R survey asked participants to list the three main causes for T2DM. The results of this question are discussed later on in this chapter. Table 7.4 highlights the mean scores of each IPQ-R construct across each participant group.

IPQ-R domains	T2DM		Non-T2DM		Young females	
	M	SD	M	SD	M	SD
Identity (14)	6.24	3.83	6.13	3.61	5.57	2.63
Timeline (30)	23.59	5.10	21.64	4.18	23.17	4.18
Consequences (30)	19.71	3.91	20.34	4.26	20.21	3.99
Personal control (30)	21.73	3.61	21.23	4.30	22.52	4.03
Treatment control (25)	17.66	3.28	17.38	2.96	18.60	2.90
Illness coherence (25)	17.10	5.23	14.87	4.46	17.83	4.49
Timeline cyclical (20)	12.34	3.86	13.00	2.91	12.38	2.14
Emotional representations (30)	20.80	5.20	19.04	5.88	16.95	5.09
Psychological attributions	18.75	4.90	15.32	5.37	14.71	5.21
Risk factors	20.80	3.97	23.62	17.01	23.40	4.46
Immunity	6.80	1.99	7.32	2.48	7.40	2.02
Accident/chance (10)	4.51	1.21	5.36	2.01	5.10	2.35

Table 7.4 Mean scores and standard deviations of IPQ-R constructs across the three participant groups
NB. Maximum score in brackets next to each construct

One-way ANOVAs were also conducted to statistically compare the IPQ-R data across the groups.

IPQ-R domains	f	P
Identity	0.471	0.626
Timeline	2.331	0.101
Consequences	0.290	0.749
Personal control	1.162	0.316
Treatment control	1.889	0.155
Illness coherence	4.790	0.010
Timeline cyclical	0.664	0.517
Emotional representations	5.257	0.006
Psychological attributions	7.428	0.001
Risk factors	1.458	0.237
Immunity	0.918	0.402
Accident/chance	2.205	0.114

Table 7.5 One-way ANOVA results for twelve IPQ-R domains

Although several of these comparisons appear to be statistically significant there is a risk of family-wise error. Thus Bonferroni-Holm correction (P) was applied to the above data, using a significant α of 0.05 and 12 IPQ-R domains $P=0.004$. In order of the lowest α , psychological attributions domain ($p=0.001$) is smaller than P therefore the null hypothesis was rejected suggesting there is a significant difference between psychological attributions domain across the three groups. Emotional representation domain ($p=0.006$) is greater than P, therefore the null hypotheses could not be rejected suggesting there are no significant differences between the remaining 11 IPQ-R domains across the three groups.

The significant difference of psychological attributions ($p=0.001$) and near significant difference of emotional representations (0.006) between the groups validate the focus group data. Although the statistical test does not highlight where the significance lies within the three groups it supports significant difference between groups, validating and generalising the qualitative data further. For example, mothers with T2DM had a lot of emotions regarding T2DM illness and would feel sympathy towards anyone who had or developed the disease, old or young, whereas the non-T2DM mothers and young female group perceived more negative emotions if a younger person especially a child was diagnosed with T2DM.

The three participant groups can be grouped in two ways to try and clarify the results. Firstly as those with a diagnosis of T2DM verses non-T2DM. Participants with a diagnosis of T2DM

were able to identify the symptoms of T2DM more than participants without T2DM and they understood the consequences of the disease better. Participants without T2DM scored risk factors, immunity and accident/chance higher than women with T2DM which illustrated that they perceived many causes of T2DM out of their control which generalises the findings of the qualitative studies e.g. these women discussed hereditary factors as a main causal factor. Secondly the participants can be grouped as mothers verses young females (who are not mothers). Emotional representations and psychological attributions scores are higher in mothers than non-mothers as they discussed in depth about their daily stresses and pressures as well as discussing stress and depression as important influential factors on developing T2DM especially by T2DM mothers. However the young female group scored slightly higher in personal control and treatment control domains reflecting their perceptions of them having more confidence in the treatment of T2DM and more control in hypothetically managing the illness. From a prevention perspective young females perceived that they have control over developing the disease but many are not enforcing that control which again is reflected in the qualitative findings.

Personal control is a very important domain especially when discussing prevention. The T2DM prevention perception questionnaire measures British-Pakistani women's beliefs about the importance of factors which were within or outside their control. In order to prevent the onset of T2DM, participants would be predicted to have significant personal control. In the statistical data above (table 7.5) personal control did not differ amongst the three population groups. This was surprising as women with T2DM discussed having more personal control in the focus groups compared to women without the illness.

The IPQ-R has yielded some interesting findings as well as aiding to validate and generalise the focus groups data further. Next both questionnaires have been used to explore the relationship (if any) between the perceptions of British-Pakistani women on aspects of the

prevention of T2DM and their perceptions of T2DM more generally. This was done by conducting a multiple regression analysis.

7.3.5 Comparing Correlations

Another statistical analysis of the data performed before conducting the multiple regression was to assess the size of the correlations between all of the different variables; T2DM prevention perceptions and the 12 different IPQ-R items in order to avoid multi-collinearity. In order for variables to significantly correlate with each other the correlations need to be greater than 0.8 (Clark-Carter, 1997). Some authors suggest using a lower level of 0.7 (Tabachnick & Fidell, 2007), however the majority of literature supports a consensus level of 0.8. None of the variables was greater than 0.80 (please refer to appendix 7.16) thus the variables were not highly correlated. They were included in the regression analysis to illustrate any possible correlations.

7.3.6 Multiple regression

The IPQ-R and group variables were regressed on the T2DM prevention perception variable. For this, regression test adjusted Rsquare=0.06 so explained 6% of the variance in prevention perceptions scores using group, identity, timeline, consequences, personal control, treatment control, illness coherence, timeline cyclical, emotional representation, psychological attributions, risk factors, immunity and accident/chance ($F=1.574$, $df=13$, $p=0.103$). Personal control ($t=-2.072$, $p=0.041$) was a significant predictor of prevention perceptions of T2DM. However the remaining IVs formed non-significant relationships.

Variables	Beta	t value	p value
Group	0.014	0.143	0.886
Identity	.074	.785	.434
Timeline	.026	.266	.790
Consequences	.094	.911	.364
Personal control	.215	2.072	.041*
Treatment control	-.103	-1.046	.298
Illness coherence	-.078	-.756	.451
Timeline cyclical	-.166	-1.710	.090
Emotional representation	-.059	-.532	.596
Psychological attributions	-.163	-1.526	.130
Risk factors	.045	.469	.640
Immunity	-.006	-.053	.958
Accident/chance	.141	1.320	.189

Table 7.6 Multiple regression summary results for T2DM participant group

*significant result $p < 0.05$

7.3.7 Causal factors

The last task on the IPQ-R requested participants to rank in order their top three causal factors for developing T2DM. Out of the 130 completed questionnaires 14 participants did not give any causal answers and three participants only gave one reason rather than three. Figure 7.1 below illustrates that bad diet, hereditary and lack of exercise are the main perceived causal factors for T2DM among British-Pakistani women. Stress, sugar and being overweight were also significant causal factors.

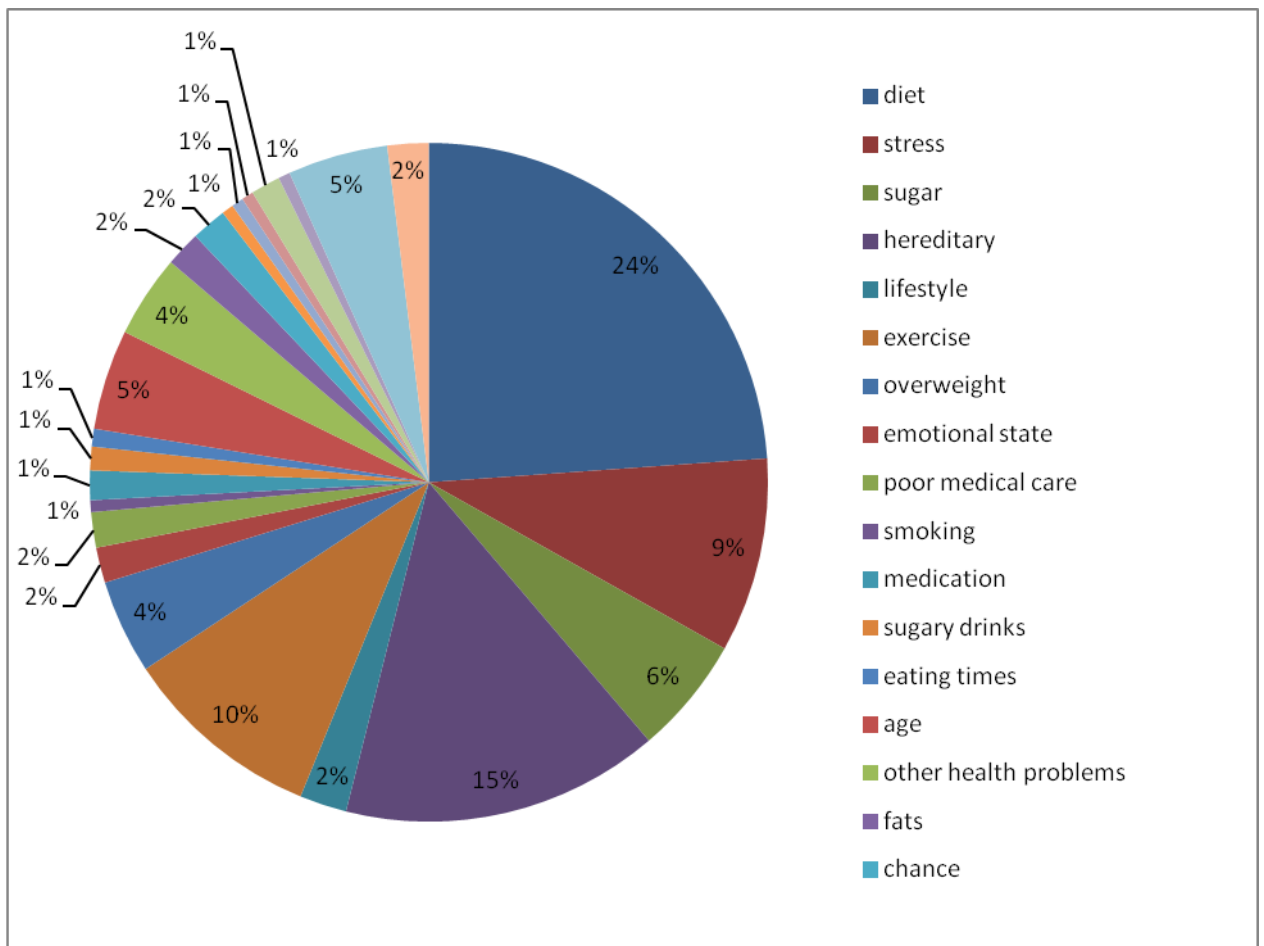


Figure 7.1 Overall responses percentage of causal factors by all the participants

7.3.8 Summary

Overall the mean scores across the three participant groups were very similar for the T2DM prevention perceptions survey and the IPQ-R. Where variations were found, differences could be split into two groups: women with T2DM v women without T2DM, and mothers v young females (without children). Sugar ($p=0.006$) item statistically differed between the three population groups using the T2DM prevention perceptions, whereas psychological attributions statistically differed between the groups for the IPQ-R. Overall both questionnaires validated the focus group findings to some extent and were able to demonstrate that the results are generalisable on a larger British-Pakistani women sample.

Multiple regression illustrated that for the most part there were non-significant relationships between participants' illness perceptions and their preventative perceptions of T2DM.

However it supported a significant relationship between personal control and the T2DM prevention perception scale. In other words, for the most part the new questionnaire measures something different from the IPQ-R and so perceptions of T2DM prevention could not be predicted by more general illness perceptions. Finally bad diet is the main causal factor of T2DM according to British-Pakistani women followed by hereditary factors and lack of exercise.

7.4 Discussion

7.4.1 Summary

There are two main outcomes of this research study. Firstly the production of the T2DM prevention perception questionnaire has to a large extent successfully generalised the qualitative findings from chapter 4 and 5. These findings have also been generalised using the IPQ-R on items not measured by the T2DM prevention perception questionnaire e.g. stress. Secondly the IPQ-R was used to measure generic T2DM illness perceptions of British-Pakistani women whereas the T2DM prevention perception questionnaire measure 12 specific T2DM prevention perceptions as the IPQ-R (designed to measure illness perceptions in people who already have the condition) does not include a measure on prevention. Multiple regression illustrated non-significant relationships between participants' illness perceptions and their T2DM preventative perceptions. However personal control does seem to have a significant role to play in future prevention interventions. Bad diet is seen as the main causal factor of T2DM according to British-Pakistani women followed by hereditary factors and lack of exercise in this study. Overall all three groups shared similar illness and prevention beliefs and perceptions regarding T2DM. This study's findings as well as the qualitative studies' findings in chapter 4 and 5 can be generalised supporting the provision of effective prevention strategies targeting the British-Pakistani population.

7.4.2 IPQ-R

The IPQ-R was a good tool to use as it highlighted the main T2DM illness perceptions of the British-Pakistani women in this study. This survey helped to generalise some of the focus group findings and to also explore any significant relationships between T2DM prevention perceptions and illness perceptions. The IPQ-R was easily adaptable to the dimensions to suit this study i.e. T2DM disease, cultural settings of the participant groups, etc. supported by

Moss-Morris, Weinman, Petrie, et al. (2002). This was also successfully done by Barnes (2001) who explored cultural differences in belief about T2DM between Tongan and European groups in New Zealand. She found perceptions of diabetes differed between the two ethnic groups and that the Tongan participants tend to have lower adherence to dietary and medication recommendations. They also believed their diabetes to be a more cyclical and acute illness, and were more likely to attribute their illness to external factors i.e. beliefs of poor medical care in the past, environmental pollution and God's will caused their diabetes. According to Hughner and Kleine (2004) this type of questionnaire is useful to assess lay health-related views in a general population, which was ideal to use with non-T2DM participants as they could not comment on experiencing the disease for themselves. Weinman et al. (1996) expressed the opinion that adaptations can be made to the IPQ to test the psychometric status of it especially with different illness populations therefore in this study the IPQ-R was used with mothers with T2DM and an adapted version of the IPQ-R for mothers without T2DM and young females. Figueiras and Alves (2007) research using the IPQ-R provided empirical support for the theoretically derived dimensions of individuals' illness representations in healthy population groups. Their research suggests that the CSM seem to exist independently of the direct experience with the illness influencing other health-related beliefs. They asked healthy individuals about illness perceptions of AIDS, skin cancer or TB. Their results indicated significant predictors of attitudes and intentions towards preventative behaviours. Timeline, consequences, illness coherence and psychological attributions were significant predictors of attitudes towards preventative behaviours and illness coherence, emotional representations and illness coherence were significant predictors of intentions. These three domains were also significantly different between the groups of this study.

An advantage of using the IPQ-R over the IPQ included the added element of psychological attribution item as stress is regarded as an important consequence and perceived causal factor for T2DM. These quantitative findings helped to validate the qualitative findings highlighting that participants especially mothers with T2DM believed that stress is a

perceived causal factor of diabetes. The IPQ-R also clearly highlights the main symptoms and causal factors from the participant's point of view, which helps to highlight beliefs and knowledge which need to be tackled when trying to prevent the onset of T2DM in British-Pakistani women. The written causal task at the end of the IPQ-R demonstrated the main causes of T2DM perceived by British-Pakistani women across different age groups. Thus prevention strategies do not necessarily need to target particular age groups but they do need to be culturally applicable to British-Pakistani women, i.e. recognising the significance of food not just regarding their diet but as part of the lives.

Personal control domain of the IPQ-R was the only construct which yielded a statistically significant relationship with the prevention perceptions scores in this study. Psychological and risk factor attributions are related to an increased sense of personal and treatment control suggesting that British-Pakistani women feel more in control of T2DM if they acknowledge behavioural and psychological causal factors such as diet, stress, or overwork. Figueiras and Alves (2007) reported that healthy participants seem to have clear ideas about the types of symptoms and causal beliefs that are associated with specific illnesses and that an individuals' causal attributions for a disease may influence their personal control and treatment beliefs, and may help them to make sense of the illness.

The IPQ-R has previously been used on a healthy population sample to analyse illness perceptions and predict preventative behaviours (Figueiras & Alves, 2007) supporting the use of this questionnaire with the non-T2DM groups in this study. For the non-T2DM women the survey was modified to ask participants to score the items according to if they were diagnosed with T2DM. There are limited studies focussing on how healthy people view and perceive health and illness, and how their ways of thinking relate to health-related behaviours (Figueiras & Alves, 2007). Using the IPQ-R across the three groups encouraged consistency and reliability of the study. A benefit of using the IPQ-R was that illness perceptions can illustrate attitudes towards preventive behaviours and intentions to adopt them (Figueiras & Alves, 2007). Therefore it was used with the prevention perception survey to see if there

was a relationship between illness perceptions and T2DM prevention perceptions; this study did not yield any significant relationships. This finding is further discussed below.

7.4.3 T2DM prevention perception questionnaire

The purpose of the 12-item prevention perception scale was to generalise the qualitative findings of this thesis and then to explore any significant relationships between T2DM prevention perceptions and illness perceptions. Being able to generalise the qualitative findings is very important as these perceptions and beliefs of participants can be used to inform culturally effective tools for British-Pakistani women. Non-T2DM mothers and young females in the qualitative studies highlighted that they have negative emotions towards the disease and perceive it to be a common disease, and that T2DM mothers perceive T2DM as serious and worry about their families especially their children developing the disease thus they try to prevent it in their families. This was reflected in this quantitative study. The only item which did not reflect the qualitative findings was T2DM is an old age disease. There was no statistical difference between the groups on this item which means that although in the qualitative study majority of the non-T2DM participants perceived T2DM as an old age disease, this difference was not generaliseable on a large British-Pakistani women sample. For the statistical tests in this study, the significant outcomes did not highlight where the significance lies within the three groups. Further analysis may have helped to do this e.g. conducting a post-hoc analysis. However in general the results do validate and generalise the qualitative data.

The lack of significant regression findings does not mean that the non-significant results from this study should be dismissed. Rather it suggests that perceptions about aspects of the condition which are preventable are different from illness perceptions more generally and the questionnaire designed for this study measures something different from the IPQ-R. French, Wade and Farmer (2011) conducted a study into self-care behaviours of T2DM patients and they found that these patients self-care behaviours were predicted by beliefs about behaviour

and not just illness perceptions. They too yielded non-significant results when statistically testing self-care behaviours on illness perceptions. They reported that behavioural beliefs need to be added to the CSM to make it stronger as perceptions are simply not enough to explain behaviours towards an illness. Even though there were non-significant relationships between illness perceptions and T2DM prevention perceptions in this study this does not mean that British-Pakistani women do not try to prevent the onset of T2DM. In fact from the qualitative study, T2DM mothers were the only group that actively tried to prevent the onset in their family as they were more aware of the causes and consequences of the disease. Further research could look at behavioural beliefs as well as illness perceptions in order to achieve more conclusive findings with this population group.

Rather than being a tool used to measure T2DM prevention perceptions it is possible that this survey can be easily mistaken to be a tool used to measure T2DM illness perceptions which is the purpose of the IPQ-R. However the T2DM prevention perception questionnaire aims to measure specific aspects of T2DM perceptions relevant to prevention which the IPQ-R does not exclusively measure. The survey was not meant to be an illness perception survey which is why the IPQ-R was not used to validate it. The T2DM prevention perception questionnaire was developed with a unique purpose of measuring specific T2DM prevention perceptions according to the qualitative data collected in studies 4 and 5 in order to produce valuable data which is different from previous research that can be used to inform practical solutions for the British-Pakistani population group. By using this questionnaire clear constructive data will be produced regarding participants' beliefs and perceptions prior to a diagnosis or development of T2DM which can help to design effective prevention interventions for high at-risk groups. It also highlighted perceptions which participants believed are in their personal control thus they can be targeted to try to prevent the disease. Simply changing views or perceptions of individuals is not enough to help them perform preventative behaviours therefore the IPQ-R is not enough to design a successful intervention to prevent T2DM; however the T2DM prevention perception questionnaire does have the potential to do so. The IPQ-R findings alone cannot be used to move forward on to

the next step which is to focus on designing effective preventative tools and resources, but by using the T2DM prevention perception questionnaire this is plausible.

As an improvement to the T2DM prevention perception questionnaire to emphasise its purpose as a prevention perception measurement tool the wording could be better. The five items which were excluded from the analysis differed across the participant groups as explained in the result section due to prevention of children or self and family, but they also were very similar to items included in the IPQ-R. For example on the T2DM prevention perception questionnaire participants were asked '*How much control do you feel you have over you getting this illness?*' which is very similar to a control item statement from the IPQ-R i.e. '*There is a lot which I can do to control my symptoms*'. However the control item in the IPQ-R measured the amount of perceived control one has over their symptoms compared to the control item in the T2DM prevention perception questionnaire which measured how much perceived control an individual has over preventing themselves from developing T2DM therefore these two items are very different. The last item on the T2DM prevention perception questionnaire was worded wrongly as it asked participants to report on actual behaviour (e.g. '*How much do you try to prevent getting this illness*') however it should have been worded to reflect perceived efficacy (e.g. '*How much do you think you are able to prevent yourself from developing this illness*'). An alternative to excluding the items would have been to reword them however as the questionnaire had already been used to collect data from participants, it was not plausible to reword the questionnaire after data collection. Thus in order to use this questionnaire in any future research it would need to be reworded to differentiate itself from other surveys and clearly illustrate its purpose to assess T2DM representations relevant to T2DM prevention.

The results of this study can help British-Pakistani women to understand that their T2DM perceptions need to motivate them to change their behaviour to lead healthier lifestyles which will benefit the whole family. Prevention strategies can be designed to tackle mistaken beliefs about the cause, timeline, management and consequences of T2DM. The IPQ-R and

the 12-item T2DM prevention perceptions are extremely vital data and highlight an understanding of the way in which British-Pakistani women understand T2DM and how it relates to the world around them.

7.4.4 Lifestyle factors

Bad diet was the main causal factor of T2DM reported across all three groups. Lack of exercise and hereditary factors were also significant factors. The T2DM group ranked lack of exercise higher than non-T2DM but this could be because they are more educated about the impact of exercise on T2DM. However all groups admit to not doing enough or any exercise. Previous studies have shown that physical activity is particularly low among women and older people (Hayes, White, Unwin, et al., 2002; Fischbacher, Hunt & Alexandra, 2004). Hayes et al. (2002) reported that the level of physical activity declined with age, and they did not find any differences between physical activity levels between South-Asians born here and those who migrated. This can also be found in all the studies' findings in this thesis. Some T2DM mothers actively tried to exercise regularly by power-walking however they did not doing it for significant amount of time. From the young female group some participants acknowledge doing some exercise but this was to stay healthy or slim, rather than reducing their risk of developing T2DM. In this project participants also gave many reasons for not exercising, mainly because they were too busy with other things going on in their lives. Lawton, Ahmad, Hanna, et al. (2006) reported the lack of exercise and physical activity down to lack of time and obligation to others and climate conditions (as suggested by the participants in the qualitative studies in this project), as well as fear and shame.

Diet and exercise are appropriate components to living a healthy lifestyle but there is a low compliance rate for lifestyle modification purposes (Chowdhury and King, 2007). Clearly education has a significant role in emphasising the importance of physical activity and healthy diets for the prevention and delay of diabetic complications. It is also important to educate the whole family and not just the person with T2DM or at the risk of developing

T2DM, as supported by Lawton et al. (2006). The fact the young female and non-T2DM groups place hereditary factors high up the list of T2DM causes may reflect their beliefs that the disease is inevitable among the British-Pakistani community.

T2DM is an important precursor to future morbidity from other diseases and early diagnosis and necessary treatment may delay the onset of health problems (Ehtisham, Barrett & Shaw, 2000). Lawton et al. (2006) found that South-Asians do not participate much in exercise or physical activities due to co-morbidities associated with T2DM, and that T2DM was seen as bodily decline. This is supported by this study as many participants believed that T2DM is a by-product of another illness, or that it causes other health problems. Similarly participants across the groups reported sugar as a causal factor. Therefore these main causal factors can be generalised across all British-Pakistanis. Sugar and Pakistani traditional food specifically have a unique cultural significance amongst British-Pakistani women as they believe they contribute to the onset of T2DM in high-risk individuals. Therefore it needs to be considered when developing T2DM prevention interventions, as well as the role of mothers as providers of food.

7.4.5 Limitations

One of the limitations of the T2DM prevention perception questionnaire was the lack of clarity for combining the seven items (common, old age, health service, sugar, diet, physical activity and England v Pakistan) into one dependent variable. The justification for this was done was for regression purposes to use one dependent variable rather than seven dependent variables. These items individually refer to perceptions of the importance of specific preventable factors but collectively they demonstrated an overall single T2DM prevention perception score. However combining the seven T2DM prevention perception items could have possibly impacted on the lack of significant findings in the multiple regression. The intent was to measure perceptions of T2DM preventability using the T2DM prevention perceptions questionnaire and regress these on perceptions of the diabetes illness itself.

Future work can be done to analyse in depth meaning associations between the IPQ-R domains and the items of the T2DM prevention perception questionnaire by running factor analysis as well as hierarchical regression.

A larger sample size would have required a smaller effect size for statistical significance and may have helped to yield some more significant findings in this study. Alternative tests could have been conducted on different aspects of the T2DM prevention perceptions to analyse them further which may have yielded significant results e.g. by separating the preventable perception items which participants described as being within personal control from the three non-personal control prevention perception items. Also to validate the T2DM prevention perception questionnaire specific items similar to IPQ-R domains could have been analysed to measure associations between the scores.

Age was not used as a measure in this study as it was found to be a confounding variable. However the age ranges of the participants in this study are very important as data has been collected from different, albeit overlapping, generations of British-Pakistani women. The fact there are many similar perceptions and beliefs of illness and prevention across the three participant groups illustrated that age is not an important factor to consider. Prevention resources and tools need to focus on culturally relevant aspects applicable to British-Pakistani women and not their age.

7.4.6 Conclusion

This study illustrated the illness perceptions and beliefs of British-Pakistani women relevant to their T2DM prevention perceptions. It gives validity to the previous qualitative studies which demonstrated common, shared and different view points. By combining all three studies and all three research groups these findings, perceptions and beliefs can be generalised across the British-Pakistani women population making this research invaluable.

This research should be used to educate relevant healthcare providers and policymakers into developing culturally relevant prevention programmes targeted at British-Pakistani women.

Chapter 8

Thesis Discussion

8.1 Introduction

The purpose of this thesis project was to explore the perceptions and beliefs regarding T2DM amongst British-Pakistani women and any preventative behaviours they perform towards developing the disease in themselves (if they do not already have a diagnosis) and their families. Vyas, Greenhalgh, Cade et al. (2003) reported that in the UK, risk factors for long-term chronic disease are the highest in Pakistani women thus it was necessary to tackle the barriers and issues British-Pakistanis women are faced with when trying to prevent the onset of T2DM. British-Pakistani females are also at the forefront of familial responsibilities, another reason it was deemed appropriate to research this group. They continue to have responsibility for the food and meals of their family as well as themselves and they are in the best position to encourage and support others to live healthy lifestyles (Fagerli & Wandel, 1999). Previous research has shown that a family member being diagnosed with T2DM adds extra pressure on women as they have to manage the relationship between the family and food (Burns & Gavey, 2004). From the British-Pakistani mothers' qualitative study (chapter 4), mothers with T2DM reported how they changed the diets of the families and not just their own to control their diabetes and reduce the risk in their family. This contrasts with Peel, Parry, Douglas and Lawton's study (2005) which found that British women do not change the diet of their family when they themselves are diagnosed with T2DM, but only when another family member is diagnosed. The participants in Peel et al.'s study were predominately white highlighting clear cultural differences between British-Pakistanis and British-whites.

The four studies presented in this thesis project aimed to answer specific research questions. A systematic review was conducted to analyse previous T2DM literature and prevention

interventions. Two qualitative studies were then conducted to explore the perceptions and beliefs of British-Pakistani mothers and young women via focus groups analysed using thematic analysis. These were followed by a questionnaire study to measure illness representations relevant to T2DM prevention and to generalise the qualitative findings. Each of the studies was informed by the previous study. This chapter will summarise the findings of each study and explain how they complement and add to the current existing body of research on T2DM prevention and health policy work. The chapter will also present the possible limitations and recommendations for future work.

8.2 Summary of Thesis Findings

8.2.1 Systematic review

The systematic review highlighted the strength and validity of lifestyle programmes in aiding T2DM prevention. The numerous diabetes prevention trials (discussed in chapter 2) support lifestyle interventions compared to standard-care interventions (Leventhal, Weinman, Leventhal & Phillips, 2008). The Finnish Diabetes Prevention Study Group (Lindstrom, Louheranta & Mannelin, 2003; Tuomilehto, Lindstrom, Eriksson et al., 2001) reported that about 60% of the lifestyle intervention participants remained T2DM-free compared to those in the control group who received standard-care over the four years of the intervention, and the benefits of lifestyle change were sustained for three years following the end of the intervention. The trial of individuals at high-risk of developing T2DM conducted in the US confirmed the Finnish findings (Diabetes Prevention Program Research Group, 2002). The quality of these trials were very high as well as the adherence to the interventions being excellent (Leventhal, Weinman, Leventhal & Phillips, 2008). The systematic review highlighted the need to incorporate an education component to lifestyle prevention interventions to improve knowledge and behaviour change. Repetition of knowledge is good and focusing on the overall implications of research can help devise a practical and beneficial tool. It is also important to conduct research with the relevant population sample

e.g. overweight, IGT, non-T2DM participants with familial T2DM, to develop appropriate prevention interventions.

One of the aims of the systematic review was to explore any prevention interventions focussing on South-Asians particularly Pakistanis. Although many of the studies were conducted around the world in different countries only two of the studies in this review focussed on South-Asians, Ramachandran, Snehalatha, Mary et al. (2006) in India and Baradaran, Knill-Jones, Wallia and Rodgers (2006) in the UK. Therefore it was not feasible to conduct a synthesis on T2DM prevention interventions only for South-Asians. The literature has demonstrated that South-Asians have the highest T2DM prevalence rates in the UK and more RCTs are needed in the South-Asian population groups (Lawton, Ahmad & Hallowell et al, 2005). The progression rate of IGT to T2DM is very high amongst South-Asians and Ramachandran et al.'s study demonstrated that lifestyle interventions can prevent the onset of T2DM in this high-risk group. Baradaran et al.'s review has found that future research should be aimed at developing culturally appropriate interventions encouraging healthy lifestyles and exploring motivating strategies for diabetes prevention.

8.2.2 British-Pakistani mothers' qualitative study

The qualitative study conducted with British-Pakistani mothers demonstrated that they believed there were many causal factors contributing towards T2DM onset in this population group. In this study non-T2DM participants were more carefree with their lifestyles and struggled to live healthy lifestyles due to hindrances which they felt were out of their control. T2DM participants were more aware of the disease and its complications thus did their best to try and prevent it in their families and practised control over themselves. Overall participants from both groups admitted to not doing enough, or any, exercise. A significant finding of this study was how traditional food formed part of celebrations which had an impact on British-Pakistani mothers' health. The key to being successful is to lead by example. They all believed that the health service provided resources and care although the support they were offered was ineffective, and some traditional/herbal medicines were used as an

alternative to western medication. They also voiced the opinion that the media played a part in luring them into unhealthy habits yet on the other hand it also helped to promote healthy living campaigns and T2DM awareness.

8.2.3 Young British-Pakistani females' qualitative study

The next study was conducted with young British-Pakistani females who believed that there are many causal factors of T2DM and they perceived it to be an old age disease which is inevitable among Pakistanis. They recognise that their lifestyles especially their diets are poor but they enjoy their carefree lifestyles and will deal with the development of T2DM when/if it happens. They would be more concerned if a younger person developed the disease rather than an older person. They also recognised that food is a pivotal part of Pakistani culture preserved through celebrations. Also living in Pakistan rather than England is perceived to be better due to the weather and a more active lifestyle, which was also a finding in the older women (previous study); however the younger females believed that the healthcare and diabetes campaigns are better in the UK. They discussed how older generations have used traditional/herbal medication to help with managing T2DM, but were cynical towards using it themselves. It is also important to highlight that the participants in this group were all undergraduate students studying at University whilst living at home. Therefore the culture of their student lifestyle is different from other students. They are still faced with the same cultural pressures that other Pakistani women endure, however they have adapted to balancing their study lives with their home lives.

8.2.4 British-Pakistani women's quantitative study

The final study was conducted with the three participant groups; T2DM and non-T2DM mothers and young females. There were non-significant relationships between T2DM prevention perceptions and illness perceptions of T2DM except that personal control was a significant predictor for British-Pakistani women. Bad diet was seen as the main causal factor of T2DM followed by hereditary factors and lack of exercise. Although the results from the T2DM prevention perception questionnaire need to be used with caution, the

quantitative results were able to generalise the qualitative results of this project highlighting that British-Pakistani women share similar T2DM beliefs and perceptions regarding T2DM prevention. The questionnaire was also shown to be measuring different constructs to the IPQR.

8.3 Pakistani mothers are crucial to the prevention of T2DM

Pakistani women are at the forefront of familial responsibilities and this was emphasised in this thesis research. In this project the British-Pakistani mothers' views of themselves and the young females' views of their mothers were the same. All the British-Pakistani women conveyed that it is the mother figures of the household who cater for the individuals with diabetes in the family (who are mainly male) as well as everybody else. This has been reported in previous research too (Lawton, Ahmad, Hanna et al., 2006) encouraging them to cook healthily for the whole family rather than making several dishes. Those mothers who did not need to cater for any family members with diabetes would still try to cook healthily to maintain general good health or to lose weight, rather than to prevent diabetes in the household. The mothers were more concerned with their children's health and the young females reiterated this point in regards to themselves and their mothers. Different generations were represented in the participant population groups in this study yet there was a consensus that it is the women who are in control of family diets and some of the younger generation have started to demonstrate this in their households.

It is crucial to involve British-Pakistani mothers in T2DM prevention interventions as well as partners and family members. This will allow for families to work together and support each other. This is supported by Stone and colleagues (2005) who reported that high T2DM prevalence and strong family links are an important source of knowledge and emotional support for South-Asians. British-Pakistani mothers who participated in the focus groups suggested support networks to be set-up where women with and without T2DM can meet to discuss the disease and even swap their own diabetes-friendly recipes that are enjoyed by

their families. Stone et al. also suggested the need to consider a convenient venue for T2DM initiatives where cultural preferences were accommodated, e.g. separate gender sessions. Research has suggested that there are many barriers to Pakistani women getting together however the issue of language being the main barrier is outdated. As part of management it may be a significant barrier in the older Pakistani generation however for the purpose of prevention, strategies need to target younger generations groups for whom language is not be a barrier as demonstrated by the British-Pakistanis in this project.

Another way of reaching this high-risk group is during pregnancy as gestational diabetes (GD) was a common theme among the British-Pakistani mothers. This is supported by a study in Leicester that reported that four years after diagnosis South-Asian women with GD were twice as likely to develop T2DM (Oldfield, Donley, Walwyn, Schudamore & Gregory, 2007). Some participants had developed T2DM from GD and others knew of mothers with T2DM who once had GD in this project. The prevalence of GD is increasing along with increasing obesity and T2DM (Korpi-Hyovalti, Laaksonen, Schwab et al., 2011) and ethnicity is one of the predominate risk factors of GD supported by Dornhorst and colleagues (1992). Therefore taking pregnancy as an opportunity to educate mothers and screen them from an earlier stage would be appropriate. It would also be useful to monitor the child as it grows because he/she is especially at high-risk of developing T2DM.

8.4 Importance of Prevention and Self-Care Behaviours

8.4.1 Self-Care Behaviours

This thesis project demonstrates that it is important to investigate the self-care behaviours of British-Pakistani women with T2DM to explore the factors that have a major impact on T2DM prevention and management, also supporting previous research (Harvey & Lawson, 2009; Leventhal, Weinman, Leventhal & Phillips, 2008). These T2DM self-care behaviours include dietary change, exercise, self-monitoring of blood glucose, and regular attendance at screening programmes. As supported by this project, focusing on behaviour change is key

for T2DM prevention and the promotion of healthy living. Behaviour is affected by numerous factors such as economic, ecological and cultural pathways, and genetics which are factors that cannot be changed or altered, compared with psychological traits, cognitive competency and individual's behaviours that can be changed on an individual level (House, Kessler, Herzog et al., 1992; Kaplan 1992). Hence the best way to affect health outcomes will be through the factors influencing health behaviours which are possible to change (Leventhal, Weinman, Leventhal & Phillips, 2008). However these behaviours and the desired diabetes care are often not achieved despite their value being understood by both patient and professional (Harvey & Lawson, 2009). The financial implications are also vast when treating chronic illnesses and the financial burden increases as the population ages (McKinlay & McKinlay, 1977). This is a major problem for the healthcare system, thus it is fully justified to focus on prevention and control aspects (Baum & Posluszny, 1999).

8.4.2 Education

Illness education provides the appropriate knowledge to deal with T2DM but is not currently very effective (Harvey & Lawson, 2009). According to Harvey and Lawson, education is very important in understanding diabetes and lack of knowledge is the main reason for not achieving good self-care. However Mazucca (1982) conducted a meta-analysis of 30 studies exploring patient education in chronic disease and found that improving patient knowledge alone is not sufficient in improving adherence to treatment regimes. It has also been reported that there is no good evidence of a relationship between knowledge and treatment adherence, and that some individuals with a good level of knowledge are poor treatment adherers (Al-Deagi, McElroy & Scott, 1995; Anon, 1992). Individualised education seems to improve treatment adherence regime but is independent of knowledge (Horne, 1995). This is because people's actions and behaviours are determined by their health beliefs and illness perceptions of T2DM (Harvey & Lawson, 2009). This project emphasises that it is important to get British-Pakistanis thinking about their health sooner rather than later as it will be of huge benefit to them as well as the health service. From data collected in this project educational sessions will clearly not work as the British-Pakistani women in the qualitative

studies discussed excluding themselves from them as they perceive the information to not be of relevance to them. However if these sessions were made more relevant and held at appropriate and relevant places then British-Pakistani women expressed the view that they may attend them. Therefore it is crucial to incorporate families in adjusting to illness and a need for education interventions to include the family especially as the potential for learning from experienced relatives appears high. Greenhalgh, Helman & Chowdhury (1998) reported that South-Asians reflect on personal experience and the experiences of friends and relatives as the best way to find out about T2DM. They are also a major part of the support and hindrances for British-Pakistani women.

Greenhalgh, Helman & Chowdhury (1998) research complements this project by reporting that youth and health are perceived as synonymous and physical degeneration and weakness are seen as inevitable consequences of aging. Although T2DM is perceived to be a common disease among Pakistanis there is still a minority who did not know about it or the risks of the disease. Therefore prevention tools need to contain basic background information which needs to reach this minority group. Correct background information will also help to build on current knowledge and eradicate incorrect assumptions and myths. For example T2DM labelling is confusing among British-Pakistanis. This thesis research has illustrated that the universal term used among British-Pakistanis for T2DM is “sugar”. This could be as a result of no direct medical translation of the term type 2 diabetes and health professionals have called it “sugar” in reference to problems with glucose and sweet foods. These tools need to also highlight the main symptoms of the disease as many non-T2DM participants recognise that due to the disease being so familiar the signs and symptoms are easily missed.

8.4.3 Dietary behaviours

Diet can be influenced by many cognitive factors such as an individual’s beliefs about the seriousness of an illness and its treatment effectiveness (Skinner, Hampson & Fife-Schaw, 2002; Hampson, Glasgow & Strycker, 2000), increased perception of control, increased

understanding and better adherence to diet (Watkins, Klem, Connell et al., 2000), and perceived consequences (Searle, Norman, Thompson & Vedhara, 2007). Jayne & Rankin (2001) reported that the immigrant participants in their study believed that poor eating behaviour was one of the main causes of diabetes, supported by the British-Pakistani females in this project. Young females were encouraged to eat healthily by their mothers and did so at home but outside the home they had no routine and ate mainly high sugar, high fat foods such as chocolate. Pakistani mothers who took part in this project also highlighted that they encouraged their children to eat healthily but they themselves struggled, especially the non-T2DM participant group. Jayne & Rankin's study also reported the different variations in reference to poor eating included eating too much sugar, overeating, eating the wrong foods, eating foods high in fat, eating too much meat, or eating on an irregular schedule which is again supported by this thesis study. Many non-western immigrants believe that the main cause of diabetes and of poor diabetic control is excess sugar intake and the other perceived features of a Western diet (Greenhalgh, Helman & Chowdhury, 1998; Pierce, 1997). This needs to be considered when designing prevention materials especially for British-Pakistanis. Health professionals need to educate the Pakistani community in regards to what diabetes actually is and how sugar is a part of but not the whole problem. The problem consists of numerous causal factors and varies due to individual differences.

Lazarus and Folkman (1984a) define coping as an individual's cognitive and behavioural efforts to manage specific demands that are exceeding their resources (Lazarus & Folkman, 1984b). Most of the identified coping mechanisms in this project were from the emotion-focussed pathway, particularly escape-avoidance strategies, rather than the problem-focussed pathway. For example in the qualitative studies one British-Pakistani mother without T2DM discussed how some women with T2DM refrain from attending a social event like a wedding because they know they will indulge in glucose-rich fattening food as eating is a fundamental way of partaking in the celebrations. Overeating would cause T2DM complications later, but not eating would cause them and their hosts emotional distress.

They avoid this emotional distress by using their illness as an excuse not to attend at all rather than thinking of strategies to change their diet in that situation. However the majority of the British-Pakistanis in the current research believed that most T2DM individuals did not distance themselves from gatherings as they are perceived to be culturally important activities and that eating traditional food has cultural meaning, thus they simply excluded eating at significant events from food restrictions they may impose on themselves and others in everyday life. Jayne & Rankins (2001) also reported that individuals with T2DM are annoyed with food restrictions, the effect of food restrictions on socialisation, and presence of stigmatisation. British-Pakistani women indulged and enjoyed celebratory and traditional food although many with T2DM tried to control the amount they have because of their diabetes. Freedom from food restrictions was also seen by many participants as important for the kind of carefree life they wished for their families, and gifts of food they gave were symbolic of love and friendship. Recognising these feelings in their friends and relations meant they felt exempt from healthy eating on many occasions.

8.4.4 Physical activity

Physical activity is another significant aspect of an individual's T2DM control and prevention as well as impacting treatment effectiveness (Hampson, Glasgow & Foster, 1995; Hampson, Glasgow & Toobert, 1990). Glasgow and colleagues (1997) found that beliefs about treatment effectiveness and seriousness predicted exercise self-management. Sriskantharajah & Kai (2006) highlighted the need for better information and guidance on physical activity and they found that South-Asians women's motivations and attitudes towards physical activity were very similar to the majority of the general population. Therefore challenges to physical activity and ways of enhancing it may be more similar than different across cultural and ethnic groups. Sriskantharajah & Kai reported that these women give low priority to physical activity as their spare time is limited and set against family and other obligations (Rai & Finch, 1997; Eyler, Baker, Cromer et al. 1998). Walking is one of the best forms of physical activity for this group (Lamb, Bartlett, Ashley et al., 2002; Drinkwater et al., 1999).

Lack of exercise is a universal problem and a major challenge for the healthcare service to promote. The majority of British-Pakistanis of all ages do not engage in exercise and there is a need to improve especially young people's health and physical activity levels to prevent the onset of chronic diseases (Khunti, Stone, Bankart et al., 2007). Despite the increasing risk and prevalence rates of T2DM, Sriskantharajah & Kai (2006) found that women's main motivation towards physical activity was to improve body appearance and weight control which is common with other populations (Rai & Finch, 1997) and in line with the findings of this project. Health professionals need to be sensitive to these motivations whilst emphasising the specific benefits of physical activity to improve T2DM and reduce the complications to this group (Boule, Haddad, Kenny et al., 2001; Ades, 2001; Sriskantharajah & Kai, 2006).

Proactive targeting of information and knowledge is required, combined with specific guidance and reassurance about the safety of appropriate physical activity, and this should be sensitive to women's concerns and motivations (Mir & Sheikh, 2010). Measures to improve access and reduce barriers to exercise and leisure activity for all sections of society (Rai & Finch, 1997; Chinn, White, Harland et al., 1999), including exercise on prescription schemes (Carrol, Ali & Azam, 2002) should not be ignored. Increased provision of women-only activity is a crucial request from British-Pakistanis. Barriers of cultural differences are overemphasized to highlight their significance but they can induce a defeatist attitude among health promoters (Lamb, Bartlett, Ashley et al., 2002; Harland, White, Drinkwater et al., 1999). However there are many social and physical activities which are appealing to British-Pakistani women, such as walking, therefore approaches might build upon the potential of 'lay-led' walking schemes (Lamb, Bartlett, Ashley et al., 2002). When dealing with chronic illnesses and ethnic minority groups, Lawton and colleagues (2006) stated that health professionals need to work with instead of against cultural norms and individual perceptions when tackling the barriers to physical activity amongst British-Pakistanis with T2DM.

8.4.5 Stress

In this project some British-Pakistani women believed stress and depression to be the cause of diabetes especially among British-Pakistani women with T2DM. Stress seems to be associated with perceived seriousness illness representations and inversely with perceived treatment effectiveness in individuals with T2DM (Hampson, Glasgow & Foster, 1995; Jayne & Rankins, 2001), however a comparison between seriousness, treatment effectiveness and control illness representations with depression found that whereas the three illness representations predicted eating patterns, HbA1c and physical functioning; depression symptoms did not (Hampson SE, Glasgow RE, Strycker, 2000). This research supports the current project that in T2DM British-Pakistanis increased perceptions of control and understanding of diabetes are associated with less interference with social and personal functioning, fewer negative feelings and a more positive attitude (Eiser, Riazi, Eiser et al., 2004; Watkins, Klem, Connell et al., 2000). Edgar and Skinner (2003) similarly found perceived treatment effectiveness to predict emotional well-being in adolescents with type 1 diabetes, as well as social support impacting diabetes (Skinner, John & Hampson, 2000; Weinman, Petrie, Moss-Morris & Horne, 1996). Understanding the implications that stress has on T2DM is very important for prevention interventions as stress is experienced by all people in different situations. The mothers in the qualitative study (chapter 4) discussed family life stress and the young females (in chapter 5) discussed stress as a result of their busy student lifestyle, therefore it is important to consider the stress that will be caused by the onset of T2DM and include this into prevention strategies.

8.5 Ethnicity

8.5.1 British-Pakistani Muslims

British-Pakistani Muslims have the poorest overall health profile in Britain (Mir & Sheikh, 2010) and it is reported that Muslims experience particular disadvantage in self-reported ill-health, limiting long-term illness and disability (Office for National Statistics, 2004). Reasons for this include disadvantage focused on community mindset, socio-economic position and

ignorance about long-term diseases (Muslim Health Network, 2004; Greenhalgh, 2005; Platt, 2005), hence the social structures within which individuals live are crucial to understanding ethnic health inequalities (Karlsen & Nazroo, 2002a). '*Multilayered, multi-causal explanations*' of health inequalities are increasingly being developed (Davidson, Kitzinger & Hunt, 2006) alongside recognition that stress and self-esteem affect physical well-being (Marmot & Siegrist, 2004; Wilkinson & Pickett, 2009). Mir and Sheikh (2010) found that religious identity plays a central role in many Pakistani Muslims' attempts to make sense of their personal illness by offering them spiritual guidance to come to terms with an illness. Health professionals and patients are unwilling to discuss religious influences on a patient's decision-making, reflecting patients' lack of confidence in raising religious issues and professionals' lack of awareness of their importance. These social dynamics are reflected throughout UK society and they affect the psychosocial well-being of Pakistani Muslims and their ability to manage long-term conditions.

8.5.2 Language barriers

Previous research has emphasised language barriers as a main challenge for the healthcare service especially with the older Pakistani generation (Lawton, Ahmad, Hanna et al., 2006; Ilett & Freeman, 2004; Shaukat; Vyas, Haidery, Wiles et al., 2003). There were some difficulties in recruiting T2DM participants for the qualitative study of this research project from diabetes clinics however due to the author's bilingual skills one of the T2DM focus groups consisted of British-Pakistani mothers who were illiterate and could not converse in English. Therefore the focus group took place in Urdu, was then transcribed in Urdu and then translated into English. The decision to use this group was made due to their availability and because they were a hard to reach vulnerable group giving more validity to the findings that emerged. Language barriers still may be an obstacle in the older Pakistani generation groups especially to try and improve their self-management of diabetes but the current project emphasises that language is not much of a problem for prevention purposes. This is because prevention needs to be targeted at younger Pakistani generations for whom speaking and understanding English is not a problem.

8.5.3 Ramadan

A significant religious event which clashes with the prevention and management of T2DM among British-Pakistanis is Ramadan. This was a predominant issue across all participant groups in this project and is a significant part of their life. Fasting in Ramadan is obligatory for all healthy Muslim adults (Beshyah, Benbarka & Sherif, 2008). No food or drink may be consumed between dawn and sunset. Certain groups are exempt from fasting including the sick, the elderly, travellers and expectant and nursing mothers, yet many of those who are exempt may wish to observe the fast including those with T2DM (Salti, Benard, Detournay et al., 2004). It is the responsibility of the medical professional to empower patients to make an informed and an evidence-based decision (Glimepiride in Ramadan (GLIRA) Study Group, 2005; Salti, Benard, Detournay et al., 2004; Kadiri, Al-Nakhi, El-Ghazali et al., 2001). The management and prevention of diabetes during Ramadan should be considered well in advance of the holy month. For individuals with T2DM, many of them develop their own opinions and establish their own practices of amending their diabetes management plans from previous personal experience, therefore these individuals need to be encouraged to seek advice before considering fasting during the month of Ramadan (Al-Amoudi, Al-Ulagi, Bashir et al., 2006). Special classes may need to be considered by health professionals to enhance self-management during this month (Chowdhury, Hussain & Hayes, 2003), and it would be ideal to use these classes as prevention aids too, for individuals without diabetes who come along with T2DM patients. Health professionals should have a clear understanding of the religious ruling on fasting so that they can give their advice with confidence (Beshyah, Benbarka & Sherif, 2008). Preventative lifestyle behaviours should be re-enforced before and during Ramadan, and Muslims need to be encouraged to pay careful attention to their diet when eating is permitted to avoid excessive gorging, compensatory eating of carbohydrates and fatty foods, contributions to poor control and wide excursions in blood glucose and weight gain. The British-Pakistanis in this project reiterated how during Ramadan Muslims do not adhere to healthy practices and instead gorge on food especially as a lot of family gatherings take place during and after this religious period. Ramadan can

be seen as a perceived barrier to not adhering to healthy living as it is used as an excuse not to adopt prevention behaviours during this significant time. They are already depriving themselves of food and drink during daylight hours thus they do not want to deprive themselves of other pleasures. Therefore British-Pakistanis need to be encouraged to maintain their good dietary habits and to resist any temptation to break from their dietary restrictions. This may also be a reason for why British-Pakistanis do not adopt prevention behaviours throughout the rest of the year as Ramadan is the one time of the year that they demonstrate self-control and therefore do not wish to do it for the other eleven months.

Regular light to moderate exercise during Ramadan fasting can be tolerated and is safe for T2DM British-Pakistanis (Salti, Benard, Detournay et al., 2004) and thus needs to be encouraged as well as healthy eating. The DESMOND project which is a theoretically based diabetes education and self-management programme based in the UK aims to deliver high quality patient education to people with T2DM or who are at risk of it (DESMOND, 2008). It has started to tackle this issue of Ramadan and T2DM care as well as other smaller local projects as Ramadan will be during the longest days of the year over the next half decade or so. This means that Muslims will be keeping fasts as long as 18-20 hours per day. For individuals suffering from T2DM this has huge implications on their treatment regimes, and huge implications on motivating individuals to continuing preventing T2DM in themselves and their families.

8.6 Theory-based research and implications

8.6.1 Illness perceptions support and critique

The uniqueness of CSM (Leventhal, Meyer, Nerenz, 1980) is that it takes into account the emotional and rational responses to illness and therefore is one of the best models for identifying the causes of self-care behaviours. Jayne & Rankin (2001) found that the representation stage of the model indicates Chinese T2DM immigrants' experience both cognitive and emotional pathways. When a health threat is imminent or probable an

individual displays threat avoidance and control (Wakslak et al. 2006). Mental and behavioural representations of the illness are initially generated via symptoms, physical dysfunctions, illnesses in others, and a variety of social and media messages to control and regulate a chronic illness threat. Treatment behaviours understand and react with consequences, time lines, efficacy (control), and route of action (causal) expectations.

Individuals are motivated by short and long-term perceptions of diabetes including views on adverse effects, perceived impact on their everyday life, perceived personal control and perceptions of the effectiveness of preventative strategies (Harvey & Lawson, 2009). The CSM also suggests that individuals respond to avoid danger as well as avoid the emotion of fear (Leventhal, Cameron, 1987; Leventhal, Meyer, Nerenz, 1980). French, Wade & Farmer's (2011) study into the self-care behaviours of T2DM patients found that a patient's self-care behaviour was predicted not only by illness perceptions but also by beliefs about behaviour. French et al.'s study yielded non-significant results when statistically testing self-care behaviours on illness perceptions. They reported that beliefs about behaviour need to be added to the CSM to make it stronger as illness perceptions are simply not enough to explain behaviours towards an illness. Further research could look at beliefs about prevention behaviours and prevention behaviours themselves in order to achieve a more conclusive outcome, both in French et al.'s study and the current project.

Leventhal suggested that a person is an active problem-solver demonstrating behaviour to try and close the perceived gap between their current status and a goal or ideal state. Another way the CSM differs from other health belief models is that it acknowledges an individual's current and past experience. The model implies that an individual can be influenced to achieve a more adaptive understanding of their condition and to evaluate the effects of acting on this understanding. Support for the CSM is overwhelming supporting the validity of the model (Harvey & Lawson, 2009; Hagger & Orbell, 2003; Heijmans & de Ridder, 1998), thus it is favoured by health psychologists as people take an active role in managing their own condition (Harvey & Lawson, 2009; Jayne & Rankin 2001). This model had also

been successfully used in research dealing with adolescent illness perceptions (Skinner & Hampson, 1998; Skinner, John & Hampson, 2000) and healthy populations (Figueiras & Alves, 2007). As a result it was the best model to use in this thesis project with the three varied participant groups.

A limitation of integrating the CSM with new approaches to clinical trials is that the focus of the intervention is on health professionals as well as on patients. This raises problems and concerns with communications with one another and with family members, genetic and cultural issues (Leventhal, Weinman, Leventhal & Phillips, 2008). Another limitation is concerning the linear nature of the model not being effective in understanding nonlinear processes such as culture or ethnicity (Jayne & Rankin 2001). These nonlinear processes are very complex and cannot fit into such a straightforward model.

The interaction between perceptions of seriousness and treatment effectiveness are important (Skinner, John & Hampson, 2000; Harvey & Lawson, 2009). These perceptions highlight the belief that T2DM is a serious illness and is a positive motivator for effective treatment unless emotion perceptions dominate (Witte & Allen, 2000; Ruiters, Verplanken, Kok & Verrij, 2003). In the qualitative studies British-Pakistani women viewed T2DM as a serious disease especially its complications. When discussing the severity of the disease they perceived T2DM to be chronic, medication to be very important to help with the treatment, that insulin was a harsh invasive and severe alternative form of treatment, and changes especially in lifestyle habits would prevent the onset of the disease (Jayne & Rankin, 2001). Jayne & Rankin (2001) also reported that avoiding sweets was one of the most common cognitive coping mechanisms, demonstrated in this project. Participants in this project discussed how sugar was a major causal factor and how it was one of the first things T2DM individuals gave up especially in their tea. However many British-Pakistanis (especially those who do not have a diagnosis of T2DM but are at high risk) are non-compliant even blasé yet they are very fearful of the disease. Therefore knowledge and education is simply not enough to change the behaviours of the British-Pakistani women to

help them adhere to healthier lifestyle and actively prevent the risk of them developing T2DM.

8.6.2 The Protection Motivation Theory (PMT)

PMT promotes fear appeal studies aimed to impart information about the value of health protective behaviours and risks of non-compliance. Health protective behaviour is believed to be dependent on the amount of fear drive created (Harvey & Lawson, 2009). The PMT recognises that high levels of fear will lead to avoidance/denial and that low to moderate fear levels will motivate people to comply. There is limited research using the PMT model (Beck & Frankel, 1981) for tackling the prevention of T2DM however the messages and constructs of the model mirrored the aims of this project, therefore it was used as the theory-base underpinnings of this project. It complements the workings of the CSM and research exploring illness perceptions. The findings of the qualitative research in this thesis support the notion for using fear as part of awareness and prevention education.

British-Pakistani women were fearful when they discussed the possibility of T2DM in their children or younger acquaintances. They understood the implications of the disease and when discussing it in references to children they were more fearful of it due to the disease's severity. For older people T2DM was perceived as just another illness they developed but for youngsters it would be detrimental as they would have to be cautious for the rest of their lives and may even end up adhering to an insulin injections regime. Thus using fear appeals in T2DM prevention materials in a holistic family environment maybe very beneficial. Fear communication studies identify this form of avoidance behaviour (Ruiter, Abraham & Kok, 2001) and there are clear differences in health-related behaviour between young and old individuals (Lawson, Lyne, Bundy & Harvey, 2005). Age may result in different symptoms as well as representation of these symptoms. In older people illness representations are based on life experience and social experience. They experience greater feelings of vulnerability, practise risk aversion and more self-care (except for exercise) (Leventhal & Crouch, 1997). Thus the elderly tend to show more adaptive coping behaviour. In this project studies,

British-Pakistani women believed T2DM to be more common among the elderly and that it is more sinister for children and the younger generation than the older generations. They were easily dismissive when an older person was diagnosed with T2DM.

8.7 Health Policy

8.7.1 Health reform

Health system reform is a priority for many developed countries in order to meet increasing health service demands. Empowerment promotes efficiency at the system and service level. In contrast self-efficacy relates specifically to an individual's beliefs about his/her abilities to produce desired levels of performance that influence events that affect their lives (Bandura, 1994). The main features that support empowerment and strategies for implementation are not well documented (Segal, 1998). This reflects the lack of appropriate tools for the measurement of individual and community empowerment, thus a lack of evidence between empowerment, health, well-being and system efficiency. Segal (1998) commented on a micro-economic framework to define universal performance characteristics for optimal health funding arrangements. This model focuses on two things, demand and supply: demand side reform to empower consumers and supply side reform to promote opportunities and incentives for a responsive service system and competition amongst providers. A focus on supply side issues will only fail to promote an efficient solution to the distribution of health resources. Segal reported that the mechanisms to promote active patient involvement in healthcare decisions are identified as a central requirement in health system reform.

Numerous studies support the role of diabetes education in effective self-care and improved health outcomes (Cox, Gonder-Frederick, Julian & Clark, 1994; Hanefeld, Fischer, Schmechel et al., 1991; Mazzuca, Moorman, Wheeler et al., 1986). An evaluation of a diabetes education service in Melbourne reported an improvement in health outcomes (blood glucose, weight and blood pressure) and in perceived well-being, relative to standard-care. In qualitative research patients identified that the comprehensive educational programme

and supportive staff enhanced their knowledge, skills and confidence in their capacity for effective self-care (Segal, Ruth, Lampshire & Pasani, 1994). Lifestyle attributes provide much of the explained variation but a strong positive socio-economic gradient is also widely observed (Evans, Barer & Marmor, 1994). Empowerment is proposed as a major determinant of the socio-economic gradient in health, possibly mediated through stress, as well as an influence on lifestyle behaviours (Evans, Barer & Marmor, 1994, Syme, 1996).

8.7.2 Screening

It is an important issue for the health service to screen for T2DM as the increase in risk starts below the level of blood glucose used to define the disease and IGT individuals are not included (Waugh, Scotland, McNamee et al., 2007). This is a significant method that can be used to identify people who are at risk of developing T2DM and then target them with T2DM prevention interventions. Earlier detection and treatment reduces the development of specific T2DM problems and can be cost-effective. Several trials have shown that both lifestyle measures and pharmacological treatment can reduce the proportion of people with IGT who would otherwise develop T2DM. Diet and exercise treatment is the most cost-effective option. Treatment with metformin may be less cost-effective than lifestyle changes but would be inappropriate in some groups. Waugh and colleagues (2007) suggest that screening could be two-stage: people at higher risk based on primary care records of age, weight and other indicators of metabolic risk, and then the second-stage could be identifying people at higher risk based on the oral glucose tolerance test (OGTT). However the limitation of the OGTT is that it is expensive, inconvenient and has weak reproducibility. The case for screening for undiagnosed T2DM is strong because of the rising prevalence of obesity and T2DM.

8.7.3 Reaching out to British-Pakistanis

With specific reference to British-Pakistani Muslims, the health service can use Islam to aid and educate them. Islam emphasises mental and physical well-being and diet as important factors for promoting health, which is in accordance with previous research and

recommendations for individuals with T2DM (Hjarpe, 1992; Svanberg & Westerlund, 1999; Samuelsson, 2001). Thus it would be beneficial to incorporate Islamic teachings endorsing healthy living into preventions. Imams (Islamic priests) can be used in developing and delivering these types of T2DM prevention programmes as they will have a better knowledge concerning Islamic teaching and they will be able to target Muslim population groups outside healthcare remits. The health service has an influential and vital role to play and by taking into account the expectations of the British-Pakistani population they can become aware of cultural differences. From this project and past research it is naïve to think of developing a generic prevention tool for T2DM. Resources need to be planned so that they are culturally sensitive and adaptable.

Healthcare professionals should think about the different mediums of promoting resources and utilising them especially as funding and budgets are scarce. One way to do this is by empowering Pakistanis to take control of their families and to be more assertive in their food choices. There are many programmes available that demonstrate how you can make a cheap and quick healthy meal for the family. British-Pakistanis need to realise that healthy foods are not expensive and that they do not need to shop at a big brand store to get the right products. There is a lot of literature available and some in different languages too. Leaflets also need to be culturally sensitive and appealing e.g. using pictures of traditional foods the likes of curry and chapatti instead of a western culinary dish, a glass of lassi instead of alcohol or a picture of a family in traditional Pakistani attire rather than western clothing. Although religion cannot replace ethnicity, social class, gender or other aspects of identity when trying to research and understand British-Pakistani communities, it could aid to develop a more complete picture of their experience. Thus it may be appropriate to incorporate it into a framework for understanding health inequalities (Mir & Sheikh, 2010). British-Pakistanis are a very complex group as they have a lot of cultural and religious obligations which are embedded in their everyday lives. Researching ethnicity helps to tap into their culture but adding religion will have to understand their behaviour and practices better.

8.7.4 Traditional medicines

Another key aspect of Pakistani culture which needs to be addressed in healthcare policy is traditional medicines. Pieroni and colleagues (2008) illustrated that Pakistani migrants have their own strategies within their households for counteracting T2DM and some use herbal remedies. Detailed knowledge of these practices could be crucial for public health interventions. Participants in this project emphasise the use of herbal and traditional medicines, especially food remedies. It is therefore important to acknowledge these in health policy making and designing. Trans-cultural healthcare has become a crucial issue to many involved in setting governmental health-policy agendas. In recent years increasing numbers of academics have begun to cross-culturally study traditional healing practices and medicines within multi-cultural societies (Pieroni, M'unz, Akbulut et al., 2005;Reiff O'Connor, Kronenberg et al., 2003; Balick, Kronenberg, Ososki et al., 2002).

8.7.5 Patient-professional relationship

Another significant area to focus on is patient-professional relationships for T2DM management. Mir & Sheikh (2010) reported that health professionals need to realise and demonstrate the significance of being able to talk with Pakistani patients and to try and initiate this dialogue themselves where relationships are not well developed. Failure to do this fuels the differences between lay-professional perspectives which exist across cultural groups (Lambert & Sevak, 1996; Stevenson et al., 2000). As emphasised by Mir & Sheikh health professionals are not aware of British-Pakistanis' concerns regarding incorporating treatment into daily life and influences affecting their decision-making predominantly due to this lack of speech. Thus issues of risk are not discussed nor explained, decisions of Pakistani patients are not fully informed and health inequalities are sustained. Approaches that are supposed to aid health professionals in asking appropriate questions during consultations demonstrate the variety of misconceptions that exist (Davis et al., 2007; Stevenson et al., 2000). Increased knowledge and confidence to effectively engage with Muslim Pakistani patients would help practitioners avoid situations that prevent or delay

accurate diagnosis and intervention. This could be done by training health professionals to understand the cultural context of this population group and achieve shared understanding of long-term illness management (Kai et al., 2007). Such interventions would require resources and leadership alongside organisational and individual development to achieve real significant change (Mir & Tovey, 2002). Short-term investments in healthcare are likely to result in long-term gains and prevention of avoidable illness suffering otherwise health inequalities may continue over many generations (Abbotts et al., 1997). Mir & Sheikh (2010) suggest a need to determine the exact relationship between psychosocial well-being and health in British-Pakistani Muslims and clearly defined pathways from micro issues of communication to macro issues of health inequalities. This would inform future policy development and establish a more definitive relationship between the subjective assessments of Pakistanis and health inequalities in this community.

8.7.6 Culture and prevention interventions

It is of great importance to consider cultural differences and needs in T2DM prevention (Hawthorne, 2001; Hjelm, Bard, Nyberg & Apelqvist, 2003). All persons with T2DM need knowledge about the management of the disease and prevention to encourage healthy lifestyles in others. Hence it is important to promote policy that satisfies individual needs and favours patient education, aiming at empowering patients' participation in self-care (Hjelm, Bard, Nyberg & Apelqvist, 2003). Educational approaches in many cultures tend to emphasise storytelling and role modelling (Finucane & McMullen, 2008; Gotay, Banner, Matsunaga et al., 2000). Differences between the way educational programs deliver information and the natural way individuals receive information can influence the effectiveness of health-promotion programmes. Strategies for effective culturally appropriate T2DM programmes have been proposed which include storytelling to communicate information and skills about diabetes (Braun, Mokuau & Tsark, 1997; Griffin, Gilliland, Perez et al., 1999).

There is a small body of research on the cultural characteristics of Filipino-Americans that may influence healthcare (Becker, 2003; Becker, Beyene, Newsom et al., 1998; Braun, 1997). The relative importance of these characteristics for self-care behaviours depend on an individual's time of immigration (i.e. first, second, third generation born in US) (Hahn, Truman & Barker, 1996; Phinney & Alipuria, 1996; Turner, Oakes, Haslam & McGarty, 1994). The importance of family, social relationships, food and faith is considered key in understanding effective health promotion and care with Filipino-Americans (Edman & Kameoka, 1997; DiPasquale-Davis & Hopkins, 1997), and is reflected in this project with British-Pakistanis. These results are also consistent with literature emphasising that cultural beliefs influence perceptions of illness and understandings of the way in which chronic disease can be managed (Caban & Walker, 2006; Scollon-Koliopoulos, O'Connell & Walker, 2005; Mau, Glanz & Serverino, 2001). The importance of qualitative aspects of perceptions of diabetes risk is consistent with risk-perception research (Finucane, Peters & Slovic, 2003; Loewenstein, 2005; Slovic, Peters, Finucane & MacGregor, 2005).

Behavioural health research can contribute to the prevention and control of T2DM; the design, implementation, and testing of interventions need to be a top priority. Behavioural interventions work but their adoption requires effectiveness and efficiency from the healthcare system, the family as well as the patient. Developing and testing theory-based prevention interventions requires that integrated multidisciplinary research teams be involved at every stage from planning to implementing and making sure the integration of behavioural, bio-medical, and the beliefs of people and families in specific institutional and cultural contexts occurs producing substantial health benefits and satisfaction. For example using link workers and extra community diabetes specialist nurses together with treatment protocols in primary care might prove a useful strategy in working towards National Service Framework targets for diabetes management (O'Hare, Raymond & Mughal, 2004; Gray, Clarke, Farmer & Holman, 2002).

8.8 Future direction and recommendations

Mixed-methodology has a significant role in research especially when exploring illness perceptions and conducting research in diverse communities. Qualitative data allows for rich and explorative data, and quantitative research allows for comparisons with other studies on psychosocial well-being and health as well as further exploration of diversity within communities (Marmot & Siegrist, 2004; Abbotts et al., 1997). Future healthcare practice, policy and research needs to engage with a mixed-methodology approach with British-Pakistanis in order to adequately understand and challenge the barriers relevant to this group.

Previous research has proposed a number of reasons for the lack of prevention adherence and improvements in regards to T2DM and British-Pakistani groups. Some of these reasons included questionnaires/resources used to measure changes were not sensitive enough, the frequency of education sessions were not sufficient to bring about a change, interventions with a period of one year were not long enough in a population with complex language and cultural constructs, the patients did not understand the relevance of knowing the answers to the questions and the responses may not have been correctly expressed (Greenhalgh et al., 1998; Vyas, Haidery, Wiles et al., 2003). Many educational programmes based on conventional clinical models are ineffective in specific cultural groups (Greenhalgh et al., 1998), therefore there is a need for less formal educational sessions in a relaxed group atmosphere enabling the development and exploration of topics raised by the participants (Vyas, Haidery, Wiles et al., 2003).

T2DM in British-Pakistanis is a major problem and all British-Pakistanis are responsible for their own health. One of the concerns for health policymakers is dealing with the failure to translate research knowledge into action in healthcare and as a result there are health inequities and it wastes costly and time-consuming research (Graham, Logan, Harrison et al., 2006; World Health Organization, 2004). Knowledge transfer is the exchange, synthesis and application of research results and other evidence between academic and practice

settings (Graham, Logan, Harrison et al., 2006). The gap between what is known and what is done leads to the under-use of effective treatments, the wrong use of treatments and the over-use of unhelpful or unproven treatments, leading to negative outcomes for patients. The evidence for knowledge transfer interventions is sparse and descriptions of the processes involved are vague because rather than focusing on the evaluation of knowledge transfer interventions previous literature focussed on theories, models or frameworks of the knowledge transfer process (Ward, House & Hamer, 2009). Therefore as a future direction of this project the aim is to disseminate the findings in appropriate Birmingham healthcare media and encourage stakeholders and health policy makers to rethink their strategies to combating T2DM especially within the British-Pakistani community. It will also be disseminated into educational newsletters and forums to encourage British-Pakistani parents to adhere to health lifestyles and to promote T2DM awareness and knowledge.

The main recommendation of this project is to design and implement a culturally appropriate prevention intervention for British-Pakistani women targeting a mixture of age groups not just the older generations. The majority of younger generations do not have a diagnosis of T2DM therefore they need prevention interventions to reduce their risk of T2DM. It is also important to target young adult women as they are 'future' mothers so by embedding prevention perceptions, intentions and behaviours in them early should have a ripple effect later on in their lives and with their future families and children. A culturally appropriate prevention intervention for British-Pakistani women must tackle cultural and ethnic issues i.e. food, family, lay beliefs.

Another recommendation of this research is to design a prevention intervention targeting GD. British-Pakistani women in this project knew of women who had developed T2DM after having GD. Women are regularly monitored throughout pregnancy and after child birth. This would be a good time and opportunity to encourage them to take part in behaviour change activities to help them to live healthier lifestyles. This will also help to reduce their risk of GD and T2DM after birth.

8.9 Conclusion

In conclusion this project has targeted three important areas that have been currently under-researched. The studies have highlighted the importance of targeting not just a British-Pakistani ethnic group but British-Pakistani women. This is such a vital population group to research as one can learn about cultural and ethnical issues, matters surrounding British-Pakistani women and their barriers for not adhering to healthy lifestyles, and most importantly their role in family to help with T2DM prevention. From this project, the studies have highlighted the perception that bad diet due to British influence is the main cause for the high prevalence rates and high at-risk rates of T2DM among British-Pakistanis. However British-Pakistanis also acknowledged that lack of exercise, genetic factors and high consumption of sugar, as well as other causal factors all contribute to the inevitable onset. There is a visible shift in T2DM once being viewed as an old age disease to becoming a likely illness for young adults. Future prevention intervention must include lifestyle modifications as well as an education component, and demonstrate cultural sensitivity towards British-Pakistanis. Health policies and promoters need to do everything they can to encourage these groups even though ultimately the responsibility lies with the individual.

DOCTOR OF PHILOSOPHY

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Aston University

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Appendix 2.1 - Data Extraction Form

Author: _____

Year of publication: _____

a. Setting for intervention:

1. Location (city and country)
2. Clinical setting of trial
3. Trial dates

b. Population

1. Specific characteristics of those recruited, e.g. diagnosis of T2DM
2. How were participants recruited?

3. Total number of participants recruited

4. Number of groups

5. Number randomised into a group

6. Gender

7. Age (means and range)

8. Ethnicity

9. Occupation

10. SES

11. Drop outs during intervention

12. Total number lost after follow up

c. Prevention

1. Describe all the specific elements of the intervention

2. Duration of intervention or specific elements

3. Duration and specific of follow up period

d. Dichotomous outcomes

1. Describe the specific outcomes and how the data was obtained?

2. At what point(s) of the intervention was the outcome assessed?

3. Events at baseline

4. Number available at follow-up 1

5. Events at follow up 1

6. Number available at follow up 2

7. Events available at follow up 2

8. Details of further follow ups

9. Statistical data for each group (including test conducted and values, p values, etc)

10. Outcome

Appendix 2.2 – Quality Assessment Table

		Baradaran et al.	Brekke et al.	Carels et al.	Carpeleijn et al.	Diabetes Prevention Programme Research Group	Glasgow et al.	Gregg et al.	Hardeman et al.	Kinmonth et al.	Kosaka et al.	Lakshman et al.	Lindstrom et al. (03)	Lindstrom et al. (06)	Orchard et al.	Ramachandran et al.	Sakane et al.	Siitonen et al.	Simmons et al.	Vermans et al.	Warren et al.	
a	i	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
	ii	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
b	i	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
c	i	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	ii	N	N	N	N	N	Y	N	N	N	N	N	N	N	N	N	Y	N	N	Y	N	N
d	i	N	N	N	N	N	DK	N	N	N	N	N	N	DK	N	N	DK	N	N	DK	N	N
	ii	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	iii	N	N	N	N	N	N	N	DK	N	N	N	N	DK	N	N	DK	N	N	N	N	N
	iv	DK	N	N	DK	DK	N	N	DK	N	N	DK	Y	DK	DK	Y	Y	DK	N	DK	N	N
e	i	DK	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	DK	Y
	ii	DK	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	DK	Y
f	i	Y	Y	Y	Y	DK	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	ii	DK	DK	Y	Y	DK	DK	Y	DK	Y	Y	Y	Y	Y	Y	Y	Y	DK	DK	Y	DK	DK
	iii	DK	N	Y	Y	DK	DK	Y	DK	Y	Y	Y	Y	Y	Y	Y	Y	DK	Y	Y	Y	Y
Score		4	4	4	4	3	4	5	3	4	4	4	4	4	5	5	4	4	4	4	4	
Quality		M	M	M	M	M	M	H	M	M	M	M	M	M	H	H	H	M	M	M	M	

M = Medium Research Quality

H = High Research Quality

Y = Yes
 N = No
 DK = Do not Know

Appendix 2.3 - Potential Relevant Journals

Journal	Included	Excluded	Reason for exclusion
Akhtar, M. S., Almas, K., Kauser, T. & Wolever, T. M. S. (2002), 'Blood glucose responses to traditional South Asian dishes in normal and diabetic human subjects', <i>Nutrition Research</i> , 22, pp.989-996		✓	Did not evaluate a prevention intervention
Almeida-Pititto, B., Hirai, A. T., Sartorelli, D. S., Harima, H. A., Gimeno, S. G. A., Ferreira, S. R. G & The Japanese-Brazilian Diabetes Study Group. (2010), 'Predictive factors of non-deterioration of glucose tolerance following a 2 year behavioural intervention', <i>Diabetology & Metabolism Syndrome</i> , 2:52		✓	No control group
Baradaran, H. R., Knill-Jones, R. P., Wallia, S. & Rodgers, A. (2006), 'A controlled trial of the effectiveness of a diabetes education programme in a multi-ethnic community in Glasgow', <i>BMC Public Health</i> , 6, pp. 134-142	✓		n/a
Bergland, J. E., Heuer, L. & Lausch, C. (2007) 'The use of prayer by hispanic migrant farmworkers with type 2 diabetes', <i>Journal of Cultural Diversity</i> , 14(4), pp. 164-168		✓	Qualitative research study
Berlin, K. S., Sass, D. A., Davies, W. H., Reupert, S. & Hains, A. A. (2005), 'Brief report: parental perceptions of hypoglycaemic symptoms of youth with diabetes; diabetes disclosure minimizes risk of negative evaluations', <i>Journal of Pediatric Psychology</i> , 3(2), pp.207-212		✓	No control group and did not evaluate a prevention intervention
Bindler, R. M. & Bruya, M. A. (2006), 'Evidence for identifying children at risk for being overweight, cardiovascular disease, and type 2 diabetes in primary care', <i>Journal of Pediatric Health Care</i> , 20(2), pp. 82-87		✓	No control group

Journal	Included	Excluded	Reason for exclusion
Boltri, J. M., Davis-Smith, M. V., Seale, P. J., Shellenberger, S., Okosun, I. S. & Cornelius, M. E. (2008), 'Diabetes prevention in a faith-based setting: results of translational research', <i>Journal of Public Health Management & Practice</i> , 14(1), pp. 29-32		✓	No control group
Brekke, H. K., Jansson, P. A. & Lenner, R. A. (2005), 'Long-term (1- and 2-year) effects of lifestyle intervention in type 2 diabetes relatives', <i>Diabetes Research and Clinical Practice</i> , 70, 225-234	✓		n/a
Browning, C., Chapman, A., Cowlshaw, S., Li, Z., Thomas, S. A., Yang, H. & Zhang, T. (2011), 'The Happy Life Club study protocol: a cluster randomised controlled trial of a type 2 diabetes health coach intervention', <i>BMC Public Health</i> , 11(90)		✓	No results reposted, design and methodology only
Carels, R. A., Darby, L., Cacciapaglia, H. M., Konrad, K., Coit, C., Harper, J., Kaplar, M. E., Young, K., Baylen, C. A. & Versland, A. (2007), 'Using motivational interviewing as a supplement to obesity treatment: a stepped-care approach', <i>Health Psychology</i> , 26(3), pp. 369-374	✓		n/a
Cartwright, M., Wardle, J., Steggle, N., Simon, A. E., Croker, H. & Jarvis, M. J. (2003), 'Stress and dietary practices in adolescents', <i>Health Psychology</i> , 22(4), pp. 362-369		✓	Did not evaluate a prevention intervention
Castelnuovo, G., Manzoni, G. M., Cuzziol, P., Cesa, G. L., Tuzzi, C., Villa, V., Liuzzi, A., Petroni, M. L. & Molinari, E. (2010), 'TECNOB: study design of a randomised controlled trial of a multidisciplinary telecare intervention for obese patients with type-2 diabetes', <i>BMC Public Health</i> , 10(204)		✓	Not a prevention intervention and no results reported, only design and methodology
Chang, M. W., Brown, R. & Nitzke, S. (2009), 'Participant recruitment and retention in a pilot program to prevent weight gain in low-income overweight and obese mothers', <i>BMC Public Health</i> , 9(424)		✓	No result section containing data of the prevention intervention

Journal	Included	Excluded	Reason for exclusion
Cho, Y. M., Ritchie, M. D., Moore, J. H., Park, J. Y., Lee, K. U., Shin, H. D., Lee, H. K. & Park, K. S. (2004). 'Multifactor-dimensionality reduction shows a two-locus interaction associated with type 2 diabetes mellitus', <i>Diabetologia</i> , 47, pp.549-554		✓	Did not evaluate a prevention intervention
Chowdhury, S. M., Brophy, S., Fareedi, M. A., Zaman, B., Ahmed, P. & Williams, D. R. R. (2008), 'Intervention, recruitment and evaluation challenges in the Bangladeshi community: experience from a peer lead educational course', <i>BMC Medical Research Methodology</i> , 8(64)		✓	Did not evaluate a prevention intervention
Chowdhury, T. A. & Lasker, S. S. (2002), 'Complications and cardiovascular risk factors in South Asians and Europeans with early onset type 2 diabetes', <i>Q J Med</i> , 95, pp. 241-246		✓	Did not evaluate a prevention intervention
Classen, L., Henneman, L., Jassens, A. C. J. W., Wijdenes-Pijl, M., Qureshi, N., Walters, F. M., Yoon, P. W. & Timmermans, D. R. M. (2010), 'Using family history information to promote healthy lifestyles and prevent disease; a discussion of the evidence', <i>BMC Public Health</i> , 10(248)		✓	Did not evaluate a prevention intervention
Corpeleijn, E., Feskens, E. J. M., Jansen, E. H. J. M., Mensink, M., Saris, W. H. M., de Bruin, T. W. A. & Blaak, E. E. (2006), 'Improvements in glucose tolerance and insulin sensitivity after lifestyle intervention are related to changes in serum fatty acid profile and desaturase activities: the SLIM study', <i>Diabetologia</i> , 49, pp. 2392-2401	✓		n/a
Draper, C. E., de Villiers, A., Lambert, E. V., Fourie, J., Hill, J., Dalais, L., Abrahams, Z. & Steyn, N. P. (2010), 'HealthKick: a nutrition and physical activity intervention for primary schools in low-income settings', <i>BMC Public Health</i> , 10:398		✓	No results stated, only design and methodology

Journal	Included	Excluded	Reason for exclusion
Eakin, E. G., Reeves, M. M., Marshall, A. L., Dunstan, D. W., Graves, N., Healy, G. N., Bleier, J., O'Moore-Sullivan, T., Russell, A. & Wilkie, K. (2010), 'Living well with diabetes: a randomised controlled trial of a telephone-delivered intervention for maintenance of weight loss, physical activity and glycaemic control in adults with type 2 diabetes', <i>BMC Public Health</i> , 10(452)		✓	No results stated, only design and methodology
Edwards, S., Murphy, C., Feltbower, R. G., Stephenson, C. R., Cade, J. E., McKinney, P. A. & Bodansky, H. J. (2006), 'Changes in the diet of a South Asian transmigratory population may be associated with an increase of childhood diabetes', <i>Nutrition Research</i> , 26, pp.249-254		✓	No control group
Ekelund, U., Griffin, S. J. & Wareham, N. J. (2007), 'Physical activity and metabolic risk in individuals with a family history of type 2 diabetes', <i>Diabetes Care</i> , 30, pp. 337-342		✓	No control group
Ezendam, N. P. M., Oenema, A., van de Looij-Jansen, P. M. & Brug, J. (2007), 'Design and evaluation protocol of "FATaintPHAT", a computer-tailored intervention to prevent excessive weight gain in adolescents', <i>BMC Public Health</i> , 7(324)		✓	No results reported, design and methodology only
Francis, J. J., Eccles, M. P., Johnston, M., Whitty, P., Grimshaw, J. M., Kaner, E. F. S., Smith, L. & Walker, A. (2008), 'Explaining the effects of an intervention designed to promote evidence-based diabetes care: a theory-based process evaluation of a pragmatic cluster randomised controlled trial', <i>Implementation Science</i> , 3(50)		✓	Did not evaluate a prevention intervention
Glasgow, R. E., Nelson, C. C., Kearney, K. A., Reid, R., Ritzwoller, D. P., Strecher, V. J., Couper, M. P., Green, B. & Wildenhaus, K. (2007), 'Reach, engagement, and retention in an internet-based weight loss program in a multi-site randomized controlled trial', <i>Journal of Medical Internet Research</i> , 9(2)	✓		n/a

Journal	Included	Excluded	Reason for exclusion
Gorley, T., Nevill, M. E., Morris, J. G., Stensel, D. J. & Nevill, A. (2009), 'Effect of a school-based intervention to promote healthy lifestyles in 7-11 year old children', <i>International Journal of Behavioural Nutrition and Physical Activity</i> , 6:5		✓	Did not evaluate a T2DM prevention intervention
Griffin, S. J., Simmons, R. K., Williams, K. M., Prevost, A. T., Hardeman, W., Grant, J., Whittle, F., Boase, S., Hobbis, I., Brage, S., Westgate, K., Fanshawe, T., Sutton, S., Wareham, N. J., Kinmonth, A. L., the ADDITION-Plus study team. (2011), 'Protocol for the ADDITION-Plus study: a randomised controlled trial of an individually-tailored behaviour change intervention among people with recently diagnosed type 2 diabetes under intensive UK general practice care', <i>BMC Public Health</i> , 11(211)		✓	No results reported, design and methodology only
Grace, S. L., Barry-Bianchi, S., Stewart, D. E., Rukholm, E. & Nolan, R. P. (2006), 'Physical activity behavior, motivational readiness and self-efficacy among ontarians with cardiovascular disease and diabetes', <i>Journal of Behavioral Medicine</i> , 30(1), pp. 21-29		✓	No control group
Gregg, J. A., Callaghan, G. M., Hayes, S. C. & Glenn-Lawson, J. L. (2007), 'Improving diabetes self-management through acceptance, mindfulness, and values: a randomized controlled trial', <i>Journal of Consulting and Clinical Psychology</i> , 75(2), pp.336–343	✓		n/a
Haapala, I., & Probart, C. (2004), 'Food safety knowledge, perceptions, and behaviors among middle school students', <i>Journal of Nutritional Education Behavior</i> , 36, pp.71-76		✓	No control group
Hamman, R. F., Wing, R. R., Edelstein, S. L., Lachin, J. M., Bray, G. A., Delahanty, L., Hoskin, M., Kriska, A. M., Mayer-Davis, E. J., Pi-Sunyer, X., Regensteiner, J., Venditti, B. & Judithwylie-Rosett, E. (2006), 'Effect of weight loss with lifestyle intervention on risk of diabetes', <i>Diabetes Care</i> , 29, pp. 2102-2107		✓	Not original study, data reported elsewhere

Journal	Included	Excluded	Reason for exclusion
Hardeman, W., Kinmonth, A. L., Michie, S., Sutton, S., The ProActive Project Team. (2009), 'Impact of a physical activity intervention program on cognitive predictors of behaviour among adults at risk of type 2 diabetes (ProActive randomised controlled trial)', <i>International Journal of Behavioural Nutrition & Physical Activity</i> , 6(16)	✓		n/a
Hayes, L., White, M., Unwin, N., Bhopal, R., Fischbacher, C., Harland, J. & Alberti, K. G. M. M. (2002), 'Patterns of physical activity and relationship with risk markers for cardiovascular disease and diabetes in Indian, Pakistani, Bangladeshi and European adults in a UK population', <i>Journal of Public Health Medicine</i> , 24(3), pp. 170-178		✓	No control group and did not evaluate a prevention intervention
Halperin, F., Beckman, J. A., Patti, M. E., Trujillo, M. E., Garvin, M., Creager, M. A., Scherer, P. E. & Goldfine, A. B. (2005), 'The role of total and high-molecular-weight complex of adiponectin in vascular function in offspring whose parents both had type 2 diabetes', <i>Diabetologia</i> , 48, pp. 2147-2154		✓	No control group
Hofsteenge, G. H., Chinapaw, M. J. M., Weijs, P. J. M., van Tulder, M. W. & Delemarre-van de Wall, H. A. (2008), 'Go4it; study design of a randomised controlled trial and economic evaluation of a multidisciplinary group intervention for obese adolescents for prevention of diabetes mellitus type 2', <i>BMC Public Health</i> , 8:410		✓	No results reported, design and method only
Jenum, A. K., Holme, I., Graff-Iversen, S. & Birkeland, S. K. (2005), 'Ethnicity and sex are strong determinants of diabetes in an urban Western society: implications for prevention', <i>Diabetologia</i> , 48, pp. 435-439		✓	Did not evaluate a prevention intervention

Journal	Included	Excluded	Reason for exclusion
Jolley, K., Daley, A., Adab, P., Lewis, A., Denley, J., Beach, J., Aveyard, P. (2010), 'A randomised controlled trial to compare a range of commercial or primary care led weight reduction programmes with a minimal intervention control for weight loss in obesity: the Lighten Up trial', <i>BMC Public Health</i> , 10(439)		✓	No results reported, only design and methodology
Keogh, K. M., White, P., Smith, S. M., McGilloway, S., O'Dowd, T. & Gibney, J. (2007), 'Changing illness perceptions in patients with poorly controlled type 2 diabetes, a randomised controlled trial of a family-based intervention: protocol and pilot study', <i>BMC Family Practice</i> , 8(36)		✓	Did not evaluate a prevention intervention and no results reported, only design and methodology
Khan, H. A., Sobki, S. H. & Khan, S. A. (2007), 'Association between glycaemic control and serum lipids profile in type 2 diabetic patients: HbA1c predicts dyslipidaemia', <i>Clin Exp Med</i> , 7, pp. 24-29		✓	Did not evaluate a T2DM prevention intervention
Khunti, K., Stone, M. A., Bankart, J., Sinfield, P., Pancholi, A., Walker, S., Talbot, D., Farooqi, A. & Davies, M. J. (2007), 'Primary prevention of type-2 diabetes and heart disease: action research in secondary schools serving an ethnically diverse UK population', <i>Journal of Public Health</i> , 30(1), pp.30-37		✓	Qualitative research
Khunti, K., Stone, M. A., Bankart, J., Sinfield, P., S., Talbot, D., Farooqi, A. & Davies, M. J. (2007), 'Physical activity and sedentary behaviours of South Asian and white European children in inner city secondary schools in the UK', <i>Family Practice Advance Access</i> , 24, pp.237-244		✓	No control group and did not evaluate a prevention intervention
Kinmonth, A.L., Wareham, N. J., Hardeman, W., Sutton, S., Prevost, A. T., Fanshawe, T., Williams, K. M., Ekelund, U., Spiegelhalter, D. & Griffin, S. J. (2008), 'Efficacy of a theory-based behavioural intervention to increase physical activity in an at-risk group in primary care (ProActive UK): a randomised trial', <i>Lancet</i> , 371, pp. 41-48	✓		n/a

Journal	Included	Excluded	Reason for exclusion
Korpi-Hyovalti, E. A., Laaksonen, D. E., Schwab, U. S., Vanhapiha, T. H., Vihla, K. R., Heinonen, S. T. & Niskanen, L. K. (2011), 'Feasibility of a lifestyle intervention in early pregnancy to prevent deterioration of glucose tolerance', <i>BMC Public Health</i> , 11(179)		✓	Evaluated a gestational diabetes prevention intervention rather than a T2DM prevention intervention
Kosaka, K., Nodaa, M. & Kuzuya, T. (2005), 'Prevention of type 2 diabetes by lifestyle intervention: a Japanese trial in IGT males', <i>Diabetes Research and Clinical Practice</i> , 67, pp. 152-162	✓		n/a
Kumari, M., Head, J. & Marmot, M. (2004), 'Prospective study of social and other risk factors for incidence of type 2 diabetes in the Whitehall II study', <i>Arch Intern Med</i> , 164, pp. 1874-1880		✓	No control group and did not evaluate a prevention intervention
Laatikainen, T., Dunbar, J. A., Chapman, A., Kilkkinen, A., Vartiainen, E., Heistaro, S., Philpot, B., Absetz, P., Bunker1, S., O'Neil1, A., Reddy, P., Best, J. D. & Janus, E. D. (2007), 'Prevention of Type 2 Diabetes by lifestyle intervention in an Australian primary health care setting: Greater Green Triangle (GGT) Diabetes Prevention Project', <i>BMC Public Health</i> , 7, pp. 249-255		✓	No control group
Lakshman, R. R., Sharp, S. J., Ong, K. K. & Forouhi, N. G. (2010), 'A novel school-based intervention to improve nutrition knowledge in children: cluster randomized controlled trial', <i>BMC Public Health</i> , 10(123)	✓		n/a
Lengerke, T. V., Janssen, C. & John, J. (2007), 'Sense of coherence, health locus of control, and quality of life in obese adults: physical limitations and psychological normalcies', <i>International Journal of Public Health</i> , 52, pp. 16–26		✓	Did not evaluate a T2DM prevention intervention

Journal	Included	Excluded	Reason for exclusion
Liebreich, T., Plotnikoff, R. C., Courneya, K. S. & Boule, N. (2009), 'Diabetes NetPLAY: a physical activity website and linked email counselling randomised intervention for individuals with type 2 diabetes', <i>International Journal of Behavioural Nutrition and Physical Activity</i> , 6(18)		✓	Did not evaluate a T2DM prevention intervention
Lindstrom, J., Louheranta, A., Mannelin, M., Rastas, M., Salminen, V., Eriksson, J., Uusitupa, M. & Tuomilehto, J. (2003), 'The Finnish Diabetes Prevention Study (DPS) Lifestyle intervention and 3-year results on diet and physical activity', <i>Diabetes Care</i> , 26(12), pp. 3230-3236	✓		n/a
Lindström, J., Ilanne-Parikka, P., Peltonen, M., Aunola, S., Eriksson, J. G., Hemiö, K., Hämäläinen, H., Härkönen, P., Keinänen-Kiukaanniemi, S., Laakso, M., Louheranta, A., Mannelin, M., Paturi, M., Sundvall, J., Valle, T. T., Uusitupa, M. & Tuomilehto, J. (2006), 'Sustained reduction in the incidence of type 2 diabetes by lifestyle intervention: follow-up of the Finnish Diabetes Prevention Study', <i>Lancet</i> , 368, pp. 1673-79	✓		n/a
Lombard, C., Deeks, A., Jolley, D. & Teede, H. J. (2009), 'Preventing weight gain: the baseline weight related behaviours and delivery of a randomised controlled intervention in community based women', <i>BMC Public Health</i> , 9:2		✓	No result reported
Ma, J., Strub, P., Camargo Jr, C. A., Xian, L., Ayala, E., Gardner, G. D., Buist, A. S., Haskell, W. L., Lavori, P. W. & Wilson, S. R. (2010), 'The Breathe Easier through Weight Loss Lifestyle (BE WELL) Intervention: a randomised controlled trial', <i>BMC Pulmonary Medicine</i> , 10:16		✓	No results reported, only design and methodology

Journal	Included	Excluded	Reason for exclusion
Maddigan, S. L., Feeny, D. H., Majumdar, S. R., Farris, K. B. & Johnson, J. A. (2006) 'Understanding the determinants of health for people with type 2 diabetes', <i>American Journal of Public Health</i> , 96(9), pp. 1649-1655		✓	No control group
Mainous III, A. G., Baker., R, Koopman, R. J., Saxena, S., Diaz, V. A., Everett, C. J. & Majeed, A. (2007), 'Impact of the population at risk of diabetes on projections of diabetes burden in the United States: an epidemic on the way', <i>Diabetologia</i> , 50, pp. 934-940		✓	No human participants used
Martin, L. J., Burke, S. M., Shapiro, S., Carron, A. V., Irwin, J. D., Petrella, R., Prapavessis, H. & Shoemaker, K. (2009), 'The use of group dynamic strategies to enhance cohesion in a lifestyle intervention program for obese children', <i>BMC Public Health</i> , 9:277		✓	No results reported
McClain, M. R., Srinivasan, S. R., Chen, W., Steinmann, W. C. & Berenson, G. S. (2000), 'Risk of type 2 diabetes mellitus in young adults from a biracial community: the bogalusa heart study', <i>Preventive Medicine</i> , 31, pp. 1-7		✓	Did not evaluate a prevention intervention
McCoy, M. R., Couch, D., Duncan, N. D. & Lynch, G. S. (2005), 'Evaluating an Internet weight loss program for diabetes prevention', <i>Health Promotion International</i> , 20(3), pp. 221-228		✓	No control group
Meisinger, C., Lowel, H., Thorand, B. & Doring, A. (2005), 'Leisure time physical activity and the risk of type 2 diabetes in men and women from the general population The MONICA/KORA Augsburg Cohort Study', <i>Diabetologia</i> , 48, pp.27-34		✓	No control group
Morrato, E. H., Hill, J. O., Wyatt, H. R., Ghushchyan, V. & Sullivan, P. W. (2007), 'Physical activity in u.s. adults with diabetes and at risk for developing diabetes, 2003', <i>Diabetes Care</i> , 30, pp. 203-209		✓	No control group

Journal	Included	Excluded	Reason for exclusion
Nang, E. E. K., Khoo, E. Y., Salim, A., Tai, E. S., Lee, J. & Dam, R. M. V. (2010), 'Patterns of physical activity in different domains and implications for intervention in a multi-ethnic Asian population: a cross-sectional study', <i>BMC Public Health</i> , 10(644)		✓	No control group and did not evaluate a prevention intervention
Nicklas, J. M., Zera, C. A., Seely, E. W., Abdul-Rudloff, Z. S., Rudloff, N. D. & Levkoff, S. E. (2011), 'Identifying postpartum intervention approaches to prevent type 2 diabetes in women with a history of gestational diabetes', <i>BMC Pregnancy and Childbirth</i> , 11(23)		✓	Evaluated a gestational diabetes prevention intervention rather than a T2DM prevention intervention
Nyberg, G., Sundblom, E., Norman, A. & Elinder, L. S. (2011), 'A healthy school start-parental support to promote healthy dietary habits and physical activity in children: Design and evaluation of a cluster-randomised intervention', <i>BMC Public Health</i> , 11(185)		✓	No results reported, only design and methodology
Oberlinner, C., Neumann, S. M., Ott, M. G. & Zober, A. (2008), 'Screening for pre-diabetes and diabetes in the workplace', <i>Occupational Medicine</i> , 58, pp. 41-45		✓	Screening tool therefore did not evaluate a prevention intervention
Orchard, T. J., Temprosa, M., Goldberg, S., Haffner, S., Ratner, R., Marcovina, S & Fowler, S. (2005), 'The effect of metformin and intensive lifestyle intervention on the metabolic syndrome: the diabetes prevention program randomized trial', <i>Ann Intern Med</i> , 142, pp. 611-619	✓		n/a
Pagoto, S. L., Kantor, L., Bodenlos, J. S., Gitkind, M. & Ma, Y. (2008), 'Translating the diabetes prevention program into a hospital-based weight loss program', <i>Health Psychology</i> , 27(1, Suppl.), pp. S91-S98		✓	No control group

Journal	Included	Excluded	Reason for exclusion
Parchman, M. L., Pugh, J. A., Culler, S. D., Noel, P. H., Arar, N. H., Romero, R. L. & Palmer, R. F. (2008), 'A group randomized trial of a complexity-based organizational intervention to improve risk factors for diabetes complications in primary care settings: study protocol', <i>Implementation Science</i> , 3(15)		✓	No results reported, design and methodology only
Pardhan, S. & Mahomed, I. (2004), 'Knowledge, self-help and socioeconomic factors in South Asian and Caucasian diabetic patients', <i>Eye</i> , 18, pp. 509-513		✓	Did not evaluate a prevention intervention
Paul, G., Smith, S. M., Whitford, D., O'Kelly, F. & O'Dowd, T. (2007), 'Development of a complex intervention to test the effectiveness of peer support in type 2 diabetes', <i>BMC Health Services Research</i> , 7(136)		✓	Qualitative research study
Petrella, R. J., Aizawa, K., Shoemaker, K., Ocerend, t., Piche, L., Marin, M., Shapiro, S. & Atkin, S. (2011), 'Efficacy of a family practice-based lifestyle intervention program to increase physical activity and reduce clinical and physiological markers of vascular health in patients with high normal blood pressure and/or high normal blood glucose (SNAC): study protocol for a randomised control trial', <i>Trials</i> , 12(45)		✓	No results reported, design and methodology only
Ramachandran, A., Snehalatha, C., Mary, S., Mukesh, B., Bhaskar, A. D. & Vijay, V. (2006), 'The Indian Diabetes Prevention Programme shows that lifestyle modification and metformin prevent type 2 diabetes in Asian Indian subjects with impaired glucose tolerance (IDPP-1)', <i>Diabetologia</i> , 49, pp. 289-297	✓		n/a
Richie, L. D., Sharma, S., Ikeda, J. P., Mitchell, R. A., Raman, A., Green, B. S., Hudes, M. L. & Fleming, S. E. (2010), 'Taking action together: a YMCA-based protocol to prevent type-2 diabetes in high-BMI inner-city African American children', <i>Trials</i> , 11(60)		✓	No results reported

Journal	Included	Excluded	Reason for exclusion
Riste, L., Khan, F. & Cruickshank, K. (2001), 'High prevalence of type 2 diabetes in all ethnic groups, including Europeans, in a British inner city relative poverty, history, inactivity, or 21st century Europe?', <i>Diabetes Care</i> , 24, pp. 1377-1383		✓	Did not evaluate a prevention intervention
Rosecrans, A. M., Gittelsohn, J., Ho, L. S., Harris, S. B., Naqshbandi, M. & Sharma, S. (2007), 'Process evaluation of a multi-institutional community-based program for diabetes prevention among First Nations', <i>Health Education Research</i>		✓	Mixed-methods design
Sakane, N., Sato, J., & Tsushita, K., Tsujii, S., Kotani, K., Tsuzaki, K., Tominaga, M., Kawazu, S., Sato, Y., Usui, T., Kamae, I., Yoshida, T., Kiyohara, Y., Sato, S. & Kuzuya, H. (2011), 'Prevention of type 2 diabetes in a primary healthcare setting: three-year results of lifestyle intervention in Japanese subjects with impaired glucose tolerance', <i>BMC Public Health</i> , 11(40)	✓		n/a
Siega-Riz, A. M., Ghormli, L. E., Mobley, C., Gillis, B., Stadler, D., Hartstein, J., Volpe, S. L., Virus, A. & Bridgman, J. (2011), 'The effects of the HEALTHY study intervention on middle school student dietary intakes', <i>International Journal of Behavioural Nutrition and Physical Activity</i> , 8(7)		✓	Lack of statistical results data reported
Siitonen, N., Lindström, J., Eriksson, J., Valle, T. T., Hämäläinen, H., Ilanne-Parikka, P., Keinänen-Kiukaanniemi, S., Tuomilehto, J., Laakso, M. & Uusitupa, M. (2004), 'Association between a deletion/insertion polymorphism in the $\alpha 2B$ -adrenergic receptor gene and insulin secretion and type 2 diabetes. The Finnish Diabetes Prevention Study', <i>Diabetologia</i> , 47, pp. 1416-1424	✓		n/a
Simmons, R. K., Griffin, S. J., Steele, R., Wareham, N. J. & Ekelund, U. (2008), 'Increasing overall physical activity and aerobic fitness is associated with improvements in metabolic risk: cohort analysis of the ProActive trial', <i>Diabetologia</i> , 51, pp. 787-794	✓		n/a

Journal	Included	Excluded	Reason for exclusion
Simmons, R. K., Harding, A. H., Jakes, R. W., Wlech, A., Wareham, N. J. & Griffin, S. J. (2006), 'How much might achievement of diabetes prevention behaviour goals reduce the incidence of diabetes if implemented at the population level?', <i>Diabetologia</i> , 49, pp.905-911		✓	No control group
Sonneville, K R., Pelle, N. L., Taveras, E. M., Gillman, M. W. & Prosser, L. A. (2009), 'Economics and other barriers to adopting recommendations to prevent childhood obesity: results of a focus group study with parents', <i>BMC Pediatrics</i> , 9(81)		✓	Qualitative research study
Steele, R. M., Mummery, W. K. & Dwyer, T. (2007), 'Examination of program exposure across intervention delivery modes: face to face versus internet', <i>International Journal of Behavioural Nutrition and Physical Activity</i> , 4(7)		✓	Did not evaluate a T2DM prevention intervention
Stone, M. A., Bankart, J., Sinfield, P., Pancholi, A., Walker, S., Talbot, D., Farooqi, A., Davies, M. J. & Khunti, K. (2007), 'Dietary habits of young people attending secondary schools serving a multiethnic, inner-city community in the UK', <i>Postgraduate Medicine Journal</i> , 83, pp.115-119		✓	Did not evaluate a prevention intervention
Suris J. C. & Parera, N. (2005), 'Youth Health Sex, drugs and chronic illness: health behaviours among chronically ill youth', <i>European Journal of Public Health</i> , 15(5), pp. 484-488		✓	Did not evaluate a prevention intervention
Thamer, C., Haap, M., Bachmann1, O., Nieden, T. Z., Tschritter, O., Stefan, N., Fritsche, A., Jacob, S., Stumvoll1, M. & Häring, H. (2004), 'Serum adiponectin levels predict the effect of short-term dietary interventions on insulin sensitivity in humans', <i>Diabetologia</i> , 47, pp. 1303-1305		✓	No control group

Journal	Included	Excluded	Reason for exclusion
Thanopoulou, A., Karamanos, B., Angelico, F., Assaad-Khalil, S., Barbato, A., Del Ben, M., Djordjevic, P., Dimitrijevic-Sreckovic, V., Gallotti, C., Katsilambros, N., Migdalis, I., Mrabet, M., Petkova, M., Roussi, D. & Tenconi, M. T. (2004), 'Nutritional habits of subjects with type 2 diabetes mellitus in the Mediterranean Basin: comparison with the non-diabetic population and the dietary recommendations. Multi-Centre Study of the Mediterranean Group for the Study of Diabetes (MGSD), <i>Diabetologia</i> , 47, pp. 367-376		✓	Did not evaluate a prevention intervention
The Diabetes Prevention Program Research Group. (2005), 'Role of insulin secretion and sensitivity in the evolution of type 2 diabetes in the diabetes prevention program effects of lifestyle intervention and metformin', <i>Diabetes</i> , 54, pp. 2404-2414	✓		n/a
The Diabetes Prevention Program Research Group. (1999), 'The Diabetes Prevention Program Design and methods for a clinical trial in the prevention of type 2 diabetes', <i>Diabetes Care</i> , 22, pp. 623-634		✓	Not all results reported as emphasis on design and method of study
The DREAM Trial Investigators. (2004), 'Rationale, design and recruitment characteristics of a large, simple international trial of diabetes prevention: the DREAM trial', <i>Diabetologia</i> , 4, pp.1519-1527		✓	Screening tool not prevention intervention
Vadstrup, E. S., Frolich, A., Perrild, H., Borg, E. & Roder, M. (2009), 'Lifestyle intervention for type 2 diabetes patients – trial protocol of the Copenhagen Type 2 Diabetes Rehabilitation Project', <i>BMC Public Health</i> , 9(166)		✓	No results reported, only design and methodology
Venmans, L. M. A. J., Gorter, K. J., Baard, K. P., Rutten, G. E. H. M. & Hak, E. (2007), ' Acceptability and effects of an educational leaflet on infections in type 2 diabetes patients: A randomized controlled trial in primary care', <i>Primary Care Diabetes</i> , 1, pp. 135-142	✓		n/a

Journal	Included	Excluded	Reason for exclusion
Von Lengerke, T., Janssen, C., John, J. & KORA Study Group. (2007), 'Sense of coherence, health locus of control, and quality of life in obese adults: physical limitations and psychological normalcies', <i>International Journal of Public Health</i> , 52, pp.16-26		✓	Did not evaluate a T2DM prevention intervention
Warren, J. M., Henry, C. K. J., Lightowler, H. J., Bradshaw, S. M. & Perwaiz, S. (2003), 'Evaluation of a pilot school programme aimed at the prevention of obesity in children', <i>Health Promotion International</i> , 18(4), pp. 287-297	✓		n/a
Waters, L. A., Reeves, M. M., Fjeldsoe, B. S. & Eakin, E. G. (2011), 'Characteristics of control group participants who increased their physical activity in a cluster-randomised lifestyle intervention trial', <i>BMC Public Health</i> , 11(27)		✓	No result section containing data of the prevention intervention
Weyrich, P., Machicao, F., Reinhardt, J., Machann, J., Schick, F., Tshritter, o., Stefan, N., Fritsche, A. & Haring, H.U. (2008), 'SIRT1 genitiv bariants associate with the metabolic response of Caucasians to a controlled lifestyle intervention – the TULIP study', <i>BMC Medical Genetics</i> , 9(100)		✓	No control group
Williams, K., Prevost, A. T., Griffin, S., Hardeman, W., Hollingworth, W., Spiegelhalter, D., Sutton, S., Ekelund, U., Wareham, N. & Kinmonth, A. L. (2004), 'The <i>ProActive</i> trial protocol – a randomised controlled trial of the efficacy of a family-based, domiciliary intervention programme to increase physical activity among individuals at high risk of diabetes', <i>BMC Public Health</i> , 4, pp. 48-59		✓	No result section containing data of the prevention intervention
Wilson, D. K., Ainsworth, B. E. & Bowles, H. (2007). 'Body mass index and environmental supports for physical activity among active and inactive residents of a U.S. southeastern county', <i>Health Psychology</i> , 26(6), pp. 710–717		✓	No control group

Journal	Included	Excluded	Reason for exclusion
Wing, R. R., Epstein, L. H., Nowalk, M. P., Koeske, R. & Hagg, S. (1985), 'Behavior change, weight loss, and physiological improvements in type II diabetic patients', <i>Journal of Consulting and Clinical Psychology</i> , 53(1), pp. 111-122		✓	Did not evaluate a prevention intervention
Wu, A. Y. T., Kong, N. C. T., de Leon, F. A., Pan, C. Y., Tai, T. Y., Yeung, V. T. F., Yoo, S. J., Rouillon, A. & Wier, M. R. (2005), 'An alarming high prevalence of diabetic nephropathy in Asian type2 diabetes patients: the MicroAlbuminuria Prevalence (MAP) study', <i>Diabetologia</i> , 48, pp.17-26		✓	Epidemiological study
Yeo, K. K., Tai, B. C., Heng, D., Lee, J. M. J., Ma, S., Hughes, K., Chew, S. K., Chia, K. S. & Tia, E. S. (2006), 'Ethnicity modifies the association between diabetes mellitus and ischaemic heart disease in Chinese, Malays and Asian Indians living in Singapore', <i>Diabetologia</i> , 49, pp.2866-2873		✓	No control group and did not evaluate a prevention intervention
Zinman, B., Harris, S. B., Gerstein, H. C., Young, T. K., Raboud, J. M., Neuman, J. & Hanley, A. J. G. (2006), 'Preventing type 2 diabetes using combination therapy: design and methods of the Canadian Normoglycaemia Outcomes Evaluation (CANOE) trial', <i>Diabetes, Obesity and Metabolism</i> , 8(5), pp. 531-537		✓	No result section containing data of the prevention intervention

Appendices Chapter Four: Perceptions and prevention beliefs of type2 diabetes among British-Pakistani mothers with and without T2DM

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Appendix 4.1

AIDE MEMOIRÉ FOR FOCUS GROUP PARTICIPANTS WITH TYPE2 DIABETES

Can you tell each other how you were diagnosed with diabetes?

How did you feel when you found out?

How did your family react to your diagnosis?

What do you think caused you to get diabetes?

Use prompt about high prevalence of diabetes amongst South Asians.

Does living in England instead of Pakistani, effected you getting diabetes?

If yes, how?

If not, why not?

Do you think your diet affected you getting diabetes?

If yes, how?

If not, why not?

Tell me about how you have had to change your diet?

Have you been able to eat traditional meals?

Have you had to eat differently from your family and friends?

Prompts of traditional Asian (Pakistani) cuisine

During Ramadhan, does your diet differ from your family / friends' meals?

If yes, how?

If not, why not?

Use prompts about healthy eating during Ramadhan.

During Eid, does your diet differ from your family / friends' meals?

If yes, how?

If not, why not?

Tell me how and where you are able to do exercise?

How have you changed your exercise routine since being diagnosed with diabetes?

If yes, how?

If not, why not?

Since your diagnosis, who from the health service have you seen?
What kind of support have you received?

How often do you see a health professional regarding your diabetes?

What effect has diabetes had on your life?

What effect has diabetes had on your family?
What things have family members asked you, especially your children?

What things do you say to family members especially your children to help them not get diabetes?

What do you do different from before now that you are aware of your diabetes?

What kind of things would you like to get from the health service to help with your diabetes?

Currently how do you feel about your diabetes?
How do you feel about your children's health?

Right now, how much control do you think you have over your diabetes?
How much control do you think you have over your children get diabetes?

Is there anything you want to bring up which we haven't talked about?

Appendix 4.2

AIDE MEMOIRÉ FOR FOCUS GROUP PARTICIPANTS WITHOUT TYPE2 DIABETES

Can you tell each other your ideas about what you think diabetes is?

What do you think causes diabetes?

How would you feel if you were diagnosed with diabetes?

How would your family feel if you were diagnosed with diabetes?

Has living in England instead of Pakistani, effected Pakistanis getting diabetes?

If yes, how?

If not, why not?

Use prompt about high prevalence of diabetes amongst South Asians.

How do you think your diet affects you getting diabetes?

Tell me about how someone you know with diabetes has to change their diet? Discuss if you think they can eat traditional meals?

During Ramzan, how would their diet differ from their family's or friends' meals?

Use prompts about healthy eating during Ramadhan.

During Eid, how would their diet differ from their family's or friends' meals?

How would it make you feel if someone with diabetes could not eat the traditional foods you like to eat?

Prompts of traditional Asian (Pakistani) cuisine

Tell me how you think exercise effects someone getting diabetes?

What kind of support would you expect someone with diabetes to get from the health service?

What effects do you think diabetes would have on your life?

What effect would diabetes have on your family, your children?

What things do you and your family do to try any stop getting diabetes?

How?

If nothing, why not?

What kind of things would you like to get from the health service to help you understand diabetes better?

Currently how do you feel about your health?

How do you feel about you children's health?

Right now, how much control do you think you have over you getting diabetes?

How much control do you think you have over your children getting diabetes?

Is there anything you want to bring up which we haven't talked about?

Appendix 4.3 PARTICIPANT INFORMATION SHEET

Project Title

Type2 Diabetes Risk Perception among British Pakistani Mothers

Invitation

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. The study looks at the beliefs and experiences of British Pakistani mothers regarding type 2 diabetes. Focus groups will take place to allow for an informal and confidential discussion to take place.

What is the purpose of the study?

We are conducting research into perceptions and experiences regarding type 2 diabetes. We are looking at the beliefs of British Pakistani mothers and their experiences of the disease in order to better understand the British Pakistani community's perspective of type 2 diabetes.

Why have I been invited?

You have been invited to take part in this study because you are of Pakistani origin and you have been diagnosed with type 2 diabetes. Approximately 36 participants will be recruited for this study, and you along with five other randomly selected participants will come together to have an informal discussion.

Is it compulsory for me to take part?

No this is a voluntary study therefore it is up to you to decide. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

If you agree to take part, you will be asked to attend a focus group with approximately five others. This is a group discussion with other British Pakistani mothers about type 2 diabetes, which will be audio taped. Only one focus group attendance is required, which will approximately last for 1 hour. (Please also allow for an extra 15 minutes before and after the focus group). You will also be asked to complete a data collection form and consent form.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help improve the prevention and treatment for people with type 2 diabetes and those at risk of developing type 2 diabetes.

What if there is a problem?

Any complaints about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on contacting the relevant individual can be found on the debriefing sheet.

Will my taking part in the study be kept confidential

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The confidentiality of personal information and the anonymity of all volunteers involved in this study will be preserved. Whatever is discussed in the focus group, will remain in the focus group and will not be discussed outside. Each participant will be given an anonymity pseudo name which will be used in the finished report. All participant materials will be destroyed at the end of the programme.

What do I do now?

If you would like to take part then please sign and return the consent form.

Appendix 4.4 PARTICIPANT INFORMATION SHEET

Project Title: Type2 Diabetes Risk Perception among British Pakistani Mothers

Invitation

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. The study looks at the beliefs and experiences of British Pakistani mothers regarding type diabetes. Focus groups will take place to allow for an informal and confidential discussion to take place.

What is the purpose of the study?

I am conducting research into perceptions and experiences regarding type2 diabetes. I am looking at the beliefs of British Pakistani mother's and their experiences of the disease. This will help to demonstrate what can be done to help the Pakistani community in the fight against type2 diabetes.

Why have I been invited?

You have been invited to take part in this study because you are of Pakistani origin and you have not been diagnosed with type2 diabetes. Approxamtely 36 participants will be recruited for this study, and you along with five other randomly selected participants will come together to have an informal discussion.

Is it compulsory for me to take part?

No this is a voluntary study therefore it is up to you to decide. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

If you agree to take part, you will be asked to attend a focus group with approximately five others. This is a group discussion with other British Pakistani mothers about type2 diabetes, which will be audio taped. Only one focus group attendance is required, which will approximately last for 1 hour. (Please also allow for an extra 15 minutes before and after the focus group). You will also be asked to complete a data collection form and consent form.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help improve the prevention and treatment for people with type2 diabetes and those at risk of developing type2 diabetes.

What if there is a problem?

Any complaints about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on contacting the relevant individual can be found on the debriefing sheet.

Will my taking part in the study be kept confidential

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The confidentiality of personal information and the anonymity of all volunteers involved in this study will be preserved. Whatever is discussed in the focus group, will remain in the focus group and will not be discussed outside. Each participant will be given an anonymity pseudo name which will be used in the finished report. All participant materials will be destroyed at the end of the programme.

What do I do now?

If you would like to take part then please sign and return the consent form.

Appendix 4.5



Centre Name: Centre80 / Heart of England Foundation Trust / Highfields / Pak Medical / St Paul's / St Saviour's*

Study Number: 09/H1206/5

Patient Identification Pseudo-Name for this trial:

CONSENT FORM

Title of Project: **Risk perceptions and illness perceptions of type2 diabetes among British Pakistani mothers**

Name of Researcher: Fozia Ikram

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 10/03/2009 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that data collected during the study will be looked at by the researchers from Aston University
4. I agree to my GP being informed of my participation in the study.
5. I agree to the audiotaping of the focus group that I will take part in.
6. I agree to take part in the above study.

Name of Patient Date Signature

Name of Person Date Signature
taking consent

When completed, 1 for patient; 1 for researcher site file

*delete as appropriate

Appendix 4.6



Centre Name: Centre80 / Heart of England Foundation Trust / Highfields / Pak Medical / St Paul's / St Saviour's*

Study Number: 09/H1206/5

Patient Identification Pseudo-Name for this trial:

CONSENT FORM

Title of Project: **Risk perceptions and illness perceptions of type2 diabetes among British Pakistani mothers**

Name of Researcher: Fozia Ikram

Please initial boxes

7. I confirm that I have read and understand the information sheet dated 10/03/2009 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
8. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
9. I understand that data collected during the study will be looked at by the researchers from Aston University
10. I agree to the audiotaping of the focus group that I will take part in.
11. I agree to take part in the above study.

Name of Patient Date Signature

Name of Person Date Signature
taking consent

When completed, 1 for patient; 1 for researcher site file

*delete as appropriate

Appendix 4.7



DEBRIEF SHEET

Title of Project: **Risk perceptions and illness perceptions of type2 diabetes among British Pakistani mothers**

Thank you for taking part in this study. Your co-operation is greatly appreciated. The focus group responses collected from you will be collated with other focus group responses to look at the beliefs and experiences of British Pakistanis regarding type2 diabetes. This will provide insightful information and understanding to help demonstrate what can be done to help prevent the Pakistani community developing type2 diabetes.

Your focus group responses will be analysed to form part of my report. The group discussion on audio cassette, transcript along with your consent form will be kept confidential and in a locked cabinet and, and all electronic data will be kept securely on a password protected computer. You will be referred to only by your pseudo name in the result section of the report. The focus group data and consent form will be kept in a secure location for 5 years.

You have up to a month to decide if you like to withdraw from the study. If you do want to then please contact me on ikramf@aston.ac.uk

If you have any complaints about the way you have been dealt with during the study or if you have suffered any possible harm these can be addressed through the normal university procedures, which can be found at:

<http://www1.aston.ac.uk/registry/for-staff/regsandpolicies/complaints-procedure/>

To make a formal complaint contact:

Professor Martin Griffin (Executive Dean) m.griffin@aston.ac.uk

Dr Helen Pattison (supervisor) h.m.pattison@aston.ac.uk

If you are concerned about diabetes or any other health condition you should contact your GP. You may also find the support services below useful:

Aston University Counselling Services

Tel: 0121 2044711

Email: counselling@aston.ac.uk

Diabetes UK Care line

Tel: 0845 120 2960

Email: careline@diabetes.org.uk

NHS Direct

Tel: 0845 46 47

Website: <http://www.nhsdirect.nhs.uk/Contact.aspx>

Appendix 4.8

Surestart centre letter header

Dear Parent.

My name is Fozia Ikram and I am studying my PhD in Health Psychology at Aston University. As part of my research I am interested in talking to Pakistani mothers who have not been diagnosed with type2 diabetes. I would like to find out their perceptions of diabetes and find out the impact it has.

You have been contacted by the Surestart Centre on my behalf to invite you to attend a focus group. This is an informal group discussion with other Pakistani mothers regarding your beliefs and experiences of type2 diabetes.

The focus group will last for approximately one hour, and will take place at Surestart Centre. Free refreshments will be provided.

Your views and comments will be greatly appreciated. Your participation and views will help to highlight any problems which people like you who are suffering with type2 diabetes face. It will also help to find ways of stopping the next generation developing diabetes, helping to reduce the high type2 diabetes rates in the Pakistani community.

If you would like further information about the study, or are interested in participating please complete the form attached with this letter and handed it back into the Surestart Centre.

Thank you for your time.

Kind regards.

Fozia Ikram.

Surestart centre letter header

I am interested in participating in the focus group to find out my views and experiences regarding type2 diabetes.

I agree to my contact details being passed on to Fozia Ikram, so that she can send me further information about the focus group and study. If I agree take part, an appropriate time and date will be scheduled for the group discussion.

Name : _____

Address: _____

Contact Number: _____

Signature: _____

Date: _____

Appendix 4.9

BEN Letter headed paper

Date: _____

Dear _____

My name is Fozia Ikram and I am studying my PhD in Health Psychology at Aston University. As part of my research I am interested in talking to Pakistani mothers who have been diagnosed with type2 diabetes. I would like to find out their perceptions of diabetes and find out the impact they feel it is likely to have on their children.

You have been contacted by the Birmingham East and North PCT community diabetes team on my behalf to invite you to attend a focus group. This is an informal group discussion with other Pakistani mothers regarding your beliefs and experiences of type2 diabetes.

The focus group will last for approximately one hour, and will take place at Pak Medical Centre. Free refreshments will be provided.

Your views and comments will be greatly appreciated. Your participation and views will help to highlight any problems which people like you who are suffering with type2 diabetes face. It will also help to find ways of stopping the next generation developing diabetes, helping to reduce the high type2 diabetes rates in the Pakistani community.

If you would like further information about the study, or are interested in participating please complete the form attached with this letter and send it back to the BEN PCT community diabetes team Pak Medical Centre in the stamped addressed envelope provided.

Thank you for your time.

Kind regards.

Fozia Ikram.

BEN Letter headed paper

I am interested in participating in the focus group to find out my views and experiences regarding type2 diabetes.

I agree to my contact details being passed on to Fozia Ikram, so that she can send me further information about the focus group and study. If I agree take part, an appropriate time and date will be scheduled for the group discussion.

Name : _____

Address: _____

Contact Number: _____

Signature: _____

Date: _____

Appendix 4.10

Heart of England Foundation Trust letter headed paper.

Patient's name
Patient's address

Date

Dear _____

My name is Fozia Ikram and I am studying my PhD in Health Psychology at Aston University. As part of my research I am interested in talking to Pakistani mothers who have been diagnosed with type2 diabetes. I would like to find out their perceptions of diabetes and find out the impact they feel it is likely to have on their children.

You have been contacted by the Heart of England Foundation Trust diabetes team on my behalf to invite you to attend a focus group. This is an informal group discussion with other Pakistani mothers regarding your beliefs and experiences of type2 diabetes.

The focus group will last for approximately one hour, and will take place at St Paul's Centre, Belchers Lane. Free refreshments will be provided.

Your views and comments will be greatly appreciated. Your participation and views will help to highlight any problems which people like you who are suffering with type2 diabetes face. It will also help to find ways of stopping the next generation developing diabetes, helping to reduce the high type2 diabetes rates in the Pakistani community.

If you would like further information about the study, or are interested in participating please complete the form attached with this letter and send it back to the Heart of England Foundation Trust at Heartlands Hospital in the stamped addressed envelope provided.

Thank you for your time.

Kind regards.

Fozia Ikram.

NHS Trust letter headed paper.

I am interested in participating in the focus group to find out my views and experiences regarding type2 diabetes.

I agree to my contact details being passed on to Fozia Ikram, so that she can send me further information about the focus group and study. If I agree take part, an appropriate time and date will be scheduled for the group discussion.

Name : _____

Address: _____

Contact Number: _____

Signature: _____

Date: _____

**Appendices Chapter Five: Perceptions and prevention
beliefs of type2 diabetes among young British-Pakistani
females**

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Appendix 5.1

AIDE MEMOIRÉ FOR FOCUS GROUP WITH YOUNG BRITISH PAKISTANI FEMALE PARTICIPANTS

Can you tell each other your ideas about what you think diabetes is?

What do you think causes diabetes?

How would you feel if you were diagnosed with diabetes?

How would your family feel if you were diagnosed with diabetes?

Has living in England instead of Pakistani effected Pakistanis getting diabetes?

If yes how?

If not why not?

Use prompt about high prevalence of diabetes amongst South Asians.

How do you think your diet affects you getting diabetes?

Tell me about how someone you know with diabetes has to change their diet? Discuss if you think they can eat traditional meals?

During Ramzan how would their diet differ from their family's or friends' meals?

Use prompts about healthy eating during Ramadhan.

During Eid how would their diet differ from their family's or friends' meals?

How would it make you feel if someone with diabetes could not eat the traditional foods you like to eat?

Prompts of traditional Asian (Pakistani) cuisine

Tell me how you think exercise effects someone getting diabetes?

What kind of support would you expect someone with diabetes to get from the health service?

What effects do you think diabetes would have on your life?

What effect would diabetes have on your family, your parents?

What things do you and your family do to try any stop getting diabetes?

How?

If nothing why not?

What kind of things would you like to get from the health service to help you understand diabetes better?

Currently how do you feel about your health?

How do you feel about your family's health?

Right now, how much control do you think you have over you getting diabetes?

How much control do you think you have over your family getting diabetes?

Is there anything you want to bring up which we haven't talked about?

Appendix 5.2

PARTICIPANT INFORMATION SHEET

Project Title

Type2 Diabetes Risk Perception among British Pakistanis

Invitation

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. The study looks at the beliefs and experiences of British Pakistani regarding type2 diabetes. Focus groups will take place to allow for an informal and confidential discussion to take place.

What is the purpose of the study?

I am conducting research into perceptions and experiences regarding type2 diabetes. I am looking at the beliefs of British Pakistanis and their experiences of the disease. This will help to demonstrate what can be done to help the Pakistani community in the fight against type2 diabetes.

Why have I been invited?

You have been invited to take part in this study because you are of Pakistani origin. Approximately 18 participants will be recruited for this study, and you along with five other randomly selected participants will come together to have an informal discussion.

Is it compulsory for me to take part?

No this is a voluntary study therefore it is up to you to decide. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive. If you wish to withdraw your participation after the focus group has taken place, you have up to the end of March 2010 to do so.

What will happen to me if I take part?

If you agree to take part, you will be asked to attend a focus group with approximately five others. This is a group discussion with other British Pakistanis about type2 diabetes, which will be audio taped. Only one focus group attendance is required, which will approximately last for 1 hour. (Please also allow for an extra 15 minutes before and after the focus group). You will also be asked to complete a consent form.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help improve the prevention and treatment for people with type2 diabetes and those at risk of developing type2 diabetes.

What if there is a problem?

Any complaints about the way you have been dealt with during the study or any possible harm you might suffer will be addressed through the normal university procedures. The detailed information on contacting the relevant individual can be found on the debriefing sheet.

Will my taking part in the study be kept confidential

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The confidentiality of personal information and the anonymity of all volunteers involved in this study will be preserved. Whatever is discussed in the focus group, will remain in the focus group and will not be discussed outside. Each participant will be given a pseudo name which will be used in the finished report. All participant materials will be destroyed after the data has been analysed and written up.

What do I do now?

If you would like to take part then please sign and return the consent form.

Appendix 5.3



CONSENT FORM

Title of Project: Risk perceptions and illness perceptions of type2 diabetes among British Pakistanis

Name of Researcher: Fozia Ikram

Centre Name: Aston University

Patient Identification Pseudo-Name for this trial:

Please initial boxes

12. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
13. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. If I wish to withdraw my participation after the focus group has taken place, I am aware I have up to the end of March 2010 to do so.
14. I understand that data collected during the study will be looked at by the researchers from Aston University
15. I agree to the audiotaping of the focus group that I will take part in.
16. I agree to the group confidentiality agreement so that nothing discussed in the focus group will be revealed outside the group
17. I agree to take part in the above study.
18. Age: _____
19. I confirm that my parent(s) has type2diabetes
20. If so, who: Mother Father

Name of Patient Date Signature

Name of Person taking consent Date Signature

When completed, 1 for participant; 1 for researcher site file

Appendix 5.4

DEBRIEF SHEET

Title of Project: **Risk perceptions and illness perceptions of type2 diabetes among young British Pakistani females**

Thank you for taking part in this study. Your co-operation is greatly appreciated. The focus group responses collected from you will be collated with other focus group responses to look at the beliefs and experiences of British Pakistanis regarding type2 diabetes. This will provide insightful information and understanding to help demonstrate what can be done to help prevent the Pakistani community developing type2 diabetes.

Your focus group responses will be analysed to form part of my report. The group discussion on audio cassette, transcript along with your consent form will be kept confidential and in a locked cabinet and, and all electronic data will be kept securely on a password protected computer. You will be referred to only by your pseudo name in the result section of the report. The focus group data and consent form will be kept in a secure location for 5 years.

If you decide you would like to withdraw from the study please contact me before the end of March 2010 on ikramf@aston.ac.uk

If you have any complaints about the way you have been dealt with during the study or if you have suffered any possible harm these can be addressed through the normal university procedures, which can be found at:

<http://www1.aston.ac.uk/registry/for-staff/regsandpolicies/complaints-procedure/>

To make a formal complaint contact:

Professor Martin Griffin (Executive Dean) m.griffin@aston.ac.uk

Dr Helen Pattison (supervisor) h.m.pattison@aston.ac.uk

If you are concerned about diabetes or any other health condition you should contact your GP. You may also find the support services below useful:

Aston University Counselling Services

Tel: 0121 2044711

Email: counselling@aston.ac.uk

Diabetes UK Care line

Tel: 0845 120 2960

Email: careline@diabetes.org.uk

NHS Direct

Tel: 0845 46 47

Website: <http://www.nhsdirect.nhs.uk/Contact.aspx>

CALLING ALL PAKISTANI FEMALE STUDENTS!

**DO YOU KNOW ANYONE WHO HAS
TYPE2 DIABETES? Parent, grandparent,
aunt, uncle, sibling?**

Type 2 diabetes is very common among the Pakistani population group. Many people have the disease and the prevalence continues to rise. I am conducting research into perceptions and experiences regarding type2 diabetes. I am looking at the beliefs of British Pakistanis females and their experiences of the disease. I hope to demonstrate what can be done to help the Pakistani community in the fight against type2 diabetes.

Therefore I would like to invite you to take part in a research study. Focus groups will take place to allow for an informal and confidential discussion to take place. You can either partake on your own or as part of a group.

If you are interested in taking part please contact me at ikramf@aston.ac.uk

Appendices Chapter Seven: Illness perceptions and prevention beliefs of T2DM among British Pakistani females with and without T2DM

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Appendix 7.1

PARTICIPANT INFORMATION SHEET FOR TYPE2 DIABETES PARTICIPANTS

PART 1

Project Title

Illness perceptions of Type2 Diabetes amongst British Pakistani Mothers

Invitation

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. The study looks at the beliefs and experiences of British Pakistani mothers regarding type2 diabetes. A questionnaire will be given to you to complete and give back.

What is the purpose of the study?

I am conducting research into perceptions and experiences regarding type2 diabetes. I am looking at the beliefs of British Pakistani mother's and their experiences of the disease. This will help to demonstrate what can be done to help the Pakistani community in the fight against type2 diabetes.

Why have I been invited?

You have been invited to take part in this study because you are of Pakistani origin and you have been diagnosed with type2 diabetes. Approximately 40 participants will be recruited, and another 40 participants will be recruited who do not have type2 diabetes, an approximate total of 80 participants for this study.

Is it compulsory for me to take part?

No this is a voluntary study therefore it is up to you to decide. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw from the study, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

If you agree to take part, you will be asked to attend complete a questionnaire. Only one completed questionnaire is required, which will approximately take 15 minutes to complete. You will also be asked to complete a consent form.

Expenses and payments

There are no expenses or payments given for this study, nor is there any taken from you. If you wish to complete the questionnaire in your own time and send it back to the researcher, then a self-addressed and stamped envelope will be provided to you. Please ask for this if required.

What will I have to do?

Complete a consent form and questionnaire.

What is the procedure that is being tested?

No procedure is being tested. The questionnaire is designed to find out your beliefs and perceptions of type2 diabetes. It is not a test or a quiz. There are no right or wrong answers.

What are the alternatives?

There are no alternatives. The study consists of data collection via a questionnaire.

What are the possible disadvantages and risks of taking part?

There are unlikely to be disadvantages or risks of taking part in this study. No invasive procedures are involved. You will be asked about type2 diabetes but no sensitive information will be asked of you. If you become concerned about your health or type2 diabetes as a result of taking part, then please contact your GP.

What are the side effects of taking part?

There are no side effects to taking part in this study.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help improve our knowledge of the experience of people with type2 diabetes and the prevention of type2 diabetes in those at risk.

What happens when the research study stops?

When the study finishes, all the questionnaires will be collated and analysed. Findings will be documented and disseminated accordingly. If you would like to receive a copy of the findings please contact me via email or telephone to let me know.

What if there is a problem?

Any complaints about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on contacting the relevant individual can be found on the debriefing sheet.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The confidentiality of personal information and the anonymity of all volunteers involved in this study will be preserved. Whatever is disclosed in the questionnaire, will remain in on the questionnaire and will not be discussed outside. All participant materials will be destroyed at the end of the programme.

PART 2

What will happen if I don't want to carry on with the study?

You are free to withdraw from the study up to a month after completing the questionnaire. Please let me know if you no longer want to take part in the study and provide me with your participant number which can be found on your consent form. I will remove your questionnaire and destroy the data.

What if there is a problem?

As mentioned in Part 1 any complaints about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on contacting the relevant individual can be found on the debriefing sheet. My details can be found below.

Will my taking part in the study be kept confidential?

As mentioned in Part 1, yes your taking part will be kept confidential. We will follow ethical and legal practice and all information about you will be handled in confidence. The confidentiality of personal information and the anonymity of all volunteers involved in this study will be preserved. Whatever is disclosed in the questionnaire, will remain in on the questionnaire and will not be discussed outside. All participant materials will be destroyed at the end of the programme.

Involvement of the General Practitioner/Family doctor (GP)

No involvement of your GP is required or requested.

What will happen to any samples I give?

No samples will be taken from you.

Will any genetic tests be done?

No this is a research study about gaining your views and beliefs about type2 diabetes.

What will happen to the results of the research study?

The results of the research will be published and disseminated accordingly at conferences and in papers.

Who is organising and funding the research?

The research is being organised by myself at Aston University. No funding has been gained for this study.

What do I do now?

If you would like to take part then please [sign and return the consent form.](#)

My details:

Fozia Ikram

ikramf@aston.ac.uk

Appendix 7.2

PARTICIPANT INFORMATION SHEET FOR PARTICIPANTS WITHOUT A DIAGNOSIS OF TYPE2 DIABETES PART 1

Project Title

Illness perceptions of Type2 Diabetes amongst British Pakistani Mothers

Invitation

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. The study looks at the beliefs and experiences of British Pakistani mothers regarding type2 diabetes. A questionnaire will be given to you to complete and give back.

What is the purpose of the study?

I am conducting research into perceptions and experiences regarding type2 diabetes. I am looking at the beliefs of British Pakistani mother's and their experiences of the disease. This will help to demonstrate what can be done to help the Pakistani community in the fight against type2 diabetes.

Why have I been invited?

You have been invited to take part in this study because you are of Pakistani origin and you have not been diagnosed with type2 diabetes. Approximately 40 participants will be recruited, and another 40 participants will be recruited who do have type2 diabetes, an approximate total of 80 participants for this study. If you have type2 diabetes, then please ask for the questionnaire for participants with type2 diabetes, information sheet and consent form.

Is it compulsory for me to take part?

No this is a voluntary study therefore it is up to you to decide. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw from the study, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

If you agree to take part, you will be asked to attend complete a questionnaire. Only one completed questionnaire is required, which will approximately take 15 minutes to complete. You will also be asked to complete a consent form.

Expenses and payments

There are no expenses or payments given for this study, nor is there any taken from you. If you wish to complete the questionnaire in your own time and send it back to the researcher, then a self-addressed and stamped envelope will be provided to you. Please ask for this if required.

What will I have to do?

Complete a consent form and questionnaire.

What is the procedure that is being tested?

No procedure is being tested. The questionnaire is designed to find out your beliefs and perceptions of type2 diabetes. It is not a test or a quiz. There are no right or wrong answers.

What are the alternatives?

There are no alternatives. The study consists of data collection via a questionnaire.

What are the possible disadvantages and risks of taking part?

There are unlikely to be disadvantages or risks of taking part in this study. No invasive procedures are involved. You will be asked about type2 diabetes but no sensitive information will be asked of you. If you become concerned about your health or type2 diabetes as a result of taking part, then please contact your GP.

What are the side effects of taking part?

There are no side effects to taking part in this study.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help improve the prevention and treatment for people with type2 diabetes and those at risk of developing type2 diabetes.

What happens when the research study stops?

When the study finishes, all the questionnaires will be collated and analysed. Findings will be documented and disseminated accordingly. If you would like to receive a copy of the findings please contact me via email or telephone to let me know.

What if there is a problem?

Any complaints about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on contacting the relevant individual can be found on the debriefing sheet.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The confidentiality of personal information and the anonymity of all volunteers involved in this study will be preserved. Whatever is disclosed in the questionnaire, will remain in on the questionnaire and will not be discussed outside. All participant materials will be destroyed at the end of the programme.

PART 2

What if relevant new information becomes available?

No relevant new information will be given about the study at a later stage, as this study has been designed to gain your views and opinions not assess your behaviour.

What will happen if I don't want to carry on with the study?

You are free to withdraw at anytime of the study without any questions asked. Please let me know if you no longer want to take part in the study and provide me with your participant number which can be found on your consent form. I will remove your questionnaire and destroy the data appropriately.

What if there is a problem?

If there is a problem please inform me as soon as possible either in person, via telephone or email. Also as mentioned in Part 1 any complaints about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on contacting the relevant individual can be found on the debriefing sheet. My details can be found below.

Will my taking part in the study be kept confidential?

As mentioned in Part 1, yes your taking part will be kept confidential. We will follow ethical and legal practice and all information about you will be handled in confidence. The confidentiality of personal information and the anonymity of all volunteers involved in this study will be preserved. Whatever is disclosed in the questionnaire, will remain in on the

questionnaire and will not be discussed outside. All participant materials will be destroyed at the end of the programme.

Involvement of the General Practitioner/Family doctor (GP)

No involvement of you GP is required or requested.

What will happen to any samples I give?

No samples will be taken from you.

Will any genetic tests be done?

No this is a research study about gaining your views and beliefs about type2 diabetes.

What will happen to the results of the research study?

The results of the research will be published and disseminated accordingly at conferences and in papers.

Who is organising and funding the research?

The research is being organised by myself at Aston University. No funding has been gained for this study.

What do I do now?

If you would like to take part then please sign and return the consent form.

My detail:

Fozia Ikram

ikramf@aston.ac.uk

Appendix 7.3

PARTICIPANT INFORMATION SHEET

Project Title

Perception of Type 2 Diabetes among Young British Pakistani Females: A Quantitative Design

Invitation

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. The study looks at the beliefs and experiences of British Pakistani females about type 2 diabetes, using a questionnaire.

What is the purpose of the study?

I am conducting research into perceptions and experiences regarding type 2 diabetes. I am looking at the beliefs of British Pakistanis and their perceptions of the disease. This will help to demonstrate what can be done to help the Pakistani community in the fight against type 2 diabetes.

Why have I been invited?

You have been invited to take part in this study because you are of Pakistani origin. Approximately 40 participants will be recruited for this study.

Is it compulsory for me to take part?

No this is a voluntary study therefore it is up to you to decide. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. If you wish to withdraw your participation after you have completed the questionnaire, you have up to the end of October 2010 to do so.

What will happen to me if I take part?

If you agree to take part, you will be asked to complete a questionnaire. Only one completed questionnaire is required, which will approximately take 15 minutes. (Please also allow for an extra 5 minutes to read this sheet, read and sign the consent form before completing the questionnaire and reading the debrief sheet after). You will also be asked to complete a consent form.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study will help improve the prevention and treatment for people with type 2 diabetes and those at risk of developing type 2 diabetes.

What if there is a problem?

Any complaints about the way you have been dealt with during the study or any possible harm you might suffer will be addressed through the normal university procedures. The detailed information on contacting the relevant individual can be found on the debriefing sheet.

Will my taking part in the study be kept confidential

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The confidentiality of personal information and the anonymity of all volunteers involved in this study will be preserved. You can use a false name if you wish. All participant materials will be destroyed after the data has been analysed and written up. Results of the study will be published, but in an anonymised format that will maintain confidentiality.

What do I do now?

If you would like to take part then please sign and return the consent form.

Appendix 7.4



Centre Name: Centre80 / Heart of England Foundation Trust / Other*

Participant Number:

CONSENT FORM FOR TYPE2 DIABETES PARTICIPANTS

Title of Project: Illness perceptions of type2 diabetes amongst British Pakistani mothers

Name of Researcher: Fozia Ikram

Please initial boxes

21. I confirm that I have read and understand the information sheet dated 13th April 2010 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
22. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
23. I understand that data collected during the study will be looked at by the researchers from Aston University
24. I agree to my GP being informed of my participation in the study.
25. I confirm that I have been diagnosed with type2 diabetes.
26. I agree to take part in the above study.

Name of Participant Date Signature

Name of person taking consent Date Signature

*delete as appropriate

When completed, 1 for participant; 1 for researcher site file

Appendix 7.5



Centre Name: Centre80 / Highfields / St Saviour's / Other*

Participant Number:

CONSENT FORM FOR PARTICIPANTS WITHOUT TYPE2 DIABETES

Title of Project: Illness perceptions of type2 diabetes among British Pakistani mothers

Name of Researcher: Fozia Ikram

Please initial boxes

27. I confirm that I have read and understand the information sheet dated 13th April 2010 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
28. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
29. I understand that data collected during the study will be looked at by the researchers from Aston University
30. I confirm that to my knowledge I do not have type2 diabetes
31. I agree to take part in the above study.

Name of Participant Date Signature

Name of person taking consent Date Signature

*delete as appropriate

When completed, 1 for patient; 1 for researcher site file

Appendix 7.6



CONSENT FORM

Title of Project: Perception of Type 2 Diabetes among Young British Pakistani Females: A Quantitative Design

Name of Researcher: Fozia Ikram

Centre Name: Aston University

Patient Identification Pseudo-Name for this trial:

Please initial boxes

32. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

33. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. If I wish to withdraw my participation after I have completed the questionnaire, I am aware I have up to the end of October 2010 to do so.

34. I understand that data collected during the study will be looked at by the researchers from Aston University and results of the study will be published, but in an anonymised format that will maintain confidentiality

35. I agree to take part in the above study.

36. Age: _____

37. I confirm that my parent(s) has type 2 diabetes

38. If so, who: Mother Father

Name of Patient Date Signature

Name of Person taking consent Date Signature

When completed, 1 for participant; 1 for researcher site file

Appendix 7.7



DEBRIEF SHEET

Title of Project: **Illness perceptions of type2 diabetes among British Pakistani Mothers**

Thank you for taking part in this study. Your co-operation is greatly appreciated. The questionnaire answers collected from you will be collated with other questionnaire answers to look at the beliefs and experiences of British Pakistanis regarding type2 diabetes. This will provide insightful information and understanding to help demonstrate what can be done to help prevent the Pakistani community developing type2 diabetes.

Your responses will be analysed to form part of my report. The questionnaire along with your consent form will be kept confidential and in a locked cabinet and, and all electronic data will be kept securely on a password protected computer. The questionnaire data and consent form will be kept in a secure location for 5 years.

If you decide you would like to withdraw from the study please contact me before the end of October 2010 on ikramf@aston.ac.uk, quoting your name and participant number which can be found on the consent form.

If you have any complaints about the way you have been dealt with during the study or if you have suffered any possible harm these can be addressed through the normal university procedures, which can be found at:

<http://www1.aston.ac.uk/registry/for-staff/regsandpolicies/complaints-procedure/>

To make a formal complaint contact:

Professor Helen Griffiths (Executive Dean) h.r.griffiths@aston.ac.uk 0121 204 3950

Dr Helen Pattison (supervisor) h.m.pattison@aston.ac.uk 0121 204 4073

If you are concerned about diabetes or any other health condition you should contact your GP. You may also find the support services below useful:

Diabetes UK Care line

Tel: 0845 120 2960

Email: careline@diabetes.org.uk

NHS Direct

Tel: 0845 46 47

Website: <http://www.nhsdirect.nhs.uk/Contact.aspx>

Appendix 7.8



DEBRIEF SHEET

Title of Project: **Perception of Type 2 Diabetes among Young British Pakistani Females: A Quantitative Design**

Thank you for taking part in this study. Your co-operation is greatly appreciated. The questionnaire answers collected from you will be collated with other questionnaire answers to look at the beliefs and experiences of British Pakistanis regarding type 2 diabetes. This will provide insightful information and understanding to help demonstrate what can be done to help prevent the Pakistani community developing type 2 diabetes.

Your responses will be analysed to form part of my report. The questionnaire along with your consent form will be kept confidential and in a locked cabinet and, and all electronic data will be kept securely on a password protected computer. The questionnaire data and consent form will be kept in a secure location for 5 years.

If you would like to provide feedback regarding this study or receive a summary report of the study findings please do not hesitate to contact me:
Fozia Ikram ikramf@aston.ac.uk

If you decide you would like to withdraw from the study please contact me before the end of October 2010 on ikramf@aston.ac.uk, quoting your name and participant number which can be found on the consent form.

If you have any complaints about the way you have been dealt with during the study or if you have suffered any possible harm these can be addressed through the normal university procedures, which can be found at:

<http://www1.aston.ac.uk/registry/for-staff/regsandpolicies/complaints-procedure/>

To make a formal complaint contact:

Professor Helen Griffiths (Executive Dean) h.r.griffiths@aston.ac.uk 0121 204 3950

Dr Helen Pattison (supervisor) h.m.pattison@aston.ac.uk 0121 204 4073

If you are concerned about diabetes or any other health condition you should contact your GP. You may also find the support services below useful:

Diabetes UK Care line

Tel: 0845 120 2960

Email: careline@diabetes.org.uk

NHS Direct

Tel: 0845 46 47

Website: <http://www.nhsdirect.nhs.uk/Contact.aspx>

Appendix 7.9

Questionnaire exploring perceptions of Type2 Diabetes among British Pakistani mothers with Type2 Diabetes

We want to know your personal views about Type 2 Diabetes. For the following questions, please circle the number that best corresponds to your views. There are no right or wrong answers.

How much do you agree with this statement: *Type2 diabetes is a very common illness?*

1 . 2 . 3 . 4 . 5
Strongly Disagree Strongly Agree

How much do you agree with this statement: *Type2 diabetes is an older person's disease?*

1 . 2 . 3 . 4 . 5
Strongly Disagree Strongly Agree

How much control do you feel you have over your child(ren) getting the same illness?

1 . 2 . 3 . 4 . 5
absolutely no control Complete control

How helpful do you feel the health service is to you?

1 . 2 . 3 . 4 . 5
Not at all helpful Extremely helpful

How much does your illness affect your child(ren)?

1 . 2 . 3 . 4 . 5
No effect at all Severely affect them

How does looking after your child(ren) and family affect your illness?

1 . 2 . 3 . 4 . 5
No effect at all Extremely affect

How much do you agree with this statement: *Type2 diabetes is to do with the amount of sugar you eat?*

1 . 2 . 3 . 4 . 5
Strongly Disagree Strongly Agree

How much do you think your diet affects your illness?

1 . 2 . 3 . 4 . 5
Not at all Extreme amount

How much do you think physical activity affects your illness?

1 . 2 . 3 . 4 . 5
Not at all Extreme amount

How concerned are you about your child(ren) getting the same illness?

1 . 2 . 3 . 4 . 5
Not at all concerned Extremely concerned

How much do you think living in England rather than Pakistan affects your illness?

1 . 2 . 3 . 4 . 5
Not at all Extremely

How much do you try to stop your children from getting your illness?

1 . 2 . 3 . 4 . 5
Would not try Extreme amount

Appendix 7.10

Questionnaire exploring perceptions of Type2 Diabetes among British Pakistani mothers without Type2 Diabetes

We want to know your personal views about Type 2 Diabetes. For the following questions, please circle the number that best corresponds to your views. There are no right or wrong answers.

How much do you agree with this statement: *Type2 diabetes is a very common illness?*

1 . 2 . 3 . 4 . 5
Strongly Disagree Strongly Agree

How much do you agree with this statement: *Type2 diabetes is an older person's disease?*

1 . 2 . 3 . 4 . 5
Strongly Disagree Strongly Agree

How much control do you think you have over your child(ren) getting this illness?

1 . 2 . 3 . 4 . 5
Absolutely no control Complete control

How helpful do you think the health service would be to you if you had diabetes?

1 . 2 . 3 . 4 . 5
Not at all helpful Extremely helpful

How much do you think you having this illness would affect your child(ren)?

1 . 2 . 3 . 4 . 5
No effect at all Severely affect them

How do you think having to look after your child(ren) and family would affect diabetes?

1 . 2 . 3 . 4 . 5
No effect at all Extremely affect

How much do you agree with this statement: *Type2 diabetes is to do with the amount of sugar you eat?*

1 . 2 . 3 . 4 . 5
Strongly Disagree Strongly Agree

How much do you think your diet would affect this illness?

1 . 2 . 3 . 4 . 5
Not at all Extreme amount

How much do you think physical activity would affect this illness?

1 . 2 . 3 . 4 . 5
Not at all Extreme amount

How concerned are you about your child(ren) getting this illness?

1 . 2 . 3 . 4 . 5
Not at all concerned Extremely concerned

How much do you think living in England rather than in Pakistan would affect this illness?

1 . 2 . 3 . 4 . 5
Not at all Extremely

How much would you try to stop your child(ren) from getting this illness?

1 . 2 . 3 . 4 . 5
Would not try Extreme amount

Appendix 7.11

Questionnaire exploring perceptions of Type2 Diabetes among Young British Pakistani females

We want to know your personal views about Type 2 Diabetes. For the following questions, please circle the number that best corresponds to your views. There are no right or wrong answers.

How much do you agree with this statement: *Type2 diabetes is a very common illness?*

1 . 2 . 3 . 4 . 5
Strongly Disagree Strongly Agree

How much do you agree with this statement: *Type2 diabetes is an older person's disease?*

1 . 2 . 3 . 4 . 5
Strongly Disagree Strongly Agree

How much control do you think you have over getting this illness?

1 . 2 . 3 . 4 . 5
Absolutely no control Complete control

How helpful do you think the health service would be to you if you had diabetes?

1 . 2 . 3 . 4 . 5
Not at all helpful Extremely helpful

How much do you think you having this illness would affect your family?

1 . 2 . 3 . 4 . 5
No effect at all Severely affect them

How do you think it would/does affect you if your parent(s) would/have diabetes?

1 . 2 . 3 . 4 . 5
No effect at all Extremely affect

How much do you agree with this statement: *Type2 diabetes is to do with the amount of sugar you eat?*

1 . 2 . 3 . 4 . 5
Strongly Disagree Strongly Agree

How much do you think your diet would affect this illness?

1 . 2 . 3 . 4 . 5
Not at all Extreme amount

How much do you think physical activity would affect this illness?

1 . 2 . 3 . 4 . 5
Not at all Extreme amount

How concerned are you about you getting this illness?

1 . 2 . 3 . 4 . 5
Not at all concerned Extremely concerned

How much do you think living in England rather than in Pakistan would affect this illness?

1 . 2 . 3 . 4 . 5
Not at all Extremely

How much do you try to prevent getting this illness?

1 . 2 . 3 . 4 . 5
Not try at all Extreme amount

Appendix 7.12

Listed below are a number of symptoms that you may or may not have experienced since your diabetes. Please indicate by circling **Yes** or **No**, whether you have experienced any of these symptoms since your diabetes, and whether you believe that these symptoms are related to your diabetes.

	I have experienced this symptom <i>since my diabetes</i>			This symptom is <i>related to my diabetes</i>		
	Yes	No	Don't know	Yes	No	Don't know
Pain	Yes	No	Don't know	Yes	No	Don't know
Sore Throat	Yes	No	Don't know	Yes	No	Don't know
Nausea	Yes	No	Don't know	Yes	No	Don't know
Breathlessness	Yes	No	Don't know	Yes	No	Don't know
Weight Loss	Yes	No	Don't know	Yes	No	Don't know
Fatigue	Yes	No	Don't know	Yes	No	Don't know
Stiff Joints	Yes	No	Don't know	Yes	No	Don't know
Sore Eyes	Yes	No	Don't know	Yes	No	Don't know
Wheeziness	Yes	No	Don't know	Yes	No	Don't know
Headaches	Yes	No	Don't know	Yes	No	Don't know
Upset Stomach	Yes	No	Don't know	Yes	No	Don't know
Sleep Difficulties	Yes	No	Don't know	Yes	No	Don't know
Dizziness	Yes	No	Don't know	Yes	No	Don't know
Loss of Strength	Yes	No	Don't know	Yes	No	Don't know

We are interested in your own personal views of how you now see your current diabetes. As people are very different, there is no correct answer for this question. Please indicate how much you agree or disagree with the following statements about your diabetes by circling the appropriate response:

1 strongly disagree	2 disagree	3 neither agree nor disagree	4 agree	5 strongly agree
My diabetes will last a short time	1	2	3	4 5
My diabetes is likely to be permanent rather than temporary	1	2	3	4 5
My diabetes will last for a long time	1	2	3	4 5
This diabetes will pass quickly	1	2	3	4 5
I expect to have this diabetes for the rest of my life	1	2	3	4 5
My diabetes is a serious condition	1	2	3	4 5
My diabetes has major consequences on my life	1	2	3	4 5
My diabetes does not have much effect on my life	1	2	3	4 5
My diabetes strongly affects the way others see me	1	2	3	4 5
My diabetes has serious financial consequences	1	2	3	4 5
My diabetes causes difficulties for those who are close to me	1	2	3	4 5
There is a lot which I can do to control my symptoms	1	2	3	4 5

What I do can determine whether my diabetes gets better or worse	1	2	3	4	5
The course of my diabetes depends on me	1	2	3	4	5
Nothing I do will affect my diabetes	1	2	3	4	5
I have the power to influence my diabetes	1	2	3	4	5
My actions will have no affect on the outcome of my diabetes	1	2	3	4	5
My diabetes will improve in time	1	2	3	4	5
There is very little that can be done to improve my diabetes	1	2	3	4	5
My treatment will be effective in curing my diabetes	1	2	3	4	5
The negative effects of my diabetes can be prevented (avoided) by my treatment	1	2	3	4	5
My treatment can control my diabetes	1	2	3	4	5
There is nothing which can help my condition	1	2	3	4	5
The symptoms of my condition are puzzling to me	1	2	3	4	5
My diabetes is a mystery to me	1	2	3	4	5
I don't understand my diabetes	1	2	3	4	5
My diabetes doesn't make any sense to me	1	2	3	4	5
I have a clear picture or understanding of my condition	1	2	3	4	5
The symptoms of my diabetes change a great deal from day to day	1	2	3	4	5
My symptoms come and go in cycles	1	2	3	4	5
My diabetes is very unpredictable	1	2	3	4	5
I go through cycles in which my diabetes gets better and worse	1	2	3	4	5
I get depressed when I think about my diabetes	1	2	3	4	5
When I think about my diabetes I get upset	1	2	3	4	5
My diabetes makes me feel angry	1	2	3	4	5
My diabetes does not worry me	1	2	3	4	5
Having this diabetes makes me feel anxious	1	2	3	4	5
My diabetes makes me feel afraid	1	2	3	4	5

We are interested in what you consider may have been the cause of your diabetes. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your diabetes rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your diabetes. Please indicate how much you agree or disagree that they were causes for you by circling the appropriate response:

	1	2	3	4	5
	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
Stress or worry	1	2	3	4	5
Hereditary - it runs in my family	1	2	3	4	5
A Germ or virus	1	2	3	4	5
Diet or eating habits	1	2	3	4	5
Chance or bad luck	1	2	3	4	5
Poor medical care in my past	1	2	3	4	5
Pollution in the environment	1	2	3	4	5
My own behaviour	1	2	3	4	5
My mental attitude e.g. thinking about life negatively	1	2	3	4	5
Family problems or worries	1	2	3	4	5
Overwork	1	2	3	4	5
My emotional state e.g. feeling down, lonely, anxious, empty	1	2	3	4	5
Ageing	1	2	3	4	5
Alcohol	1	2	3	4	5
Smoking	1	2	3	4	5
Accident or injury	1	2	3	4	5
My personality	1	2	3	4	5
Altered immunity	1	2	3	4	5

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR diabetes. You may use any of the items from above, or you may have additional ideas of your own.

The most important causes for me:

1. _____
2. _____
3. _____

Thank you for you time and for completing the questionnaire.

Appendix 7.13

Listed below are a number of symptoms that people with diabetes may or may not experience. As people are very different, there is no correct answer for this question. Please indicate by circling **Yes** or **No** whether you believe that these symptoms are related to diabetes.

This symptom is related to diabetes

Pain	Yes	No	Don't know
Sore Throat	Yes	No	Don't know
Nausea	Yes	No	Don't know
Breathlessness	Yes	No	Don't know
Weight Loss	Yes	No	Don't know
Fatigue	Yes	No	Don't know
Stiff Joints	Yes	No	Don't know
Sore Eyes	Yes	No	Don't know
Wheeziness	Yes	No	Don't know
Headaches	Yes	No	Don't know
Upset Stomach	Yes	No	Don't know
Sleep Difficulties	Yes	No	Don't know
Dizziness	Yes	No	Don't know
Loss of Strength	Yes	No	Don't know

Remember we are interested in your own personal views of how you see diabetes. Please indicate whether you agree or disagree with the following statements by circling one of the responses. There are no right or wrong answers:

1 strongly disagree	2 disagree	3 neither agree nor disagree	4 agree	5 strongly agree		
Diabetes will last a short time		1	2	3	4	5
Diabetes is likely to be permanent rather than temporary		1	2	3	4	5
Diabetes will last for a long time		1	2	3	4	5
Diabetes will pass quickly		1	2	3	4	5
I expect diabetes to last for the rest of one's life		1	2	3	4	5
Diabetes is a serious condition		1	2	3	4	5
Diabetes has major consequences on one's life		1	2	3	4	5
Diabetes does not have much effect on one's life		1	2	3	4	5
Diabetes strongly affects the way others see me		1	2	3	4	5
Diabetes has serious financial consequences		1	2	3	4	5
Diabetes causes difficulties for those who are close to the patient		1	2	3	4	5
There is a lot a person can do to control the symptoms		1	2	3	4	5
What a person can do determines whether diabetes gets better or worse		1	2	3	4	5
The course of diabetes would depend on me		1	2	3	4	5

	Strongly Disagree				Strongly Agree
	1	2	3	4	5
Nothing I do will affect this illness	1	2	3	4	5
I have the power to influence this illness	1	2	3	4	5
My actions would have no effect on the outcome of diabetes	1	2	3	4	5
Diabetes would improve in time	1	2	3	4	5
There is very little that can be done to improve diabetes	1	2	3	4	5
Treatment is effective in curing diabetes	1	2	3	4	5
The negative effects of diabetes can be prevented (avoided) by treatment	1	2	3	4	5
Treatment can control diabetes	1	2	3	4	5
There is nothing which can help this condition	1	2	3	4	5
The symptoms of diabetes are puzzling to me	1	2	3	4	5
Diabetes is a mystery to me	1	2	3	4	5
I don't understand diabetes	1	2	3	4	5
Diabetes doesn't make any sense to me	1	2	3	4	5
I have a clear picture or understanding of diabetes	1	2	3	4	5
The symptoms of diabetes change a great deal from day to day	1	2	3	4	5
The symptoms come and go in cycles	1	2	3	4	5
Diabetes is very unpredictable	1	2	3	4	5
Diabetes goes through cycles in which it gets better and worse	1	2	3	4	5
I get depressed when I think about diabetes	1	2	3	4	5
When I think about diabetes I get upset	1	2	3	4	5
Thinking about diabetes makes me feel angry	1	2	3	4	5
Diabetes does not worry me	1	2	3	4	5
Thinking about having diabetes makes me feel anxious	1	2	3	4	5
Diabetes makes me feel afraid	1	2	3	4	5

We are interested in what you consider may cause diabetes. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that cause diabetes. Below is a list of possible causes for diabetes. Please indicate how much you agree or disagree that they cause diabetes by circling the appropriate response:

	1	2	3	4	5
	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
Stress or worry	1	2	3	4	5
Hereditary - it runs in my family	1	2	3	4	5
A Germ or virus	1	2	3	4	5
Diet or eating habits	1	2	3	4	5
Chance or bad luck	1	2	3	4	5
Poor medical care in my past	1	2	3	4	5
Pollution in the environment	1	2	3	4	5
My own behaviour	1	2	3	4	5
My mental attitude e.g. thinking about life negatively	1	2	3	4	5
Family problems or worries	1	2	3	4	5
Overwork	1	2	3	4	5
My emotional state e.g. feeling down, lonely, anxious, empty	1	2	3	4	5
Ageing	1	2	3	4	5
Alcohol	1	2	3	4	5
Smoking	1	2	3	4	5
Accident or injury	1	2	3	4	5
My personality	1	2	3	4	5
Altered immunity	1	2	3	4	5

In the table below, please list in rank-order the three most important factors that you now believe cause diabetes. You may use any of the items from above, or you may have additional ideas of your own.

The most important causes for me:

1. _____
2. _____
3. _____

Thank you for you time and for completing the questionnaire.

Appendix 7.14

Listed below are a number of symptoms that people with diabetes may or may not experience. As people are very different, there is no correct answer for this question. Please indicate by circling **Yes** or **No** whether you believe that these symptoms are related to diabetes.

This symptom is related to diabetes

Pain	Yes	No	Don't know
Sore Throat	Yes	No	Don't know
Nausea	Yes	No	Don't know
Breathlessness	Yes	No	Don't know
Weight Loss	Yes	No	Don't know
Fatigue	Yes	No	Don't know
Stiff Joints	Yes	No	Don't know
Sore Eyes	Yes	No	Don't know
Wheeziness	Yes	No	Don't know
Headaches	Yes	No	Don't know
Upset Stomach	Yes	No	Don't know
Sleep Difficulties	Yes	No	Don't know
Dizziness	Yes	No	Don't know
Loss of Strength	Yes	No	Don't know

Remember we are interested in your own personal views of how you see diabetes. Please indicate whether you agree or disagree with the following statements by circling one of the responses. There are no right or wrong answers:

1 strongly disagree	2 disagree	3 neither agree nor disagree	4 agree	5 strongly agree			
Diabetes will last a short time			1	2	3	4	5
Diabetes is likely to be permanent rather than temporary			1	2	3	4	5
Diabetes will last for a long time			1	2	3	4	5
Diabetes will pass quickly			1	2	3	4	5
I expect diabetes to last for the rest of one's life			1	2	3	4	5
Diabetes is a serious condition			1	2	3	4	5
Diabetes has major consequences on one's life			1	2	3	4	5
Diabetes does not have much effect on one's life			1	2	3	4	5
Diabetes strongly affects the way others see me			1	2	3	4	5
Diabetes has serious financial consequences			1	2	3	4	5
Diabetes causes difficulties for those who are close to the patient			1	2	3	4	5
There is a lot a person can do to control the symptoms			1	2	3	4	5
What a person can do determines whether diabetes gets better or worse			1	2	3	4	5
The course of diabetes would depend on me			1	2	3	4	5

	Strongly Disagree				Strongly Agree
	1	2	3	4	5
Nothing I do will affect this illness	1	2	3	4	5
I have the power to influence this illness	1	2	3	4	5
My actions would have no effect on the outcome of diabetes	1	2	3	4	5
Diabetes would improve in time	1	2	3	4	5
There is very little that can be done to improve diabetes	1	2	3	4	5
Treatment is effective in curing diabetes	1	2	3	4	5
The negative effects of diabetes can be prevented (avoided) by treatment	1	2	3	4	5
Treatment can control diabetes	1	2	3	4	5
There is nothing which can help this condition	1	2	3	4	5
The symptoms of diabetes are puzzling to me	1	2	3	4	5
Diabetes is a mystery to me	1	2	3	4	5
I don't understand diabetes	1	2	3	4	5
Diabetes doesn't make any sense to me	1	2	3	4	5
I have a clear picture or understanding of diabetes	1	2	3	4	5
The symptoms of diabetes change a great deal from day to day	1	2	3	4	5
The symptoms come and go in cycles	1	2	3	4	5
Diabetes is very unpredictable	1	2	3	4	5
Diabetes goes through cycles in which it gets better and worse	1	2	3	4	5
I get depressed when I think about diabetes	1	2	3	4	5
When I think about diabetes I get upset	1	2	3	4	5
Thinking about diabetes makes me feel angry	1	2	3	4	5
Diabetes does not worry me	1	2	3	4	5
Thinking about having diabetes makes me feel anxious	1	2	3	4	5
Diabetes makes me feel afraid	1	2	3	4	5

We are interested in what you consider may cause diabetes. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that cause diabetes. Below is a list of possible causes for diabetes. Please indicate how much you agree or disagree that they cause diabetes by circling the appropriate response:

	1	2	3	4	5
	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
Stress or worry	1	2	3	4	5
Hereditary - it runs in my family	1	2	3	4	5
A germ or virus	1	2	3	4	5
Diet or eating habits	1	2	3	4	5
Chance or bad luck	1	2	3	4	5
Poor medical care in my past	1	2	3	4	5
Pollution in the environment	1	2	3	4	5
My own behaviour	1	2	3	4	5
My mental attitude e.g. thinking about life negatively	1	2	3	4	5
Family problems or worries	1	2	3	4	5
Overwork	1	2	3	4	5
My emotional state e.g. feeling down, lonely, anxious, empty	1	2	3	4	5
Ageing	1	2	3	4	5
Alcohol	1	2	3	4	5
Smoking	1	2	3	4	5
Accident or injury	1	2	3	4	5
My personality	1	2	3	4	5
Altered immunity	1	2	3	4	5

In the table below, please list in rank-order the three most important factors that you now believe cause diabetes. You may use any of the items from above, or you may have additional ideas of your own.

The most important causes for me:

1. _____
2. _____
3. _____

Thank you for you time and for completing the questionnaire.

Appendix 7.15 SPSS Output

```
GET FILE='C:\Documents and Settings\ikramf\Desktop\Thesis\spss\mothers
data T2DM.sav'. DATASET NAME DataSet1 WINDOW=FRONT. DESCRIPTIVES
VARIABLES=age diagnosis /STATISTICS=MEAN STDDEV RANGE MIN MAX.
```

Descriptives T2DM mothers

```
[DataSet1] C:\Documents and Settings\ikramf\Desktop\Thesis\spss\mothers
data T2DM.sav
```

Descriptive Statistics

	N	Range	Minimum	Maximum	Mean	Std. Deviation
age	41	18.00	32.00	50.00	42.0732	5.49268
diagnosis	41	.00	1.00	1.00	1.0000	.00000
Valid N (listwise)	41					

```
DESCRIPTIVES VARIABLES=common old control healthcare affect care sugar diet
activity concern Pakistan prevention /STATISTICS=MEAN STDDEV RANGE MIN
MAX.
```

Descriptives

```
[DataSet1] C:\Documents and Settings\ikramf\Desktop\Thesis\spss\mothers
data T2DM.sav
```

Descriptive Statistics

	N	Range	Minimum	Maximum	Mean	Std. Deviation
common	41	4.00	1.00	5.00	4.1463	.93704
old age	41	4.00	1.00	5.00	2.5854	1.13964
control over children	41	4.00	1.00	5.00	3.4146	.97405
health service	41	4.00	1.00	5.00	3.8537	.98896
affect on children	41	4.00	1.00	5.00	3.3415	1.06324
family care	41	4.00	1.00	5.00	3.1707	1.04648
sugar	41	4.00	1.00	5.00	2.9268	1.29210
diet	41	4.00	1.00	5.00	3.7073	1.10100
physical activity	41	5.00	1.00	6.00	3.9512	1.02350
concern for children	41	4.00	1.00	5.00	3.5366	.97718
Eng v Pak	41	4.00	1.00	5.00	3.3659	1.21976
children prevention	41	4.00	1.00	5.00	3.5610	.89579
Valid N (listwise)	41					

```
DESCRIPTIVES VARIABLES=identity timeline consequences PC TC IC TLC ER PA
risk immunity AC /STATISTICS=MEAN STDDEV RANGE MIN MAX.
```

Descriptives

[DataSet1] C:\Documents and Settings\ikramf\Desktop\Thesis\spss\mothers data T2DM.sav

Descriptive Statistics

	N	Range	Minimum	Maximum	Mean	Std. Deviation
identity	41	14.00	.00	14.00	6.2439	3.82610
timeline	41	23.00	7.00	30.00	23.5854	5.09890
consequences	41	14.00	12.00	26.00	19.7073	3.90669
personal control	41	14.0	16.0	30.0	21.732	3.6126
treatment control	41	14.00	9.00	23.00	17.6585	3.28337
illness coherence	41	24.00	5.00	29.00	17.0976	5.22879
timeline cyclical	41	13.00	7.00	20.00	12.3415	3.85752
emotional representations	41	24.00	6.00	30.00	20.8049	5.19721
psychological attributions	41	22.00	8.00	30.00	18.7561	4.89275
risk factors	41	24.00	6.00	30.00	20.0488	3.97461
immunity	41	8.00	3.00	11.00	6.8049	1.99022
accident or chance	41	5.00	2.00	7.00	4.5122	1.20669
Valid N (listwise)	41					

```
GET FILE='C:\Documents and Settings\ikramf\Desktop\Thesis\spss\mothers
data nonT2DM.sav'. DATASET NAME DataSet1 WINDOW=FRONT. DESCRIPTIVES
VARIABLES=diagnosis /STATISTICS=MEAN STDDEV MIN MAX.
```

Descriptives non-T2DM mothers

[DataSet1] C:\Documents and Settings\ikramf\Desktop\Thesis\spss\mothers data nonT2DM.sav

Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
diagnosis	47	2	2	2.00	.000
Valid N (listwise)	47				

```
DESCRIPTIVES VARIABLES=common old control healthcare affect care sugar diet
activity concern Pakistan prevention /STATISTICS=MEAN STDDEV RANGE MIN
MAX.
```

Descriptives

[DataSet1] C:\Documents and Settings\ikramf\Desktop\Thesis\spss\mothers data nonT2DM.sav

Descriptive Statistics

	N	Range	Minimum	Maximum	Mean	Std. Deviation
common	47	4	1	5	4.02	.944
old age	47	4	1	5	2.94	1.292
control over children	47	4	1	5	3.36	1.112
health service	47	3	2	5	3.89	.814
affect on children	47	4	1	5	3.79	.977
family care	47	4	1	5	3.66	1.048
sugar	47	4	1	5	3.74	1.073
diet	47	3	2	5	4.17	.892
physical activity	47	4	1	5	3.70	1.196
concern for children	47	4	1	5	3.53	1.120
Eng v Pak	47	4	1	5	3.60	1.014
children prevention	47	4	1	5	4.26	.966
Valid N (listwise)	47					

DESCRIPTIVES VARIABLES=identity timeline consequences PC TC IC TLC ER PA
risk immunity AC /STATISTICS=MEAN STDDEV RANGE MIN MAX.

Descriptives

[DataSet1] C:\Documents and Settings\ikramf\Desktop\Thesis\spss\mothers
data nonT2DM.sav

Descriptive Statistics

	N	Range	Minimum	Maximum	Mean	Std. Deviation
identity	47	14	0	14	6.13	3.609
timeline	47	16	14	30	21.64	4.178
consequences	47	17	11	28	20.34	4.259
personal control	47	17	13	30	21.23	4.295
treatment control	47	10	12	22	17.38	2.960
illness coherence	47	18	5	23	14.87	4.456
timeline cyclical	47	14	4	18	13.00	2.912
emotional representations	47	22	8	30	19.04	5.879
psychological attributions	47	21	6	27	15.32	5.365
risk factors	47	123	8	131	23.62	17.007
immunity	47	10	3	13	7.32	2.477
accident or chance	47	8	2	10	5.36	2.005
Valid N (listwise)	47					

```
SAVE OUTFILE='C:\Documents and Settings\ikramf\Desktop\Thesis\spss\student
data.sav' /COMPRESSED. DESCRIPTIVES VARIABLES=age diagnosis
/STATISTICS=MEAN STDDEV RANGE MIN MAX.
```

Descriptives young females

```
[DataSet1] C:\Documents and Settings\ikramf\Desktop\Thesis\spss\student
data.sav
```

Descriptive Statistics

	N	Range	Minimum	Maximum	Mean	Std. Deviation
age	42	9.00	18.00	27.00	20.4524	2.42147
parent's diagnosis	42	2.00	1.00	3.00	2.3571	.93238
Valid N (listwise)	42					

```
FREQUENCIES VARIABLES=age diagnosis /ORDER=ANALYSIS.
```

Frequencies

```
[DataSet1] C:\Documents and Settings\ikramf\Desktop\Thesis\spss\student
data.sav
```

Statistics

		age	parent's diagnosis
N	Valid	42	42
	Missing	0	0

Frequency Table

age

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	18.00	12	28.6	28.6	28.6
	19.00	6	14.3	14.3	42.9
	20.00	9	21.4	21.4	64.3
	21.00	2	4.8	4.8	69.0
	22.00	2	4.8	4.8	73.8
	23.00	6	14.3	14.3	88.1
	24.00	2	4.8	4.8	92.9
	25.00	2	4.8	4.8	97.6
	27.00	1	2.4	2.4	100.0
	Total	42	100.0	100.0	

parent's diagnosis

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	mother or father	13	31.0	31.0	31.0
	both	1	2.4	2.4	33.3
	neither	28	66.7	66.7	100.0
Total		42	100.0	100.0	

DESCRIPTIVES VARIABLES=common old control healthcare affect parents sugar diet activity concern Pakistan prevention /STATISTICS=MEAN STDDEV RANGE MIN MAX.

Descriptives

[DataSet1] C:\Documents and Settings\ikramf\Desktop\Thesis\spss\student data.sav

Descriptive Statistics

	N	Range	Minimum	Maximum	Mean	Std. Deviation
common	42	2.00	3.00	5.00	4.0238	.68032
old age	42	4.00	1.00	5.00	2.9286	1.04515
control	42	3.00	2.00	5.00	3.2143	.75015
health service	42	4.00	1.00	5.00	3.7143	1.01898
affect family	42	3.00	2.00	5.00	3.6905	.78050
parents affect	42	3.00	2.00	5.00	3.7857	.75015
sugar	42	4.00	1.00	5.00	3.3571	1.16496
diet	42	3.00	2.00	5.00	4.1667	.90841
physical activity	42	3.00	2.00	5.00	3.8333	.90841
concern	42	4.00	1.00	5.00	3.2381	1.05483
Eng v Pak	42	4.00	1.00	5.00	3.4762	.96873
prevention	42	4.00	1.00	5.00	2.6667	1.02806
Valid N (listwise)	42					

DESCRIPTIVES VARIABLES=identity timeline consequences PC TC IC TLC ER PA risk immunity AC /STATISTICS=MEAN STDDEV RANGE MIN MAX.

Descriptives

[DataSet1] C:\Documents and Settings\ikramf\Desktop\Thesis\spss\student data.sav

Descriptive Statistics

	N	Range	Minimum	Maximum	Mean	Std. Deviation
identity	42	12.00	.00	12.00	5.5714	2.63321
timeline	42	15.00	15.00	30.00	23.1667	4.18427
consequences	42	16.00	11.00	27.00	20.2143	3.99106
personal control	42	17.00	13.00	30.00	22.5238	4.02576
treatment control	42	13.00	12.00	25.00	18.5952	2.89709
illness coherence	42	18.00	7.00	25.00	17.8333	4.48801
timeline cyclical	42	9.00	8.00	17.00	12.3810	2.14080
emotional representations	42	22.00	6.00	28.00	16.9524	5.08922
psychological attributions	42	20.00	6.00	26.00	14.7143	5.20921
risk factors	42	15.00	15.00	30.00	23.4048	4.45607
immunity	42	8.00	3.00	11.00	7.4048	2.02496
accident or chance	42	14.00	2.00	16.00	5.0952	2.34583
Valid N (listwise)	42					

Reliability

[DataSet1] C:\Users\IkramBaF\Desktop\Thesis\spss\dataset study 3 v2.sav

Scale: ALL VARIABLES

Case Processing Summary

		N	%
Cases	Valid	130	98.5
	Excluded ^a	2	1.5
	Total	132	100.0

a. Listwise deletion based on all variables in the procedure.

Reliability Statistics

Cronbach's Alpha	N of Items
.589	7

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
common	21.3385	13.373	.220	.578
old age	22.5769	12.634	.179	.602
health service	21.5769	12.711	.286	.558
sugar	22.0385	11.324	.331	.543
diet	21.3769	11.710	.419	.513
physical activity	21.5769	11.843	.352	.535
Eng v Pak	21.9154	11.566	.386	.522

CORRELATIONS /VARIABLES=PC preventionperceptions /PRINT=TWOTAIL NOSIG /MISSING=PAIRWISE.

Correlations

[DataSet1] C:\Users\IkramBaF\Desktop\Thesis\spss\dataset study 3 v2.sav

		personal control	preventionperceptions
personal control	Pearson Correlation	1	.253**
	Sig. (2-tailed)		.004
	N	130	130
preventionperceptions	Pearson Correlation	.253**	1
	Sig. (2-tailed)	.004	
	N	130	130

** . Correlation is significant at the 0.01 level (2-tailed).

```

CORRELATIONS  /VARIABLES=identity timeline consequences PC TC IC TLC ER PA
risk immunity AC preventionperceptions  /PRINT=TWOTAIL NOSIG
/MISSING=PAIRWISE.

```

Correlations

[DataSet1] C:\Users\IkramBaF\Desktop\Thesis\spss\dataset study 3 v2.sav

		identity	timeline	consequences	personal control
identity	Pearson Correlation	1	.177 ⁺	.141	.152
	Sig. (2-tailed)		.044	.109	.085
	N	130	130	130	130
timeline	Pearson Correlation	.177 ⁺	1	.371 ^{**}	.253 ^{**}
	Sig. (2-tailed)	.044		.000	.004
	N	130	130	130	130
consequences	Pearson Correlation	.141	.371 ^{**}	1	.286 ^{**}
	Sig. (2-tailed)	.109	.000		.001
	N	130	130	130	130
personal control	Pearson Correlation	.152	.253 ^{**}	.286 ^{**}	1
	Sig. (2-tailed)	.085	.004	.001	
	N	130	130	130	130
treatment control	Pearson Correlation	.153	.061	-.027	.300 ^{**}
	Sig. (2-tailed)	.083	.491	.760	.001
	N	130	130	130	130
illness coherence	Pearson Correlation	.203 ⁺	.138	.133	.338 ^{**}
	Sig. (2-tailed)	.021	.118	.131	.000
	N	130	130	130	130
timeline cyclical	Pearson Correlation	.095	-.082	.113	-.096
	Sig. (2-tailed)	.281	.354	.199	.275
	N	130	130	130	130
emotional representations	Pearson Correlation	.106	.052	.293 ^{**}	.037
	Sig. (2-tailed)	.231	.554	.001	.679
	N	130	130	130	130
psychological attributions	Pearson Correlation	.058	-.017	.004	-.112
	Sig. (2-tailed)	.515	.850	.967	.203
	N	130	130	130	130
risk factors	Pearson Correlation	-.114	-.059	.088	.201 ⁺
	Sig. (2-tailed)	.195	.504	.319	.022
	N	130	130	130	130
immunity	Pearson Correlation	-.085	-.200 ⁺	.054	-.056
	Sig. (2-tailed)	.334	.023	.542	.527
	N	130	130	130	130
accident or chance	Pearson Correlation	.184 ⁺	-.014	.061	.053
	Sig. (2-tailed)	.036	.875	.489	.549

	N	130	130	130	130
preventionperceptions	Pearson Correlation	.082	.121	.145	.253**
	Sig. (2-tailed)	.355	.171	.101	.004
	N	130	130	130	130

		treatment control	illness coherence	timeline cyclical	emotional representations
identity	Pearson Correlation	.153	.203 ⁺	.095	.106
	Sig. (2-tailed)	.083	.021	.281	.231
	N	130	130	130	130
timeline	Pearson Correlation	.061	.138	-.082	.052
	Sig. (2-tailed)	.491	.118	.354	.554
	N	130	130	130	130
consequences	Pearson Correlation	-.027	.133	.113	.293 ^{**}
	Sig. (2-tailed)	.760	.131	.199	.001
	N	130	130	130	130
personal control	Pearson Correlation	.300 ^{**}	.338 ^{**}	-.096	.037
	Sig. (2-tailed)	.001	.000	.275	.679
	N	130	130	130	130
treatment control	Pearson Correlation	1	.355 ^{**}	-.072	-.205 ⁺
	Sig. (2-tailed)		.000	.416	.019
	N	130	130	130	130
illness coherence	Pearson Correlation	.355 ^{**}	1	-.138	-.230 ^{**}
	Sig. (2-tailed)	.000		.118	.009
	N	130	130	130	130
timeline cyclical	Pearson Correlation	-.072	-.138	1	.375 ^{**}
	Sig. (2-tailed)	.416	.118		.000
	N	130	130	130	130
emotional representations	Pearson Correlation	-.205 ⁺	-.230 ^{**}	.375 ^{**}	1
	Sig. (2-tailed)	.019	.009	.000	
	N	130	130	130	130
psychological attributions	Pearson Correlation	-.185 ⁺	-.130	.033	.295 ^{**}
	Sig. (2-tailed)	.035	.140	.713	.001
	N	130	130	130	130
risk factors	Pearson Correlation	.053	-.085	-.017	-.018
	Sig. (2-tailed)	.550	.336	.851	.842
	N	130	130	130	130
immunity	Pearson Correlation	-.085	-.275 ^{**}	.182 ⁺	.161
	Sig. (2-tailed)	.336	.002	.038	.068
	N	130	130	130	130
accident or chance	Pearson Correlation	-.154	-.150	.270 ^{**}	.237 ^{**}

	psychological attributions	risk factors	immunity	accident or chance	preventionperceptions
--	----------------------------	--------------	----------	--------------------	-----------------------

	Sig. (2-tailed)	.081	.088	.002	.007
	N	130	130	130	130
preventionperceptions	Pearson Correlation	-.019	.024	-.144	-.057
	Sig. (2-tailed)	.829	.786	.102	.517
	N	130	130	130	130

identity	Pearson Correlation	.058	-.114	-.085	.184 [*]	.082
	Sig. (2-tailed)	.515	.195	.334	.036	.355
	N	130	130	130	130	130
timeline	Pearson Correlation	-.017	-.059	-.200 [*]	-.014	.121
	Sig. (2-tailed)	.850	.504	.023	.875	.171
	N	130	130	130	130	130
consequences	Pearson Correlation	.004	.088	.054	.061	.145
	Sig. (2-tailed)	.967	.319	.542	.489	.101
	N	130	130	130	130	130
personal control	Pearson Correlation	-.112	.201 [*]	-.056	.053	.253 ^{**}
	Sig. (2-tailed)	.203	.022	.527	.549	.004
	N	130	130	130	130	130
treatment control	Pearson Correlation	-.185 [*]	.053	-.085	-.154	-.019
	Sig. (2-tailed)	.035	.550	.336	.081	.829
	N	130	130	130	130	130
illness coherence	Pearson Correlation	-.130	-.085	-.275 ^{**}	-.150	.024
	Sig. (2-tailed)	.140	.336	.002	.088	.786
	N	130	130	130	130	130
timeline cyclical	Pearson Correlation	.033	-.017	.182 [*]	.270 ^{**}	-.144
	Sig. (2-tailed)	.713	.851	.038	.002	.102
	N	130	130	130	130	130
emotional representations	Pearson Correlation	.295 ^{**}	-.018	.161	.237 ^{**}	-.057
	Sig. (2-tailed)	.001	.842	.068	.007	.517
	N	130	130	130	130	130
psychological attributions	Pearson Correlation	1	.193 [*]	.388 ^{**}	.153	-.152
	Sig. (2-tailed)		.028	.000	.082	.083
	N	130	130	130	130	130
risk factors	Pearson Correlation	.193 [*]	1	.291 ^{**}	.026	.064

	Sig. (2-tailed)	.028		.001	.768	.470
	N	130	130	130	130	130
immunity	Pearson	.388**	.291**	1	.460**	-.018
	Correlation					
	Sig. (2-tailed)	.000	.001		.000	.842
	N	130	130	130	130	130
accident or chance	Pearson	.153	.026	.460**	1	.115
	Correlation					
	Sig. (2-tailed)	.082	.768	.000		.191
	N	130	130	130	130	130
preventionperceptions	Pearson	-.152	.064	-.018	.115	1
	Correlation					
	Sig. (2-tailed)	.083	.470	.842	.191	
	N	130	130	130	130	130

*. Correlation is significant at the 0.05 level (2-tailed).

** . Correlation is significant at the 0.01 level (2-tailed).

```
GET FILE='C:\Users\IkramBaF\Desktop\Thesis\spss\mothers data T2DM.sav'.
SAVE OUTFILE='C:\Users\IkramBaF\Desktop\Thesis\spss\study 3 dataset v2.sav'
/COMPRESSED. GET FILE='C:\Users\IkramBaF\Desktop\Thesis\spss\mothers data
nonT2DM.sav'. DATASET ACTIVATE DataSet1. SAVE
OUTFILE='C:\Users\IkramBaF\Desktop\Thesis\spss\study 3 dataset v2.sav'
/COMPRESSED. SAVE OUTFILE='C:\Users\IkramBaF\Desktop\Thesis\spss\study 3
dataset v2.sav' /COMPRESSED. DATASET ACTIVATE DataSet1. DATASET CLOSE
DataSet2. GET FILE='C:\Users\IkramBaF\Desktop\Thesis\spss\student
data.sav'. DATASET ACTIVATE DataSet1. DATASET CLOSE DataSet3. SAVE
OUTFILE='C:\Users\IkramBaF\Desktop\Thesis\spss\study 3 dataset v2.sav'
/COMPRESSED. SAVE OUTFILE='C:\Users\IkramBaF\Desktop\Thesis\spss\study 3
dataset v2.sav' /COMPRESSED. ONEWAY common old healthcare sugar diet
activity Pakistan BY group /MISSING ANALYSIS.
```

Oneway

[DataSet1] C:\Users\IkramBaF\Desktop\Thesis\spss\study 3 dataset v2.sav

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
common	Between Groups	.431	2	.215	.288	.750
	Within Groups	95.077	127	.749		
	Total	95.508	129			
old age	Between Groups	3.385	2	1.693	1.239	.293
	Within Groups	173.545	127	1.366		
	Total	176.931	129			
health service	Between Groups	.769	2	.385	.436	.648
	Within Groups	112.161	127	.883		
	Total	112.931	129			
sugar	Between Groups	14.648	2	7.324	5.304	.006
	Within Groups	175.360	127	1.381		
	Total	190.008	129			
diet	Between Groups	5.971	2	2.986	3.187	.045
	Within Groups	118.959	127	.937		
	Total	124.931	129			
physical activity	Between Groups	1.365	2	.683	.612	.544
	Within Groups	141.566	127	1.115		
	Total	142.931	129			
Eng v Pak	Between Groups	1.162	2	.581	.508	.603
	Within Groups	145.308	127	1.144		
	Total	146.469	129			

ONEWAY identity timeline consequences PC TC IC TLC ER PA risk immunity AC
BY group /MISSING ANALYSIS.

Oneway

[DataSet1] C:\Users\IkramBaF\Desktop\Thesis\spss\study 3 dataset v2.sav

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
identity	Between Groups	10.888	2	5.444	.471	.626
	Within Groups	1469.081	127	11.568		
	Total	1479.969	129			
timeline	Between Groups	93.987	2	46.994	2.331	.101
	Within Groups	2560.636	127	20.162		
	Total	2654.623	129			
consequences	Between Groups	9.588	2	4.794	.290	.749
	Within Groups	2098.112	127	16.521		
	Total	2107.700	129			
personal control	Between Groups	37.242	2	18.621	1.162	.316
	Within Groups	2034.951	127	16.023		
	Total	2072.192	129			
treatment control	Between Groups	35.063	2	17.531	1.889	.155
	Within Groups	1178.445	127	9.279		
	Total	1213.508	129			
illness coherence	Between Groups	213.700	2	106.850	4.790	.010
	Within Groups	2832.677	127	22.305		
	Total	3046.377	129			
timeline cyclical	Between Groups	12.268	2	6.134	.664	.517
	Within Groups	1173.124	127	9.237		
	Total	1185.392	129			
emotional representations	Between Groups	308.972	2	154.486	5.257	.006
	Within Groups	3732.259	127	29.388		
	Total	4041.231	129			
psychological attributions	Between Groups	397.047	2	198.524	7.428	.001
	Within Groups	3394.345	127	26.727		
	Total	3791.392	129			

risk factors	Between Groups	338.603	2	169.301	1.458	.237
	Within Groups	14751.128	127	116.151		
	Total	15089.731	129			
immunity	Between Groups	8.798	2	4.399	.918	.402
	Within Groups	608.771	127	4.793		
	Total	617.569	129			
accident or chance	Between Groups	16.278	2	8.139	2.205	.114
	Within Groups	468.714	127	3.691		
	Total	484.992	129			

```

COMPUTE preventionperceptions=common + old + healthcare + sugar + diet +
activity + Pakistan. EXECUTE. GET
FILE='C:\Users\IkramBaF\Desktop\Thesis\spss\student data.sav'. DATASET
ACTIVATE DataSet1. DATASET CLOSE DataSet4. REGRESSION /MISSING LISTWISE
/STATISTICS COEFF OUTS R ANOVA /CRITERIA=PIN(.05) POUT(.10) /NOORIGIN
/DEPENDENT preventionperceptions /METHOD=ENTER group identity timeline
consequences PC TC IC TLC ER PA risk immunity AC.

```

Regression

[DataSet1] C:\Users\IkramBaF\Desktop\Thesis\spss\study 3 dataset v2.sav

Variables Entered/Removed

Model	Variables Entered	Variables Removed	Method
1	accident or chance, timeline, risk factors, group, treatment control, timeline cyclical, identity, consequences, psychological attributions, illness coherence, personal control, emotional representations, immunity ^a		Enter

a. All requested variables entered.

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.387 ^a	.150	.055	3.82758

a. Predictors: (Constant), accident or chance, timeline, risk factors, group, treatment control, timeline cyclical, identity, consequences, psychological attributions, illness coherence, personal control, emotional representations, immunity

ANOVA^b

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	299.761	13	23.059	1.574	.103 ^a
	Residual	1699.439	116	14.650		
	Total	1999.200	129			

a. Predictors: (Constant), accident or chance, timeline, risk factors, group, treatment control, timeline cyclical, identity, consequences, psychological attributions, illness coherence, personal control, emotional representations, immunity

b. Dependent Variable: preventionperceptions

Coefficients^a

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	24.888	3.857		6.452	.000
	group	.069	.481	.014	.143	.886
	identity	.086	.110	.074	.785	.434
	timeline	.023	.085	.026	.266	.790
	consequences	.092	.101	.094	.911	.364
	personal control	.211	.102	.215	2.072	.041
	treatment control	-.132	.127	-.103	-1.046	.298
	illness coherence	-.063	.084	-.078	-.756	.451
	timeline cyclical	-.216	.126	-.166	-1.710	.090
	emotional representations	-.041	.078	-.059	-.532	.596
	psychological attributions	-.118	.077	-.163	-1.526	.130
	risk factors	.016	.035	.045	.469	.640
	immunity	-.011	.210	-.006	-.053	.958
	accident or chance	.286	.217	.141	1.320	.189

a. Dependent Variable: preventionperceptions

Appendix 7.16 Comparing correlations

		identity	timeline	consequences	personal control	treatment control	illness coherence	timeline cyclical	emotional representations
identity	Pearson Correlation	1	.177*	.141	.152	.153	.203*	.095	.106
	Sig. (2-tailed)		.044	.109	.085	.083	.021	.281	.231
	N	130	130	130	130	130	130	130	130
timeline	Pearson Correlation	.177*	1	.371**	.253**	.061	.138	-.082	.052
	Sig. (2-tailed)	.044		.000	.004	.491	.118	.354	.554
	N	130	130	130	130	130	130	130	130
consequences	Pearson Correlation	.141	.371**	1	.286**	-.027	.133	.113	.293**
	Sig. (2-tailed)	.109	.000		.001	.760	.131	.199	.001
	N	130	130	130	130	130	130	130	130
personal control	Pearson Correlation	.152	.253**	.286**	1	.300**	.338**	-.096	.037
	Sig. (2-tailed)	.085	.004	.001		.001	.000	.275	.679
	N	130	130	130	130	130	130	130	130
treatment control	Pearson Correlation	.153	.061	-.027	.300**	1	.355**	-.072	-.205*
	Sig. (2-tailed)	.083	.491	.760	.001		.000	.416	.019
	N	130	130	130	130	130	130	130	130
illness coherence	Pearson Correlation	.203*	.138	.133	.338**	.355**	1	-.138	-.230**
	Sig. (2-tailed)	.021	.118	.131	.000	.000		.118	.009
	N	130	130	130	130	130	130	130	130

timeline cyclical	Pearson Correlation	.095	-.082	.113	-.096	-.072	-.138	1	.375**
	Sig. (2-tailed)	.281	.354	.199	.275	.416	.118		.000
	N	130	130	130	130	130	130	130	130
emotional representations	Pearson Correlation	.106	.052	.293**	.037	-.205*	-.230**	.375**	1
	Sig. (2-tailed)	.231	.554	.001	.679	.019	.009	.000	
	N	130	130	130	130	130	130	130	130
psychological attributions	Pearson Correlation	.058	-.017	.004	-.112	-.185*	-.130	.033	.295**
	Sig. (2-tailed)	.515	.850	.967	.203	.035	.140	.713	.001
	N	130	130	130	130	130	130	130	130
risk factors	Pearson Correlation	-.114	-.059	.088	.201*	.053	-.085	-.017	-.018
	Sig. (2-tailed)	.195	.504	.319	.022	.550	.336	.851	.842
	N	130	130	130	130	130	130	130	130
immunity	Pearson Correlation	-.085	-.200*	.054	-.056	-.085	-.275**	.182*	.161
	Sig. (2-tailed)	.334	.023	.542	.527	.336	.002	.038	.068
	N	130	130	130	130	130	130	130	130
accident or chance	Pearson Correlation	.184*	-.014	.061	.053	-.154	-.150	.270**	.237**
	Sig. (2-tailed)	.036	.875	.489	.549	.081	.088	.002	.007
	N	130	130	130	130	130	130	130	130
preventionperceptions	Pearson Correlation	.082	.121	.145	.253**	-.019	.024	-.144	-.057
	Sig. (2-tailed)	.355	.171	.101	.004	.829	.786	.102	.517
	N	130	130	130	130	130	130	130	130

Table 1 Comparing correlations between T2DM prevention perception items

*. Correlation is significant at the 0.05 level (2-tailed)

**. Correlation is significant at the 0.01 level (2-tailed)

Appendix 7.16 Correlation Table continued...

		psychological attributions	risk factors	immunity	accident or chance	prevention perceptions
identity	Pearson Correlation	.058	-.114	-.085	.184*	.082
	Sig. (2-tailed)	.515	.195	.334	.036	.355
	N	130	130	130	130	130
timeline	Pearson Correlation	-.017	-.059	-.200*	-.014	.121
	Sig. (2-tailed)	.850	.504	.023	.875	.171
	N	130	130	130	130	130
consequences	Pearson Correlation	.004	.088	.054	.061	.145
	Sig. (2-tailed)	.967	.319	.542	.489	.101
	N	130	130	130	130	130
personal control	Pearson Correlation	-.112	.201*	-.056	.053	.253**
	Sig. (2-tailed)	.203	.022	.527	.549	.004
	N	130	130	130	130	130
treatment control	Pearson Correlation	-.185*	.053	-.085	-.154	-.019
	Sig. (2-tailed)	.035	.550	.336	.081	.829
	N	130	130	130	130	130
illness coherence	Pearson Correlation	-.130	-.085	-.275**	-.150	.024
	Sig. (2-tailed)	.140	.336	.002	.088	.786
	N	130	130	130	130	130

timeline cyclical	Pearson Correlation	.033	-.017	.182*	.270**	-.144
	Sig. (2-tailed)	.713	.851	.038	.002	.102
	N	130	130	130	130	130
emotional representations	Pearson Correlation	.295**	-.018	.161	.237**	-.057
	Sig. (2-tailed)	.001	.842	.068	.007	.517
	N	130	130	130	130	130
psychological attributions	Pearson Correlation	1	.193*	.388**	.153	-.152
	Sig. (2-tailed)		.028	.000	.082	.083
	N	130	130	130	130	130
risk factors	Pearson Correlation	.193*	1	.291**	.026	.064
	Sig. (2-tailed)	.028		.001	.768	.470
	N	130	130	130	130	130
immunity	Pearson Correlation	.388**	.291**	1	.460**	-.018
	Sig. (2-tailed)	.000	.001		.000	.842
	N	130	130	130	130	130
accident or chance	Pearson Correlation	.153	.026	.460**	1	.115
	Sig. (2-tailed)	.082	.768	.000		.191
	N	130	130	130	130	130
preventionperceptions	Pearson Correlation	-.152	.064	-.018	.115	1
	Sig. (2-tailed)	.083	.470	.842	.191	
	N	130	130	130	130	130

Table 1 Comparing correlations between T2DM prevention perception items

*. Correlation is significant at the 0.05 level (2-tailed)

**. Correlation is significant at the 0.01 level (2-tailed)