

**Chronic illness in
non-heterosexual contexts:
Towards a critical LGBTQ health
psychology**

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Abstract

In this thesis, I contribute to the expansion of lesbian, gay, bisexual, trans and queer (LGBTQ) psychology by examining chronic illness within non-heterosexual contexts. Chronic illness, beyond the confines of HIV/AIDS, has been a neglected topic in LGBTQ psychology and sexual identity is often overlooked within health psychology. When the health of lesbian, gay and bisexual (LGB) people has been considered there has been an over-reliance on quantitative methods and comparative approaches which seek to compare LGB people's health to their heterosexual counterparts. In contrast, I adopt a critical perspective and qualitative methods to explore LGBTQ health. My research brings together ideas from LGBTQ psychology and critical health psychology to explore non-heterosexuals' experiences of chronic illness and the discursive contexts within which LGB people live with chronic health conditions. I also highlight the heteronormativity which pervades academic health psychology as well as the 'lay' health literature. The research presented in this thesis draws on three different sources of qualitative data: a qualitative online questionnaire (n=190), an online discussion within a newsgroup for people with diabetes, and semi-structured interviews with 20 LGB people with diabetes. These data are analysed using critical realist forms of thematic analysis and discourse analysis. In the first analytic chapter (Chapter 3), I report the perspectives of LGB people living with many different chronic illnesses and how they felt their sexuality shapes their experiences of illness. In Chapter 4, I examine heterosexism within an online discussion and consider the ways in which sexuality is constructed as (ir)relevant to a diabetes support forum. In Chapter 5, I analyse LGB people's talk about the support family and partners provide in relation to their diabetes and how they negotiate wider discourses of gender, sexuality and individualism. In Chapter 6 I explore how diabetes intersects with gay and bisexual men's sex lives. In the concluding chapter, I discuss the contributions of my research for a critical LGBTQ health psychology and identify some possible areas for future research.

Key words: chronic illness; critical psychology; internet research; interviews; lesbian, gay and bisexual health; qualitative research.

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Contents

Abstract	2
Acknowledgements	3
Publications	4
Chapter 1: Introduction	8
Chronic illness and health psychology	9
Health in context: critical approaches to health psychology	12
Diabetes and psychology	17
Heteronormativity in psychology	23
LGBTQ psychology	26
LGBT health movements	30
LGBT health research	34
What is an LGBT health issue?	40
Aims and outline of the thesis	42
Chapter 2: Methodology	45
Experiential and discursive approaches within critical psychology	47
Thematic analysis	51
Discourse analysis	52
Methods of data collection	56
Online qualitative questionnaire	57
The use of pre-existing online material	59
In-depth Interviews	60
Chapter 3: Exploring non-heterosexual experiences of chronic illness: an online questionnaire study	67
Background	67
Research question	68
Method	69
Participants	69
Procedure	70
Ethical considerations	71
Method of analysis	73
Analysis	74
LGBT communities: ableist or more accepting of differences?	75
Isolation	78
Heteronormative support	82
Heterosexism and homophobia from healthcare professionals	84
Summary	87
Chapter 4: Online support seeking	89
Background	89
Research questions	93
Method	94
Procedure	94
Material used	95
Ethical considerations	95
Method of analysis	96
Analysis	97
‘Gay diabetics’: the thread	97
The opening post: a request for other gay diabetics	98
The first response: contesting the relevance of sexuality	100
Re-establishing relevance: the use of ‘Second Stories’	102

Associating diabetes and HIV	103
Speaking as a gay diabetic: invoking category entitlements	108
Resisting narrow constructions of diabetes and sexual identity	110
Summary	112
Chapter 5: Gender, sexuality and support	114
Back ground	114
Understanding same sex relationships	117
Research question	119
Method	119
Participants	119
Procedure	120
Ethical considerations	121
Method of analysis	123
Analysis	123
Gender roles and gender inversion	123
Asserting independence and claiming equality	130
Negotiating responsibility for dietary management	134
Summary	139
Chapter 6: Sex and diabetes: gay and bisexual men's experiences	141
Back ground	141
Research question	143
Method	143
Participants	143
Procedure	143
Ethical considerations	144
Method of analysis	145
Analysis	145
Erectile problems	145
Other 'physical' problems	149
Disclosing diabetes to sexual partners	152
The absence of women's accounts	154
Summary	157
Chapter 7: Discussion and conclusions	158
Summary of the findings	158
Contributions to a critical health psychology	161
Contributions to LGBTQ psychology	164
Implications for practice	168
Limitations	172
Future directions	175
From here to queer?	177
Some final reflections	180
References	184
Appendices	224
Appendix 1: Full list of illnesses reported within the survey sample	225
Appendix 2: The qualitative questionnaire	226
Appendix 3: Interview schedule	241
Appendix 4: Pre-interview demographic questionnaire	242
Appendix 5: Transcription notation (face-to-face interviews only)	243
Appendix 6: Sample consent form	244

Tables

Table 1: Gender of survey respondents.....	69
Table 2: Sexual identity of survey respondents.....	69
Table 3: Age of survey respondents.....	69
Table 4: Ethnicity of survey respondents.....	69
Table 5: The 10 most commonly reported illnesses by survey respondents.....	70
Table 6: Illness-related Yahoo Groups for LGBTQ people.....	91

Chapter 1: Introduction

My first encounters with ‘gay health’, like many gay men, were reading health promotional materials regarding HIV and sexual health distributed by organisations such as the Terrence Higgins Trust and, more locally, Birmingham’s Healthy Gay Life. Gay men in Britain today are literally bombarded by such material every time they open a gay magazine, log on to a gay website, visit a gay bar or attend a gay pride festival. There can be no getting away from the message that gay men (particularly young, currently healthy gay men) should be aware of HIV and take their sexual health very seriously. Furthermore, charity boxes on the counters of gay bars and community fundraising events, send a clear message that we should lend our support to those within the gay and bisexual community unfortunate enough to have contracted the disease. I view myself as a fortunate recipient of the hard work of lesbians and gay men who responded to the HIV crisis and those who continue to promote the sexual health of gay men, but I would often ask myself; why, as a gay man, should I be more worried about HIV than say diabetes or heart disease? Of course I should not, yet I had never seen any information or support for anyone in the LGBT community with illnesses other than HIV. Little did I know that I was not the first to ask such questions and that there was a multi-issue LGBT health movement underway that sought a more holistic approach to LGBT people’s health.

This thesis is a product of personal academic interests, my previous research experience and the institutional setting from which it emerged. I first came across lesbian, gay, bisexual, trans and queer (LGBTQ) psychology during my undergraduate psychology degree in a critical social psychology lecture. My introduction to the field at this time was particularly fortuitous, given that I had only recently come out. I was amazed to find a body of psychological literature that was life affirming for LGBTQ people and countered the negative messages I had previously come across from my evangelical Christian upbringing. I pursued my initial interest in this field through a year-long work placement as an honorary research assistant working on a qualitative project examining same sex couples’ experiences of Civil Partnership. Over this period I became increasingly drawn to critical approaches to LGBTQ psychology and to discourse analysis in particular.

Being immersed in the field of LGBTQ psychology, however served to highlight the absence of non-heterosexuals in other areas of psychology. I would scour the index pages of my psychology textbooks for words such as ‘gay’ and ‘homosexuality’. To my excitement, I found these words within the textbooks for my health psychology module. Upon closer examination, however, mentions of gay men were always in reference to psychological research about HIV or unprotected anal intercourse. In embarking on this thesis, I brought my interests in LGBTQ and critical psychology to a health psychology research group with a strong research emphasis on the management of chronic illness.

My research examines chronic illness (other than HIV) in non-heterosexual contexts, drawing on the principles and methods of critical health psychology. I was drawn to this work because I believe that there remain silences around non-heterosexuals’ lives that need to be challenged, including the way in which lesbian, gay and bisexual (LGB) lives are impacted by chronic illness.

Chronic illness and health psychology

In the editorial of the first edition of *Chronic Illness*, the term with which the journal shares its name is described as conditions that ‘are prolonged, do not resolve spontaneously, and are rarely completely cured’ (Dowrick et al., 2005: 1). The most common include cardiovascular diseases, various forms of cancer and arthritis, respiratory problems (e.g. asthma and chronic obstructive pulmonary disease), diabetes and epilepsy. In just over a century there has been a dramatic shift in the leading causes of mortality within Western societies from acute, infectious diseases such as tuberculosis, influenza, pneumonia, diphtheria and typhoid to chronic conditions such as coronary heart disease and cancer. This has been the result of social and economic circumstances such as improved sanitation, reduced poverty and increased public health surveillance, as well as biomedical advances such as vaccines and antibiotic medications (Lyons and Chamberlain, 2006). Advances in medications have led to an increase in life expectancy for those with chronic conditions and have transformed some diseases (e.g. HIV, cancer) from terminal to chronic conditions (Scandlyn, 2000).

Chronic health conditions, and indeed health and illness in general, are largely understood through a dominant biomedical model (Wellard, 1998). This approach views ill health solely in terms of physiological pathology and both the cause and treatment of disease is understood in terms of biological processes. From this perspective, the aim of treatment is to restore the body to its 'normal' biological functioning (i.e. to provide a cure) when possible. When no cure is available, as is the case with most chronic conditions, the primary aim is to control and minimise symptoms and to 'maintain a state that mimics normal health as much as possible' (Wellard, 1998: 49). The incurability of much chronic illness has, however, also led to an emphasis on disease prevention and management and with it a shift from biology to behaviour. For instance, the psychiatrist George Engel (1977), in what has become a seminal paper within health psychology, argued that the biomedical model was too reductionist and inadequate to fully understand health and illness. In its place, Engel proposed a 'biopsychosocial' model that conceptualised biological, psychological and social factors as interrelated influences on health. This new model was intended as a holistic approach to health and illness positing that in order to understand and treat illness adequately the body cannot be considered in isolation. In accordance with the three components of this model, some social scientists have deemed it useful to distinguish between the terms 'disease', 'illness' and 'sickness' (Eisenberg, 1977). The term *disease* is typically used to refer to physical pathology; *illness* is used to refer to the experience of living with a disease; while *sickness* is the societal role assigned to those considered to be ill or have a disease. As such, disease has largely been considered within the domain of biomedicine; illness has been treated as a matter for psychology; while sickness has been considered to fall within the realm of sociology (Radley, 1994).

This model was enthusiastically adopted by *health psychology*; a subfield of psychology emerging at the time the biopsychosocial model was developed. Health psychology is both a theoretical and applied field concerned with the psychological factors in physical health and illness; particularly in relation to health promotion and illness prevention and treatment (Matarazzo, 1980). The field was formally established in the late 1970s with the creation of the American Psychological Association's Division 38, however psychological factors in physical health have

been studied for much longer than this. For example, the interdisciplinary field of behavioural medicine has applied psychophysiological therapies (e.g. biofeedback) to physical conditions and the field of psychosomatic medicine has considered the psychological causes of health problems since the 1930s (Lyons and Chamberlain, 2006; Chamberlain and Murray, 2009). While sharing common ground with these prior collaborations between psychology and medicine, health psychology has as a sub-discipline has developed a much broader remit of research and practice than these earlier developments (Sarafino, 2005). In particular, health psychology has drawn heavily on social psychology, applying theoretical frameworks such as social learning theory, attribution theory and social cognition models to attitudes and beliefs about health and illness.

Health psychologists now occupy an ever increasing role in health care for a number of reasons. Many chronic conditions such as lung cancer and type 2 diabetes are commonly considered ‘diseases of lifestyle’ (Nicassio and Smith, 1995: xiii) and behaviours such as smoking and alcohol consumption are strongly associated with their onset. As a science of behaviour, psychology has been viewed as having the potential to understand, predict and ultimately reduce such behaviours (Sarafino, 2005). Psychosocial factors have also been recognised as important once someone has developed a chronic condition. For example, coping with illness, lifestyle adjustments and social support required by individuals are all of interest to health psychologists (Hymovich and Hagopian, 1992). Key areas of research for health psychology in relation to chronic illness have been compliance/adherence to medical regimens, adjustment to illness and assessing quality of life (Wellard, 1998).

For many chronic illnesses, the treatment regimens can be incredibly demanding and indeed daunting for the newly diagnosed. The term compliance has often been used to refer to the degree to which patients follow medical recommendations (Wellard, 1998). However, in recent years the concept and terminology used have changed. The concept of adherence has been used to reflect an understanding of the patient as making informed decisions and thus adhering to, rather than complying with, medical advice (Lyons and Chamberlain, 2006). Non-adherence is strongly associated with poorer health outcomes and increased use of health care services

(Clarke, 2003), yet it is commonly estimated that at least 50 per cent of people fail to adhere to their recommended regimens (Cameron and Gregor, 1987; Wright, 1993; Haynes, McKibbin and Kanani, 1996). Health psychologists have commonly sought to understand why this is the case and have examined individual differences such as health beliefs in search for explanations (Wellard, 1998). By identifying the psychological processes involved in adherence, health psychologists seek to enable clinicians to develop better strategies for increasing adherence (Clarke, 2003). The term 'concordance' is the latest reconceptualisation of compliance, which is based on the medical consultation being a therapeutic alliance between equals (Bissell, May and Noyce, 2004). However, Stevenson et al. (2000) found little evidence that both parties participated in a meaningful negotiation in doctor-patient interactions and Bissell et al. (2004) found that patients with type 2 diabetes could not comprehend what equal negotiation with health professionals might look like in practice.

Chronic conditions also often have negative psychosocial consequences and impact on a person's life. Those who are chronically ill more often experience stress, depression, sexual difficulties, disrupted personal relationships and disability (Smith and Nicassio, 1995). Health psychologists have attempted to understand the psychological processes involved in adapting to illness, particularly those related to 'coping'. For instance, psychologists have used various psychological assessments and outcome measures to assess how different coping strategies (e.g. problem-focused versus emotion-focused) impact psychological adjustment (e.g. Anagnostopoulos, Vaslamatzis and Markidis, 2000; Bishop and Warr, 2003; McCabe, McKern and McDonald, 2004). In addition, health psychologists have attempted to measure the Quality of Life (QoL) of people living with chronic illness (Rapley, 2003) in order to assess people's ability to adapt to illness or to evaluate new treatments.

Health in context: critical approaches to health psychology

There are, however, psychologists who are critical of the approaches and methods adopted within this emerging sub-discipline. The biopsychosocial model, for instance, has come under substantial criticism. A number of psychologists have

suggested that the model is inadequate as it fails to provide an explanatory framework for how the biological, the psychological and the social are to be *integrated* (Ogden, 1997) and, in particular, that health psychology fails to fully integrate the ‘social’ part of the model (Spicer and Chamberlain, 1996). Critical scholars have also argued that the model is more rhetoric than theory, serving largely to establish psychology as a partner of the biomedical sciences (Ogden, 1997; Stam, 2004; Suls and Rothman, 2004). Although Engel (1977) claimed that the biopsychosocial model represented a challenge to the traditional biomedical model, critics contend that health psychology and our understanding of chronic illness continues to be dominated by a biomedical perspective (Armstrong, 1987; Wellard, 1998). One implication of this is that health psychology tends to readily accept medical ideology, uncritically adopts medical concepts and focuses on individualistic views of health and illness (Lyons and Chamberlain, 2006).

As Wellard (1998: 52) notes, individualism refers to the valuing of individual interests over collective interests. The dominance of individualistic discourses within Western societies is evident in the value that is placed on personal autonomy, individual rights and responsibilities, choice, and the personal ownership of wealth and property. Wellard argues that individualism also dominates medical discourses and our understanding of chronic illness more broadly. This can be seen in healthcare’s focus on the individual ‘patient’, rather than the health and wellbeing of families or communities. Even at the level of public health, most interventions are based on health education with the underlying aim of enabling the *individual* to make an informed choice about their health (Lowenberg, 1995). Critical psychologists have suggested that this individualism has also shaped psychology as a discipline, which seeks to objectively understand individual behaviour and develop individual-level interventions (Fox, Prilleltensky and Austin, 2009). Within much mainstream psychology, the individual is viewed as a discrete entity, separate from society (Gough and Macfadden, 2006). Similarly, *critical health psychologists* (Crossley, 2000a; Murray, 2004) have argued that health psychology has been moulded by individualism. For instance, health psychology takes for granted that health is under the control of the individual in its focus on individual health behaviours (Chamberlain and Lyons, 2006). By feeding into this ideology and placing responsibility for health on the individual, some have argued that the blame

for illness is implicitly placed on the victim (Crossley, 2000a). Furthermore, some have suggested that the social cognition models used by health psychologists to understand, predict and change health behaviours (e.g. the Health Belief Model, Theory of Planned Behaviour) mask the economic, political and social inequalities that affect health (Stainton Rogers, 1996; Murray and Campbell, 2003). In contrast, critical health psychologists contend that health can only be understood in relation to wider social contexts.

Chamberlain and Murray (2009: 145) claim that the sub-discipline of health psychology largely adopted the methodological assumptions and practices of *mainstream* psychology, which ‘saw itself as a science applying an agreed scientific method to the study of individuals and their psychological processes’. As Lyons and Chamberlain (2006: 288) note, mainstream health psychology treats concepts like ‘coping’ or ‘social support’ as ‘separable and measurable process[es] occurring outside of experience’. In doing so, the social world of the ill person fails to be taken into account. Critical approaches to health psychology seek to emphasise the social embeddedness of health and illness, contending that illness is not a sphere of experience separate from other social realms of life, but always embedded within them (Radley, 1994). Radley (1999: 19) notes that becoming chronically ill ‘colours people’s lives’, by which he means that illness is imbued in the whole of a person’s lifeworld. Illness is instilled with cultural meaning and people will often draw on cultural and religious discourses to make sense of their situation (Sontag, 1988). Moreover, critical perspectives view health and illness as inseparable from relations of class, ethnicity, gender and sexuality (Murray, 2004; Hepworth, 2006). For instance, feminism has proved a profitable lens through which critical health psychologists have sought to understand issues of health, power and inequality (Travis, Gressley and Crumpler, 1991; Wilkinson, 2004). Feminists have challenged androcentrism in psychology, exposed male bias in health research and have ‘given voice’ to women whose experiences of illness have traditionally been ignored by medical ‘experts’ (Wilkinson, 2004).

One could argue that there are merits in health psychology’s specialisation at the level of the individual and that societal and cultural factors in health are matters for medical sociologists and anthropologists. However, while psychology brackets off

the social as outside of its boundaries and within the domain of sociology, the knowledge produced within each of these disciplines is destined to by-pass the other (Henriques et al., 1987). Furthermore, overspecialisation has arguably reduced psychologists' exposure to more critical theories within other social sciences. As Marks et al. (2000) argue, the contributions of these disciplines are incredibly important for health psychology. Those unfamiliar with the health literature might be surprised to discover that until relatively recently one would need to look to disciplines other than psychology in order to find in-depth studies about the experience of being ill (Crossley, 2000b). Much of this work has been conducted within medical sociology (Nettleton, 1995). Sociologists have examined how diagnoses of a chronic illness cause a major disruption to a person's sense of self in a number of ways. Michael Bury (1982) refers to this as 'biographical disruption' and suggests that the onset of illness disrupts our taken-for-granted assumptions about life, gives rise to questions like 'why me?' and requires a re-working of one's self-concept¹. Others such as Straus et al. (1984) have noted that a key part of living with chronic illness is 'normalisation', a process whereby people attempt to conceal their illness from others in order to maintain a sense of being 'normal' (see also Goffman, 1963). Charmaz (1995) has also examined how illness impacts on one's sense of self, focusing on how cultural assumptions about masculinity shape men's experiences of chronic illness. Issues such as these are clearly relevant to a psychology of health and illness, and yet have not featured largely in mainstream health psychology.

As already noted, another aspect of criticality within critical health psychology has been to question the methodological assumptions and practices within the field. For instance, Crossley (2000a) argues that the emphasis on objective scientific measurement and quantification within mainstream health psychology fails to capture the human experience of illness (Crossley, 2000). I shall discuss the emphasis placed on qualitative methods in more depth in Chapter 2, however it is worth briefly mentioning the philosophical debates, particularly around

¹ It is worth noting that although biographical disruption has become a core concept within the social scientific literature about chronic illness; it has been criticised in ways which are of relevance to this thesis. Williams (2000a) suggests that conditions which often exist from early childhood (e.g. type 1 diabetes) may not be experienced as a sudden disruption, while for other conditions (e.g. type 2 diabetes) there may be a biographical 'expectation' of the onset of the disease, as evidenced in people's causation accounts that emphasise genetics or hereditary factors (Lawton et al. 2008a).

epistemology which have been driving forces of critical psychology (Teo, 2009). Ian Parker (2007: 2) notes that ‘critical psychology is the study of the ways in which all varieties of psychology are culturally historically constructed’. In line with this definition, critical health psychologists have often been influenced by postmodernism, social constructionism and post-structuralism.

Postmodernism is notoriously difficult to define, however one of its most distinctive features is its assertion that there are multiple ‘truths’ to which one can lay claim. This movement emerged from social constructionist theory which posits that all knowledge is an ‘artefact’ of social processes. According to this approach, there are no unmediated truths, but rather all knowledge of the world is the product of broader historical, cultural and social contexts (Burr, 1995). This approach to knowledge was developed largely within sociology (e.g. Berger and Luckman, 1967) and only more recently taken up within (critical) psychology (e.g. Gergen, 1985). Post-structuralism refers to a related approach that is strongly associated with the work of French philosophers such as Michel Foucault (1978) and Jacques Derrida (1998). It developed in opposition to the (structuralist) view of language as a medium for describing the world as it is. By contrast, post-structuralists argue that language constitutes, rather than reflects reality. Like postmodernism, post-structuralism rejects the possibility of objectively uncovering ‘truth’ and argues that meaning is produced through discourse (language) and is always contestable.

The implication of this for health psychology is that psychological knowledge is viewed as ‘constructing’ a particular version of the world rather than ‘discovering’ objective truths about human nature (Henriques et al., 1984; Parker, 1992). For example, from a social constructionist perspective our knowledge about ‘disease’ is not a straightforward reflection of biological reality, but is socially produced within a culture. For instance, Bury (1986) has argued that biomedical scientists do not simply uncover the nature of disease but are actively involved in knowledge production and have definitional power over it. This is not to suggest that diseases do not exist or that people do not suffer from illness, but rather that ‘*all* knowledge (including medical and scientific) is socially contingent’ (Nettleton, 1995: 14). Diseases can only be known and interpreted through social activity and can only have *meaning* through the way they are conceptualised and represented (Lupton,

1994). For example, as already noted, Wellard (1998) argues that our understanding of chronic illness is shaped by individualistic discourses. Similarly, the experience of illness can only derive its meaning from the cultural and social context in which it is lived (Radley, 1994). Within this paradigm, the common distinction made between ‘disease’, ‘illness’ and ‘sickness’, or indeed the biological, the psychological and the social become blurred.

So while much health psychology is concerned with the psychological processes involved in adapting to and managing chronic illness, some psychologists have been critical about the traditional (individualistic) assumptions and methods used. These criticisms can be summed up broadly as being based on health psychology’s focus on the individual (which is separated from the social context), as well as the scientific traditions of measurement and quantification which psychology is grounded in. Let us consider these issues in relation to a specific chronic illness for which there has been a large body of health psychological research, and one which I shall focus on later in the thesis.

Diabetes and psychology

Diabetes mellitus (often referred to simply as diabetes) refers to a number of chronic health conditions that affect the body’s metabolism and in particular its ability to use glucose in the blood properly. There are two main types of diabetes, referred to as type 1 and type 2. Type 1 diabetes refers to the body’s inability to produce insulin and accounts for approximately 5-15% of those with diabetes (Diabetes UK, 2006). This form of the condition is typically diagnosed in childhood and requires lifetime treatment of insulin therapy (and thus is commonly also called juvenile or insulin-dependent diabetes). Type 1 diabetes is unpreventable and the exact cause is not well understood, although it is believed to be genetic or triggered by a viral infection (Diabetes UK, 2006). Type 2 diabetes is characterised by the body developing resistance to insulin (cells can no longer use insulin properly), sometimes combined with reduced insulin production. This is the most common form of diabetes and has a multifactorial aetiology. Being overweight or obese is strongly associated with an increased risk of developing the disease. This form of diabetes generally develops in later life, typically over 40, although increased rates

of childhood obesity is believed to have resulted in an increase of type 2 diabetes among younger generations (Rocchini, 2002). Other risk factors include a family history of the disease and one's ethnic origin. For instance, Pakistanis and Indians living in the UK are approximately five times more likely to develop the condition than the general population and up to ten years earlier than white people (D'Costa, Samanta and Burden, 2000). This form of diabetes can usually be self-managed through behavioural changes such as adopting a healthy diet in combination with increased physical activity, although in some cases oral medication or insulin may be needed to improve blood glucose control.

Diabetes is a serious condition, which if not managed properly can lead to premature death. Failure to adhere to medical and behavioural regimens can also lead to neuropathy (nerve damage) and atherosclerosis (narrowing of blood vessels) resulting in complications such as heart disease, stroke, blindness and amputations (Porte and Schwartz, 1996). Moreover, type 2 diabetes is said to be reaching epidemic proportions in the UK and elsewhere in the Western world, which is attributed to increased rates of obesity and more sedentary lifestyles (Zimmet, Alberti and Shaw, 2001). As one of the most common chronic conditions in Western societies, diabetes has attracted a vast amount of health psychology research in recent decades. The behavioural components of preventing type 2 and managing both types of diabetes presented opportunities for the emerging sub-discipline of health psychology (Surwit, Feinglos and Scovern, 1983). At a time when diabetes represents a significant cost to the UK's National Health Service (NHS), health psychology's claim to be able to understand, predict and control health behaviours holds great appeal for health bureaucracies.

In line with the dominance of mainstream approaches within the discipline, health psychologists have largely adopted quantitative methods to study diabetes. In particular, the condition has given rise to a considerable body of research that addresses adherence to medical advice regarding lifestyle changes such as diet and physical exercise (Wing et al., 2001). However, despite a vast amount of quantitative research on medical adherence over the last 35 years, no variables have been determined that can consistently explain non-adherence (Vermeire et al.,

2001). Health psychologists have developed an array of psychometric scales and other measuring instruments specifically for those living with diabetes. For instance, scales have been designed to measure knowledge of diabetes (Beeney, Dunn and Welch, 1994), the cognitive function of people with diabetes (Ryan, 1994), psychological adjustment to the condition (Welch, Dunn and Beeney, 1994), diabetes-specific health beliefs (Lewis and Bradley, 1994), perceived blood glucose control (Bradley, 1994), and condition specific QoL (Jacobson, 1994). Studies of QoL have attempted to identify aspects of living with diabetes that have a positive or negative impact on one's daily functioning and ability to enjoy a fulfilling life. For example, for those with type 1 diabetes, flexibility in insulin regimen and a diet that is perceived to be unrestricted has been found to be associated with higher QoL scores (Bott et al., 1998), while the need for insulin therapy has been associated with lower QoL scores among those with type 2 diabetes (Redekop et al., 2002). For people with both types, diabetic complications have been found to be related to poorer health-related QoL (Bott et al., 1998; Redekop et al., 2002). Other studies have attempted to measure the impact of specific complications such as sexual dysfunction on QoL (Fedele et al., 2000; Kaplan, 2002; Penson et al., 2003; Rance et al., 2003). However, Little et al. (1998: 1458) argue that QoL measures with predetermined items 'do little to capture the main preoccupations of those suffering from serious chronic illness'². By contrast, qualitative methods can provide a more detailed insight into experiences of living with illness (see Rapley, 2003).

There is a growing body of qualitative research about diabetes (e.g. Campbell et al., 2003; Lawton et al., 2004; Parry et al., 2004; Peel et al., 2004a; Peel et al., 2004b; Lawton et al., 2005; Peel et al., 2005; Peel et al., 2007; Ockleford et al., 2008) that seeks to gain an 'insider perspective' and a more holistic, context sensitive understanding of people's experiences of living with the condition (Anderson and Robins, 1998). Most of this research has been conducted with adult samples and has examined a range of issues including lay beliefs about its cause (Hunt, Valenzuela and Pugh, 1998; Schoenberg et al., 1998), perceptions and emotional reactions to diagnosis (Parry et al., 2004; Peel et al., 2004a), views about diabetes education and information provision (Peel et al., 2004a; Ockleford et al., 2008), patient

² Increasing recognition of this problem has led to the development of the Schedule for the Evaluation of Individual Quality of Life (SEI-OoL, Wagner, 2004) which claims to take into account that the most valued domains of life may differ across individuals.

perspectives on blood glucose self-monitoring (Lawton et al., 2004; Peel et al., 2004b) and accounts of dietary management (Maclean, 1991; Miller, Warland and Achterberg, 1997; Savoca and Miller, 2001; Peel et al., 2005).

As with research using quantitative methods, most qualitative research in this field has focused on medical concerns about diabetes management with either an explicit or implicit concern with adherence to medical advice and diabetes regimens (Campbell et al., 2003). Such research has often sought to understand self-management within the context of people's everyday lives. For example, studies have identified challenges to managing diabetes such as people's work and family lives (Radley, 1989; Peel et al., 2005), the desire to socialise without limiting constraints (Kelleher, 1988) and financial difficulties (Drummond and Mason, 1990). A meta-analysis by Vermeire et al. (2007) of focus group studies on type 2 diabetes conducted across seven European countries identified a number of obstacles to adherence. Participants often did not consider themselves to be 'ill' and diabetes was not considered a serious condition until complications arose. Negotiating social events and family eating habits were described as particular obstacles to adherence. In terms of health services, some participants felt that health professionals do not understand the difficulties of managing the condition, that they blame patients for poor outcomes and are judgemental about those who are overweight. Participants also consistently reported being presented with a lot of information about managing diabetes at once and at an inappropriate time (e.g. immediately after diagnosis). The information given was considered to be complex and contradictory messages were reportedly received from different sources. Furthermore, this information was sometimes at odds with their personal experience and lay knowledge of their condition.

More critical research conducted by critical health psychologists and allied social scientists have also examined the wider context of living with diabetes. For example, Dorothy Broom (2003: 61) has pointed out how diabetes self-management not only affects a person's health but 'also shapes the subjectivity of the person, so different management strategies may mould different selves'. Broom and Whittaker (2004) have also examined the moral context of diabetes management. They suggest that a 'rationalist medical model' of self-management attributes personal

responsibility to the individual with diabetes and that failures to adequately control blood sugar not only imply poor health outcomes but are commonly spoken about as moral failure. They contend that people with diabetes often position themselves as disobedient children or as wicked when discussing dietary non-adherence to diabetes regimens. Similarly, Peel et al. (2005) have demonstrated how people with type 2 diabetes account for 'cheating' in complex ways that function to construct a 'compliant' identity.

Other researchers have directed their attention at people of non-indigenous ethnicities in order to focus on the impact of cultural differences. Borovoy and Hine (2008) suggest that the biomedical model of diabetes management is based on Western values of individual responsibility, autonomy and choice. They argue that the application of this model to people from different cultures (which in their own study were Russian Jewish émigrés) results in a reading of their behaviour as 'non-compliant'. Anderton, Elfert and Lai (1989) however, have suggested that what could be viewed as 'cultural' differences, may alternatively be a function of their immigrant status, economic situation and lack of cultural resources (e.g. language or literacy difficulties). Lawton et al (2008b) interviewed Pakistani and Indian immigrants with type 2 diabetes living in the UK. They found that the cultural significance of certain foods, led participants to continue to consume them, despite perceiving them to be detrimental to their blood glucose control. Participants emphasised the important role South Asian foods (e.g. sweet rice, traditional sweets) played in their families and communities, describing a cultural expectation (and in some cases obligation) to eat them. Furthermore, these foodstuffs appeared to be tied intricately to their cultural identity (which were described as 'our food').

Although the way that cultural expectations affect how one lives with diabetes may be more apparent when considering non-indigenous populations, cultural roles and expectations shape all experiences of the condition. Broom and Whittaker (2004) outline ways in which diabetes imparts a 'spoiled identity' (Goffman, 1963). For instance, type 2 diabetes is commonly considered a self-induced 'lifestyle' disease. Those requiring insulin often have to contend with the negative social connotations of injecting (despite modern insulin pens which look less syringe-like) and symptoms of very low blood glucose (hypoglycaemia) such as confusion, shakiness

or loss of consciousness in public are often acutely discrediting experiences. Despite diabetes often being an 'invisible' condition, those living with this chronic condition they are still confronted with a society which views them as different (Goffman, 1963). In their qualitative study of Thai people living with type 2 diabetes, Naemiratch and Manderson (2008) found that participants attempted to maintain a sense of 'normality' and that this was largely contingent on the observable impact of the condition on their daily life and everyday activities. One male participant, for example, defined normality in terms of his ability to work and his sexual functioning. Ideas of what constitutes 'normal', however, are fluid and dependent on culture.

Balfé (2009) explored how young people's experiences of type 1 diabetes are shaped by a student culture while at university. Balfé's participants emphasised a need to be seen as a typical student, unaffected by illness. Alcohol consumption was found to be a key practice that participants would engage in, despite their concerns about diabetes control, as this was deemed to be a 'normal' student activity. Williams (2000b) explored the interaction of gender with the management of type 1 diabetes during adolescence and argued that 'the gendered ways in which specific illnesses impact on the personal and the social identities of individuals can affect how they choose to live with the illness' (p. 388). Williams found that the boys in her study were less likely to disclose their condition or view it as an integral part of their identities than the girls. Furthermore, the boys were less likely to inject insulin in public places but tried to keep their diabetes contained privately at home. She suggests that for the boys, appearing as 'normal healthy males' seemed to be more important than controlling their condition. The way that contemporary masculinities and femininities are constructed also shaped management of the condition in other ways. Boys were more likely to emphasise the importance of exercise in controlling their diabetes and self assessed their health in terms of how much sport they played. Meanwhile the girls in the study appeared to be more concerned with their diets than exercise.

Peel et al. (2005) have also asserted that gender is a central concern when considering the management of a 'diabetic diet'. In their discursive analysis of dietary management among those with type 2 diabetes, Peel et al. reported that

women often constructed dietary modifications as being in conflict with their responsibilities as mothers and wives, while men constructed the management of their diet as a family matter, implicitly placing responsibility on their female partners. Similarly, a number of other studies have observed that traditional gender roles often result in women taking responsibility for dietary management of their partners' diabetes (Maclean, 1991; Wong et al., 2005; Gallant et al., 2007).

While other kinds of diversity are acknowledged and analysed within this vast literature, one form of difference that has been overlooked is sexual identity. Despite a growing acknowledgement of the importance of cultural, family and psychosocial factors in the prevention and management of diabetes, Garner (2010) argues that LGBT issues have been ignored and that more should be done to provide more 'culturally sensitive' diabetes care and education for LGBT people. Theresa Garner is a diabetes educator and a founding member of the Diabetes and Gay Foundation based in San Francisco. This organisation was created to raise awareness of LGBT issues among diabetes healthcare professionals and to provide support to LGBT people with diabetes and their significant others. It is my argument in this thesis, as I shall discuss in more detail below, that one reason why diabetes has not been studied in the context of sexual identity is that diabetes is typically not considered to be a 'lesbian or gay health issue'. Areas of diabetes research for which the relevance of sexual identity are immediately apparent are social support, the management of diabetes within coupled relationships and diabetes related sexual dysfunction. However, within the existing literature in these areas there is a heterosexual bias. This is perhaps not surprising given the long history of heterosexual bias within psychology more broadly (Herek et al., 1991).

Heteronormativity in psychology

As Clarke et al. (2010: 20) note 'heteronormativity remains deeply embedded within the discipline of psychology'. Heteronormativity refers to the way in which heterosexuality is the taken-for-granted norm within society and its privileged status as the routinely assumed, normal form of sexuality. The concept has been used widely within political, social and critical theory (Kitzinger, 2005a)³. It describes

³ What I refer to here as heteronormativity is sometimes alternatively referred to as 'cultural heterosexism' (Bohan, 1996; Braun, 2000) or 'heterocentrism' (Ussher, 2009).

the way discourse is often structured around a normative heterosexual perspective. For example, the notion of ‘sex’ is usually equated to penis-vagina intercourse⁴ as opposed to the wide variety of sexual behaviours engaged in by lesbians, gay men, bisexuals as well as heterosexuals (see Chapter 6) and notions of ‘family’ invariably assume a heterosexual couple and their children (Clarke et al., 2010). The taken-for-granted status of heterosexuality is strongly embedded within our society and typically goes unnoticed. As Moran (2009: 283) notes, heteronormativity is ‘like the air we breathe’, all-pervasive but rarely recognised. Furthermore, Moran suggests that silence and invisibility play a key role in the maintenance of the heterosexual as a privileged subject. This privileging of normative heterosexuality is introduced at a very early age from fairytales of princes and princesses living happily ever after and is reinforced by powerful social institutions. For instance, heteronormativity is routinely (re)produced through television (Clarke and Kitzinger, 2004), newspapers (Lowe et al., 2007; Jowett and Peel, 2010) as well as in social scientific literature (Clarke, 2002).

This includes the discipline of psychology in which heteronormativity operates in ways that privilege the heterosexual subject (Riggs and Choi, 2006). Non-heterosexuals are included in less than one percent of published psychological research (Lee and Crawford, 2007) and when non-heterosexual material is present within psychology courses or texts, such coverage is often tokenistic, while the heterosexual norm is perpetuated within the rest of the curriculum (King, 1988; Kitzinger, 1996a; Peel, 2001a; Petford, 2003; Barker, 2007). As with maleness, whiteness and middle-classness, heterosexuality is the assumed norm in psychological theorising (Braun, 2000). This is no less true of the sub-field of health psychology. Heteronormativity operates in health psychology in a number of ways. Firstly, research in areas such as partner support among those living with illness are either explicitly or implicitly studies of support within *heterosexual* relationships (e.g. Trief et al., 2004; Miller and Brown, 2005; Wong et al., 2005) (also see Chapters 5 and 6). Secondly, while socio-demographic information is routinely collected in health research, the sexual identity of participants often is not. As Ussher (2009: 561) asserts:

⁴ The term ‘heterosex’ has been coined by LGBTQ scholars to refer to penis-vagina intercourse in order to avoid the heteronormative equation of ‘sex’ with heterosexual sex.

The assumption of heterosexuality in health research and clinical intervention is an insidious practice which acts to make LGBTQ individuals invisible. This operates at many levels, starting with researchers not asking about sexual identity when collecting demographic information on participants, which discursively means that LGBTQ individuals do not exist.

For example, within literature on diabetes-related sexual dysfunction, the sexual identity of participants is rarely documented (see Chapter 6). And thirdly, as I shall discuss later in this chapter, when LGBTQ people are included in health research, it invariably takes the form of comparative research whereby the health of LGBTQ people is compared to heterosexuals who are implicitly positioned as the norm.

In addition, the operation of heteronormativity within psychology is rarely recognised or explored. Often in research about health and relationships, the exclusion of non-heterosexuals does not even receive a mention, as if same sex relationships did not exist at all. When the absence of non-heterosexuals is noted, it is often described as a ‘limitation’ of the study. In some instances, the fact that the psychometric measures utilized are often themselves designed from heterosexual samples has been used to rationalise the exclusion of non-heterosexuals. For example, Banthia et al. (2003) acknowledge the absence of same sex couples in their study of the dyadic coping styles of couples faced with prostate cancer. However, they justify this exclusion by noting that the Dyadic Adjustment Scale (DAS, Spanier, 1976) used in their study was originally developed with heterosexual couples, despite the fact that the DAS has been used with same sex couples (e.g. Kurdek, 1992)⁵.

A notable exception is critical psychologist Virginia Braun (2000) who explored the operation of heteronormativity within her own qualitative research. Braun reflected on her assumptions evident within the transcripts of focus groups and observed that

⁵ Not only do such studies marginalise those in same sex relationships but also heterosexuals and non-heterosexuals alike who are single. Similarly, the DAS (Spanier, 1976) was only designed to be used with cohabiting couples. As such, heteronormativity within psychology not only marginalises those who do not identify as heterosexual, but also heterosexuals who do not conform to normative heterosexuality (Kentlyn, 2007).

her own talk about ostensibly *generic* men and women implicitly became talk about *heterosexual* men and women, thus silencing non-heterosexual experience. Seymour-Smith, Wetherell and Phoenix (2002) on the other hand, note the heterosexual assumption within their participants' accounts, observing that the medical professionals interviewed in their study about men's health consistently constructed male patients as heterosexual. However, while a reflexive exploration of heteronormativity within the research process is useful, Braun (2000) suggests psychologists also need to go beyond post hoc considerations to develop new ways of asking research questions which are not complicit with the marginalisation of non-heterosexuals. The claim that psychology (re)produces heteronormativity, does not imply that psychologists hold prejudiced attitudes or beliefs (as understood by the concept of homophobia), but rather psychology may be viewed as reinforcing ubiquitous, marginalising social norms (Kitzinger, 2005a).

LGBTQ psychology

Prior to the 1970s, psychologists understood homosexuality within what Kitzinger (1987) has referred to as a 'pathological' model. Psychology's use of the terminology of disease and illness constructed lesbians and gay men as 'sick' and in need of a 'cure'. Much psychological research focussing on homosexuality cohered around whether lesbians and gay men were sick, how homosexuality could be diagnosed and its possible 'causes' (Morin, 1977). As a result, many lesbians and gay men were incarcerated in psychiatric institutions and subjected to various forms of 'conversion therapies' (Feldman and McCulloch, 1971). In this way, psychology has played a significant part in the oppression of non-heterosexuals.

In a direct challenge to this, during the second half of the twentieth century a small number of 'gay affirmative' psychologists sought to demonstrate the (mental) 'health' and 'normality' of lesbians and gay men when compared to heterosexuals (e.g. Hooker, 1957; Thompson, McCandless and Strickland, 1971; Siegelman, 1972). Their research was used to campaign against homosexuality's inclusion in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM), leading to its removal in 1973. By the mid-1970s there was a shift away from a pathological to a 'liberal humanistic' model which considered

lesbians and gay men to be ‘human beings of equal worth and dignity to heterosexuals, contributing to a rich diversity of humankind’ (Kitzinger, 1987: 44). Within this model lesbians and gay men were considered to be ‘just the same as’ heterosexuals (Clarke, 2002) and gay affirmative psychologists asserted that lesbians and gay men could develop ‘healthy’ relationships (McWhirter and Mattison, 1984) and that children raised by same sex parents were not psychologically damaged by their upbringing (Golombok, Spencer and Rutter, 1983).

During the 1980s and 90s psychological research regarding lesbians and gay men began to diversify and focus on a wider range of topics and social issues concerning their lives. Furthermore this sub-field of psychology gained institutional recognition with the American Psychological Association’s establishment of Division 44 (the Society for the Psychological Study of Lesbians and Gay men) and in the UK the Lesbian and Gay Psychology Section (now the Psychology of Sexualities Section) was eventually established (after four rejected proposals) in the British Psychological Society (BPS). This emerging lesbian and gay psychology considered lesbians and gay men to be worthy of study in their own right and not just in comparison with heterosexuals. It aimed to counter the underrepresentation of non-heterosexuals within many areas of psychology as well as promoting positive well being and social change for lesbians and gay men (Kitzinger and Coyle, 2002).

The scope (and name) of this endeavour has widened over the last few decades, incorporating bisexuality (LGB) (Peel, Clarke and Drescher, 2007), ‘trans’ (LGBT) (Greene and Croome, 2000) and occasionally ‘queer’⁶ (LGBTQ) (Clarke and Peel, 2007; Clarke et al., 2010). The LGBT acronym will be familiar for many as an increasingly visible strand of equality and diversity. Some however may be unfamiliar with the term queer and its various uses may cause considerable confusion. This term, used for much of the 20th century as a derogatory term for gay men, was reclaimed by some during the 1980s as a positive and confrontational self-description. It is commonly used either as an umbrella term for LGBT people, or is

⁶ The Q in the acronym LGBTQ is sometimes also used to refer to ‘questioning’ – i.e. those who are sexually curious or unsure of their sexual identity. This tends to be used particularly when referring to LGBTQ youth. However within psychology and the social sciences more generally, the Q typically refers to queer.

associated with adherents of queer theory. Queer theory is a critique of heteronormativity and seeks to deconstruct binary models of sex/gender and sexuality (male or female, heterosexual or homosexual; Clarke et al., 2010). This critique was heavily influenced by post-structuralist philosophers such as Michel Foucault (1978) and Judith Butler (1990; 1993) and developed out of the perceived limitations of identity politics. From this perspective, self-identity labels such as 'lesbian', 'gay' and 'straight' are viewed as reifying a sex/gender system which naturalises heterosexuality and marginalizes those non-normative genders and sexualities. Therefore, 'queer' represents a critique of sexual identity, rather than a sexual identity in itself. When used in relation to psychology (*queer psychology*), it usually refers to the application of insights from queer theory to psychology (e.g. Minton, 1997; Hegarty and Massey, 2006; Riggs, 2007).

There is considerable debate about the scope of the field and concern about ever expanding acronyms. For this reason the BPS Lesbian and Gay Psychology Section recently changed its name to the Psychology of Sexualities Section. This change was not without controversy, however, as some have suggested that this name implies a sole concern with matters of sex rather than the wide range of issues and topics regarding the lives of LGBTQ people (Clarke et al., 2010). Furthermore, heterosexuality would now also come under the remit of the Section. While lesbian feminist and queer psychologists have focused on heterosexuality, for instance deconstructing heterosexuality or theorising it as a compulsory institution (Wilkinson and Kitzinger, 1993; Clarke and Braun, 2009), heterosexuals are not underrepresented or marginalised within the discipline.

In this thesis I refer to this field of psychology as LGBTQ psychology in order to signal inclusivity while also signifying the field's explicit focus on those that fall outside of sexuality and gender norms (Clarke and Peel, 2007). When I refer to LGBTQ psychologists, I do not refer (exclusively) to psychologists who identify as LGBTQ, but rather those psychologists who conduct research on LGBTQ topics and concerns. As Kitzinger et al. (1998: 532) note; 'a "lesbian and gay psychologist" can be heterosexual, just as a "social psychologist" can be anti-social

or a “sport psychologist” can be a couch potato⁷. The focus of this thesis is on (non-hetero)sexual⁸ identity rather than gender identity and so at times I will use the acronym LGB (although of course trans people may also identify as lesbian, gay or bisexual). The acronym LGBT is also used when referring to the social and political communities/groupings to which LGB people may belong as this is the more commonly used acronym when referring to such collectives⁹. To sum up the main aims and objectives of LGBTQ psychology, Clarke et al. (2010: 6) provide the following definition:

LGBTQ psychology is a branch of psychology that is affirmative of LGBTQ people. It seeks to challenge prejudice and discrimination against LGBTQ people and the privileging of heterosexuality in psychology and in the broader society. It seeks to promote LGBTQ concerns as legitimate foci for psychological research and promote non-heterosexist, non-genderist and inclusive approaches to psychological research and practice. It provides a range of psychological perspectives on the lives and experiences of LGBTQ people and on LGBTQ sexualities and genders.

As Clarke et al. contend, while it is relatively rare today for psychologists to (openly) portray homosexuality in pathological terms or advocate therapies to convert or ‘cure’ lesbians and gay men, heterosexist assumptions continue to inform psychological research and theorising with heterosexuality implicitly presented as the unmarked norm. LGBTQ psychology’s explicit challenge to heteronormativity places it within the broad domain of critical psychology (Kitzinger, 1997; Clarke and Peel, 2007; Clarke et al., 2010) and has relevance for all areas of psychology from social psychology (e.g. Herek et al., 1997), developmental psychology (e.g. Golombok, 2000; Patterson, 2008), counselling psychology (e.g. Milton and Coyle, 2003; Langdridge, 2007) and health psychology (Peel and Thomson, 2009).

⁷ However, perhaps unsurprisingly many LGBTQ psychologists have tended to identify themselves as non-heterosexual or trans.

⁸ Terminology in this area is by no means unproblematic. The term ‘non-heterosexual’ is used interchangeably with LGB for inclusivity, despite having reservations about the term because LGB identities are signalled negatively against heterosexuality via ‘non’.

⁹ At times I will also place certain letters of the acronyms within brackets. I do this to signal that what I am referring to may primarily concern some strands, but may equally apply to those placed in brackets. For example if much of the LGBTQ literature focuses primarily on lesbians and gay men with only recent incorporation of bisexuals and trans people I may refer to LG(BT) research.

As LGBTQ psychology has expanded into the field of health psychology, the emphasis has tended to have been on *sexual* health rather than physical health more generally (Peel and Thomson, 2009). Much of this research has been conducted within the United States and has largely adopted quantitative methods. There is a growing body of qualitative and critical LGBTQ health psychology, particularly emerging from Australasia (e.g. Adams, Braun and McCreanor, 2004; MacBride-Stewart, 2004; Riggs, 2005a; Adams, McCreanor and Braun, 2007; MacBride-Stewart, 2007; Braun et al., 2009; Riggs, 2009), however this research has yet to explore chronic illness in non-heterosexual contexts. And just as feminist health psychology has been influenced by the women's health movement (Wilkinson, 2004), so LGBT health research has had a symbiotic relationship with LGBT health activism.

LGBT health movements

LGBT health activism and research has its roots amid the women's health movement and the gay liberation movement of the 1970s. Indeed many narratives of the LGBT health movement cite the removal of homosexuality from the American Psychiatric Association's DSM II in 1973 as a major historical landmark in the early years of the movement (Mail and Lear, 2006). It represented the 'de-medicalisation' of homosexuality and as noted above over the following 20 years a dramatic shift occurred from homosexuality being viewed as a form of pathology to lesbians and gay men being viewed as a sort of ethnic group (Altman, 1982).

With homosexuality no longer deemed an illness, health professionals began to 'come out' in their workplaces and advertise their services as 'gay friendly' through lesbian and gay organisations and publications (Mail and Lear, 2006). In the late 1970s and 1980s pioneering health clinics specifically for lesbians or gay men were set up both in the US and in the UK in recognition of prejudice and discrimination within health care services (Deneberg, 1997; Mail and Lear, 2006; Fish, 2009).

Another landmark within the movement's history was the beginning of the AIDS crisis in the 1980s. Originally referred to within medicine as Gay Related Immune

Deficiency (GRID¹⁰) and dubbed a 'gay cancer' or 'gay plague' by tabloid media (Shilts, 1987; Watney, 1987; Sontag, 1988), AIDS arguably intensified prejudice against gay men (Kitzinger, 1987) including among health professionals (Scarce, 1999). However it also galvanised lesbian and gay communities and as Epstein has commented 'propelled many previously non-political gay men into activism' (1999: 53) with activist groups emerging across the US, such as ACT UP (AIDS Coalition To Unleash Power) and Gay Men's Health Crisis (GMHC) in New York. Similarly, Plummer (1999: 142) suggests that in the UK, AIDS 'rescued a slumbering gay Movement from the late 1970s and – in the midst of great tragedy – served to revitalize and reactivate the Movement'. Here in the UK, the Terrence Higgins Trust (THT) was established (and later Gay Men Fighting AIDS [GMFA])¹¹ that Plummer suggests signalled 'a different style of gay politics' (1999: 142) which was capable and willing to work with government and other professionals. The central role that lesbians played in AIDS activism has also been noted, and in particular, the insights they brought from the women's health movement (Denenberg, 1997; Epstein, 2003). The gay community's response to HIV has led to a community infrastructure for 'gay men's health' (i.e. sexual health) promotion and peer support for those with HIV. Specialist sexual health clinics for gay and bisexual men sprang up in many cities and became examples of excellence in providing 'culturally competent' care for gay and bisexual men (Lipton, 2004).

In the late 1990s and 2000s, lesbian and gay health academics/activists such as Eric Rofes (1998; 2007) in the US and Tamsin Wilton (1997; 2002) in the UK were calling for a wider range of health issues among lesbians and gay men to be considered. This saw a proliferation of community health surveys gathering data on a range of health behaviours (see Meads, Buckley and Sanderson, 2007; Fish, 2009). To promote this vision of a broader health movement and to provide a space to discuss emerging health issues, in 1999 Rofes and other activists in the US organised a 'Gay Men's Health Summit' to discuss a wide range of health issues (Epstein, 2003). The event was titled a 'summit' rather than a 'conference' by the

¹⁰ Early epidemiological evidence indicating that gay male communities were particularly affected led to assumptions among the medical establishment that the disease was in some way intrinsically linked to homosexuality (Patton, 1985; Altman, 1986).

¹¹ THT's approach was to provide support for all those affected by HIV, while GMFA focused specifically on gay men. THT, however remain a leading organisation in gay men's health.

organisers to capture the sense of urgency felt within this movement (Rofes, 2007). By 2002, the Summit took a coalitional approach broadening into an 'LGBTI Health Summit'¹². In 2006 the first UK LGBT Health Summit took place in London. Similarly, the aim of the London summit was to 'consider the health needs of LGBT communities holistically and not just centre on sexual health and substance use, in order that there could be recognition of the inequalities experienced by LGBT people' (Wilson, 2009: 5). Among the organisers and attendees of such events have often been medical professionals and policymakers who themselves identify as LGBT.

Just as professional lesbian and gay groups have been formed within national psychological associations such as the APA and the BPS, this has similarly been the case within the medical professions. Among the first of such groups was the Gay Nurses' Alliance within the American Nurses Association and the Caucus of Gay Public Health Workers¹³ within the American Public Health Association during the 1970s (Mail and Lear, 2006). During the 1980s, the American Medical Association (AMA) refused proposals for a gay caucus, resulting in its members forming a separate organisation, named the American Association of Physicians for Human Rights (Epstein, 2003). In 1994, the organisation was re-named the Gay and Lesbian Medical Association (GLMA)¹⁴. Again this trend was mirrored in the UK with the Royal College of Nursing forming a lesbian and gay working party and the formation of the Gay and Lesbian Association of Doctors and Dentists (GLADD), both of which collectively spoke out against heterosexist policies and practices within medicine and the medical professions (James, Harding and Corbett, 1994; Saunders, 2001).

Epstein (2003) has commented on the important role such groups have played through an 'insider' approach to activism. By representing the interests of LGBT

¹² The 'I' here refers to intersex people. Epstein (2003) notes that there was an expectation that in future years the Summit would alternate between focusing specifically on gay men and an inclusive Summit including lesbian, bisexual, trans and intersex issues. While Rofes (2007) and his colleagues were committed to investing in broad LGBTI concerns he also stressed the need for a gay men's health movement.

¹³ This group is currently called the LGBT Caucus of Public Health Workers.

¹⁴ In 1996 the GLMA added bisexual and transgender health issues to the organisation's remit but chose not to change its name (Epstein, 2003).

people, these groups have influenced their parent organisations from within and their associated professions. For instance, when the US Department of Health and Human Services (DHHS) failed to include LGBT health¹⁵ in *Healthy People 2010* (the government's published plan to tackle health inequalities) (DHHS, 2000), the GLMA mobilized US LGBT health activists to campaign for its inclusion. While the result was somewhat of a compromise, the GLMA had a clear influence at the highest level of health policy. The DHHS provided partial support for a 'companion document' (GLMA, 2001) which aimed to provide a comprehensive 'state of the art' overview of LGBT health and offer recommendations with regards to service provision, policy, education, training and research. Epstein (2003: 150) describes the document's status as 'semi-official' with links to the document on the DHHS website (which re-direct to the GLMA website) but with no obligation to act on the recommendations contained in the document. This pressure for inclusion by LGBT activists has led to information about LGBT health being made available on the websites of the US Centre for Disease Control and Prevention and the UK's Department of Health (DoH). The DoH now has a Sexual Orientation and Gender Identity Advisory Group and the lesbian health academic/activist Julie Fish was recently commissioned by the DoH to produce guidelines for reducing health inequalities for LGBT people (Fish, 2007). Epstein (2003: 132) characterised these developments as forms of 'State-centred' LGBT health politics:

State-centered LGBT health politics involves concerted efforts by advocates and researchers to make demands on the state for inclusion and incorporation – demands to institutionalize LGBT (or, often, just lesbian and gay) health as a formal concern of public health and health research bureaucracies. At the crux of state-centered advocacy is the claim that lesbians, gay men, bisexuals, and transgendered persons have distinctive health concerns and will benefit from research that finds them, counts them, studies them, and compares them with others.

This thesis can be considered as what Plummer (1999: 140) has called the 'academic wing' of this movement and in particular a response to calls for the

¹⁵ LGBT health was included in earlier drafts but was omitted from the final document. While the DHHS suggested that this was due to a lack of scientific evidence of health disparities (Epstein, 2003), it is widely believed to have been due to Right wing political pressure (Mail and Lear, 2006).

consideration of a wider range of health issues affecting LGBTQ people (Rofes, 1998; Wilton, 2000). In contrast to the emerging 'State-centred' approach which calls for large scale quantitative research, this thesis adopts qualitative methodology and focuses on the meaning and experience of ill health among non-heterosexuals.

LGBT health research

Homophobia and heterosexism¹⁶ have been a recurrent theme within LGBT health research since the 1970s. Early research commonly reported explicitly hostile interactions with health professionals and malicious treatment of patients' same sex partners, often resulting in delays in seeking health care (for example see Stevens, 1992 for a review of lesbians' health care experiences from 1970-1990). Although, overt prejudice and discrimination against non-heterosexuals is less common today, institutional heterosexism continues to be reported within healthcare (Beehler, 2001; Eliason and Schope, 2001). In particular, heterosexist assumptions and embarrassment in discussing issues of sexuality have been found to hinder effective provider-patient interaction (Eliason and Schope, 2001; Hinchliff, Gott and Galena, 2005). As social attitudes towards LGBTQ people have shifted from hostility to liberalism, it is likely that heterosexism within healthcare, as with society more broadly, has transformed largely from the overt to the mundane (Peel, 2001b).

A major focus of research in recent years has cohered around the disclosure of sexual identity ('coming out') to health professionals (e.g. Eliason and Schope, 2001; Boehmer and Case, 2004). The largest UK survey of lesbian health to date found that lesbians are less likely to be 'out' to health professionals than in many other spheres of life (Hunt and Fish, 2008) and Eliason and Schope (2001) found that lesbians were more likely to disclose than gay men. Many LGBT health researchers contend that such disclosure is beneficial, for example, Diamant, Schuster and Lever (2000) found a positive relationship between disclosing a

¹⁶ While these two terms are often used interchangeably within psychology they are not simply synonyms for prejudice against non-heterosexuals. The first refers to individual prejudiced attitudes as conceptualised and measured by homophobia scales (see Kitzinger, 1987). Heterosexism by contrast, conceptualises the oppression of non-heterosexuals as embedded in the social and cultural fabric of society and recognises that even individuals who would appear to lack prejudice (as measured by homophobia scales), are likely to be complicit with the many privileges heterosexuals are granted within society (Kitzinger, 1996b). Therefore when LGBT health researchers refer to heterosexism, this includes the institutional and cultural practices of medical establishments that disadvantage non-heterosexuals (Fish, 2006).

lesbian identity and the receipt of preventative health screening. Moreover, it has been suggested that disclosure may improve communication with health professionals by facilitating appropriate questioning and allowing for patients to include their same sex partners in consultations (Eliason and Schope, 2001; Cant, 2005).

During the 1990s gay men's health research focused overwhelmingly upon HIV/AIDS and its prevention, for which research funding was increasingly available (see Flowers and Duncan, 2002; Flowers, 2006 for an overview). While lesbian health researchers did conduct research on a wider range of health issues, often as sole researchers on shoe-string budgets (Epstein, 2003), HIV also influenced the direction of the lesbian research agenda. As Fish (2009: 439) contends, HIV 'placed sex centre stage' and lesbian scholars sought to counter the exclusion of lesbians in sexual health research (O'Sullivan and Parmar, 1992). Wilton (2000) has argued that such developments led 'lesbian and gay health' to be 'located under the umbrella of sexual health' (Wilton, 2000: 258). This, she argued, made it incredibly difficult for the wider health needs of LGB people to be recognised and researched. Dowsett (2007) however suggests that HIV paradoxically both hindered and stimulated research on a wider range of health issues among gay men. HIV/AIDS at the very least placed 'gay health' firmly on public health and research agendas (Rofes, 2004).

Disparities in health between LGB people and the general population have also been a central focus of research since the 1970s (Wolitski, Stall and Valdiserri, 2008). Given the difficulties of accessing LGB people to participate in studies, much of this research has used non-probability samples and compared their data with larger surveys of the (assumed-to-be-heterosexual) 'general' population. This is particularly the case with health surveys conducted by community groups (see Meads et al., 2007), but has also been common in the academic literature (Fish, 2006). Non-probability samples are commonly criticised for lacking scientific rigour, however probability samples of LGB people are particularly difficult to achieve. Participants may decline to answer questions about sexual identity, very large sample sizes are needed to produce sufficient sub-samples of LGB people and the cost of conducting such large scale research is often prohibitive (Fish, 2006). To

date, only a handful of population-based public health surveys (mainly from the USA) have included questions about sexual identity. Furthermore, most population-based studies published, to date, have examined disparities in mental health or sexual health, with only a handful reporting disparities in health behaviours such as smoking, alcohol use and diet.

From a review of the literature regarding smoking among LGB people (12 studies from 1987 to 2000), Ryan et al. (2001) found that smoking rates among LGB people were consistently higher than those nationally, in some studies almost double that of the general population. This finding has more recently been replicated in population-based studies in the US and Canada (Conron et al., 2010; Gruskin et al., 2007; Steele et al., 2009). Similarly, early research suggested that lesbians and gay men were at an alarmingly higher risk of problem drinking than their heterosexual counterparts (e.g. Fifield, Lathan, and Phillips, 1977). However these studies were often methodologically flawed. Not only were such studies conducted using convenience samples, but participants would often be recruited directly from gay bars.

A review of the literature by Bux (1996), suggested that evidence for higher levels of alcohol problems has been more robust for lesbians than gay men although both appear to be less likely to abstain from alcohol completely than heterosexuals. Again, this trend has been found more recently with a large sample of Californians in which lesbians were found to be significantly more likely than heterosexual women to be heavy drinkers, while gay men had a borderline significant increased risk for heavy drinking compared to heterosexual men (Gruskin and Gordon, 2006). Furthermore, some studies suggest that gay men may be less likely to reduce their alcohol consumption as they age than the general population (Stall and Wiley, 1988; Bergmark, 1999; Hughes and Eliason, 2002).

Within this literature, bisexuals have rarely been examined separately, however a recent population-based study conducted in Canada found that bisexual women were more likely to smoke and drink heavily than either heterosexual or lesbian women (Steele et al., 2009). Both smoking and drinking heavily are associated with an increased risk of developing a number of chronic health conditions. For instance

smoking significantly increases the risk of developing cardiovascular disease, chronic obstructive pulmonary disease, stroke, emphysema and various forms of cancer (particularly lung cancer, pancreatic cancer and cancers of the mouth and larynx) (Bartal, 2001). Similarly, excessive alcohol consumption is associated with an elevated risk of liver disease, dementia, stroke and cancers of the mouth, larynx, liver, breast and bowel (Room, Babor and Rehm, 2005).

While evidence for disparities in the use of health damaging substances between LGB people and heterosexuals are striking, the ‘causal pathways’ between sexual identity and health behaviours are not yet fully understood. A number of suggestions have been put forward. LGB youth may be particularly prone to initiate smoking given the stress associated with coming out and concerns about being ‘different’ at a time in life when individuals are already vulnerable to peer pressure. The limited social networking opportunities available for LGB people to meet, socialise or find a partner (safely) has also been theorised as shaping the use of substances such as alcohol, tobacco and other recreational drugs among these communities (Weinberg, 1994)¹⁷. As gay bars represent a rare social space in which non-heterosexuality is the norm, many LGB people may choose to socialise more in settings where the use of these substances are normalised. Socialising in such venues and taking part in what may be seen as cultural activities may also be used to reaffirm a gay identity. In a recent qualitative study examining problematic alcohol and drug use among gay and bisexual men in Britain, Keogh et al. (2009) reported that the men felt that alcohol was deeply embedded in gay culture and that this made it difficult for them to control their alcohol consumption, even once they had identified it as problematic. They also suggested that alcohol and drug use served as a ‘social lubricant’ to hide low self-esteem and was used to gain confidence in order to approach potential sexual partners. Interestingly, rather than gay venues being described as safe havens, they were described as sites of personal discomfort, in which alcohol and drugs were used to ease their anxiety. Some of the men also suggested that substance use was used as a form of self-medication in order to deal with conflicting feelings about their sexuality.

¹⁷ No research to date has examined if the ban on smoking in enclosed public spaces (including pubs and clubs) in the UK has had any impact on smoking among LGBT people. Most bars, clubs and pubs have, however introduced outdoor areas for smoking perhaps diminishing the impact of the law.

The concepts of ‘internalised homophobia’ and ‘minority stress’ have been widely used in theorising about the increased use of health damaging substances among LGB people (Williamson, 2000). Internalised homophobia has been defined as a non-heterosexual’s ‘direction of negative social attitudes toward the self, leading to a devaluation of the self and resultant internal conflicts and poor self-regard’ (Meyer and Dean, 1998: 161). This ‘poor self-regard’ resulting from internalised homophobia is often theorised as undermining LGB people’s concern with their own health, interfering with health behaviour decision making¹⁸. Williamson (2000: 98) suggests that the concept of internalised homophobia has been widely used as it is ‘easily understood by clients within the therapeutic milieu’ and ‘strikes a chord with almost all gay men and lesbians’. Meyer (1995: 35) has conceptualised internalized homophobia as a component of ‘minority stress’ arising ‘from the totality of the minority person’s experience in dominant society’. From this perspective, internalised homophobia represents one dimension of minority stress, together with perceived stigma and actual experiences of discrimination. One possible reason why bisexuals may report higher rates of smoking and excessive alcohol consumption is that bisexuals may experience greater levels of minority stress due to stigma from both heterosexuals *and* the lesbian and gay community (Dobinson et al., 2005). In this way, LGBTQ psychologists have suggested that living in a heterosexist society may contribute to poorer health behaviours among LGB people (Hillier et al., 2004).

In addition, there may be protective factors that non-heterosexuals may be less likely to benefit from. For instance, there is evidence to suggest that parents are less likely to be substance users than non-parents, with the exception of non-custodial parents who are more likely to be substance users (Merline et al., 2004). This may be important as lesbians and gay men are less likely to have children than heterosexuals and gay men who do have children in the context of previous heterosexual relationships are often non-custodial parents (Barrett and Tasker,

¹⁸ The concept of ‘internalised homophobia’ has, however, been criticised by critical LGBTQ psychologists. Celia Kitzinger (1996b), in particular, has argued that by focusing on the individual, rather than structural oppression, the concept of internalised homophobia implies that LGB people need to be ‘cured’ of their own low self-regard which, she argues, amounts to victim blaming rather than addressing heterosexism.

2002). Furthermore, Skinner and Otis (1996) found significantly lower levels of alcohol consumption among lesbians with children, than childless lesbians.

Much less LGBT research has explored other factors associated with the development of illness such as nutrition, diet, exercise and weight. There is some evidence, however to suggest that lesbians may be at a higher risk of being overweight and obese. For instance, Saphira and Glover (2000) found that 45 per cent of lesbians in New Zealand were overweight or obese compared with 36 per cent among the 'general' female population, while a population-based study conducted in the USA reported that more than twice as many lesbian women were overweight or obese than heterosexual women (Boehmer, Brown and Bauer, 2007). Interestingly, however Boehmer et al. (2007) found that women who identified as bisexual or 'something else' were no more likely to be overweight or obese than the heterosexual women. Another recent population-based study by Conron, Mimiaga and Landers (2010) in the US also reported this trend, as well as finding that gay men were less likely to be overweight/obese than heterosexual men. Again, bisexual men did not differ from heterosexual men in this regard. This finding may fit well with findings that gay men appear to be at a higher risk of developing eating disorders such as anorexia nervosa (Williamson and Hartley, 1998; Williamson and Spence, 2001; Russel and Keel, 2002). Siever (1994) has suggested that this may be a result of men placing greater emphasis on the slenderness of their partners within Western cultures. Consequently, like heterosexual women, there may be greater pressure on gay men to be thin than on heterosexual men or lesbian women. Of course LGB communities are not homogenous. For instance, there is a growing subculture of gay and bisexual men who identify as 'bears'. In contrast to the 'twink', used within LGB communities to describe young, slim and hairless gay men, those identifying as 'bears' appear to celebrate being physically large and having considerable body and/or facial hair as more masculine (Gough and Flander, 2009). As critical health psychologists have argued, health-related behaviours (e.g. smoking, alcohol consumption) and signifiers of health (e.g. weight) are not purely individual but are imbued with cultural meaning and bound with our identities in complex ways (Crossley, 2000).

What is an LGBT health issue?

The US National Gay and Lesbian Task Force defined a gay or lesbian health issue as ‘diseases or conditions which are unique, more prevalent, more serious and for which risk factors and interventions are different’ for lesbians or gay men (Plumb, 1997: 365). In particular, this notion that LGBT health issues, are health concerns which are *more prevalent* among LGBT people has led to this dominant paradigm of comparative research to uncover health inequalities between LGBT people and the (assumed-to-be heterosexual and non-trans) ‘general’ population (e.g. Wolitski, Stall and Valdiserri, 2008). As Epstein (2003: 158) notes, it has also led the research agenda to become defined around ‘questions that are amenable to quantification and measurement’. However, there remains little epidemiological data on the prevalence of many of the most common chronic conditions among the LGBT population.

Sexually transmitted infections and particularly HIV have been viewed as *the* gay men’s health issue, however ever since its public conceptualisation as a ‘gay plague’ in the 1980s there has been those who wish to disassociate sexual identity and the disease. For instance, with HIV fuelling homophobia, AIDS activists deployed the argument that it is ‘what you do’ and not ‘what you are’ which increases one’s risk of HIV infection (Epstein, 2003). Similarly, Kitzinger and Peel (2005) note that in decades since, health education has often sought to portray HIV as an ‘equal opportunity virus’ (i.e. it can affect anyone) and it has become conventional wisdom that the notion of HIV as a ‘gay disease’ is homophobic. Some gay activists, however have argued that this ‘de-gayng’ of AIDS downplays the disproportionate way in which HIV affects gay and bisexual men and may lead to resources being taken away from gay men’s sexual health promotion and services, leading to what has been referred to as the degaying and regaying of AIDS debate (King, 1993; Kitzinger and Peel, 2005).

In a similar way, there has been debate as to whether breast cancer is a ‘lesbian health issue’ amid press reports during the 1990s that one in three lesbians (compared to one in eight heterosexual women) would develop the disease (e.g. Selvin, 1993). This reported elevated risk was attributed to lesbians being less likely to have children, in addition to research suggesting that lesbians consume alcohol

more heavily and are more likely to be overweight (as noted above). Such claims however have been hotly debated and have a number of possible political implications. On the one hand, they can be used profitably to mobilize lesbian health activists, however on the other, identity and behaviour may become conflated (Wilkinson, 2002). As Wilkinson (2002) and Wilton (2002) have noted, it is not lesbianism *per se* which puts women at greater risk of breast cancer, but rather, not having children, smoking and being overweight. Furthermore, Fish (2009: 445), contends that to define lesbian health in this way, may promote a ‘discourse of culpability’ as ‘their life choices could be used, by some, to blame them for a possible increased risk of breast cancer’ (see also Fish, 2006). In other words, as observed with HIV and gay men above, the claim that lesbians have a higher risk of breast cancer may be used to support heterosexist discourses. For this reason, Wilton (2002) has argued that researchers need to take particular care in the way they present their findings.

More recently, research suggesting that lesbians may be more than twice as likely to develop polycystic ovarian syndrome (PCOS) (Agrawal et al., 2004) carries similar political risks. This research was widely reported within UK press, with the researchers quoted as asserting that they ‘do not view lesbianism as a disease in need of a cure’ (Hutchinson, 2003). However it was also commonly reported that a ‘hormone *imbalance*’ (emphasis added) associated with PCOS ‘could be linked to both the medical condition and sexuality’ (Hutchinson, 2003), despite the fact that no differences were found in the androgen levels of lesbian and heterosexual women with normal ovaries. Such statements construct lesbianism within a discourse of biological abnormality and positions heterosexual bodies as the norm (Sedgwick, 1990; see also Hegarty, 2003).

So the way in which LGBT researchers (including LGBTQ psychologists) construct LGBT health has important political implications. By framing LGBT health in terms of difference between LGBT people and the ‘general population’, heterosexual privilege may go unmarked. Comparative studies often treat the ‘general population’ as if that population is not also made up of LGBT people. By comparing LGBT health with the ‘general’ population as opposed to a heterosexual population, not only may any health disparities be underestimated, but heterosexual

privilege is also rendered invisible. A critical examination of 'straight' cultures may also be needed in order to avoid them becoming a 'healthy' norm against which LGBT people's health is compared against. Moreover Epstein (2003: 158) has argued that this focus on what he refers to as 'epidemiological similarity' - treating LGBT people as having a distinct health profile - may have a number of other unintended consequences:

[LGBT] group members may overemphasize the threat posed by those conditions that are seen as group specific, while failing to attend to health risks (such as cardiovascular disease) that may be substantially larger for many individuals in the group but that are not restricted to the group. In addition, group members may assume that what the group has in common (a sexual identity) is necessarily more consequential for the health of group members than the ways in which they differ (by social class, race, ethnicity, nationality, region, religion, and so on).

It is my assertion that heteronormativity within health psychology, together with the way in which LGBT health has been framed by LGBT activists has led to certain illnesses (e.g. diabetes) not being considered in non-heterosexual contexts. Framing certain illnesses as 'LGBT health issues' has helped to perpetuate heteronormativity in our thinking about illness and rendered LGBT people living with illnesses other than HIV/AIDS invisible (Lipton, 2004).

Aims and outline of the thesis

My aim in this thesis is to contribute to developing a critical LGBTQ health psychology. It aims to establish all non-heterosexual experiences of illness as worthy of study and not only in comparison to heterosexuals. In doing so I begin to envisage what a health psychology might look like which deems sexuality always to be relevant. This thesis utilizes qualitative methodology, and in contrast to the model of positivist empiricism, I do not postulate a hypothesis but instead the thesis coheres around a number of broad research questions.

Firstly, I ask, how does (non-hetero)sexual identity shape people's experiences of chronic illness and, in particular, how do non-heterosexuals themselves deem their

sexuality to be relevant to their experience of chronic illness? In answering this question, I aim to ‘give voice’ to those who have not been represented in the health psychology literature. I adopt qualitative methods as a corrective to traditional psychological practices which deny marginalised groups the opportunity to be heard within psychology (Sampson, 1993).

Secondly, I ask how is chronic illness and sexual identity socially constructed? In particular, I aim to explore how connections between these aspects of the self are made. I also aim to examine how heteronormativity shapes discourse in order to construct sexual identity as irrelevant to health. In doing so I will examine how talk about illness is informed by wider discourses of gender and sexuality, and how these multiple identities are negotiated within their talk.

In the next chapter, I discuss qualitative methodology and how it has been usefully adopted in both critical health psychology and (particularly British) LGBTQ psychology. I will then outline my own use of qualitative methods and introduce the data sets upon which the three consecutive analytic chapters are based.

In Chapter 3, I explore non-heterosexual experiences of a range of chronic illnesses based on responses to a qualitative online questionnaire. Thematic analysis is used to examine the responses and explicate how (non-hetero)sexual identity is experienced as relevant to the experience of living with a long term illness. This approach allows for a wide range of perspectives as the experiences of a large number of people are considered.

Chapter 4 focuses on online support seeking by LGB(TQ) people. In light of a proliferation of internet support groups for non-heterosexuals living with a wide range of illnesses, I examine a diabetes newsgroup in which a ‘gay diabetic’ seeks the support of other non-heterosexuals with diabetes. Here I draw on a discursive approach in order to examine how some discussants position the original post as inappropriate and how others work up the relevance of (non-hetero)sexual identity to the experience of living with diabetes. In doing so the ways in which both diabetes and sexual identity are socially constructed is considered.

In Chapter 5 I continue to use discourse analysis to examine talk from interviews with LGB people with diabetes. In particular I consider how cultural discourses around gender, sexuality and diabetes management are drawn upon in their talk about the support they receive from significant others. Here I analyse talk about illness and its management in relation to the socio-cultural context of being a lesbian, a gay man or a bisexual person.

Chapter 6 also draws on the interview data, however both the focus and analytic method used are different. In this chapter I return to using thematic analysis and consider the gay and bisexual men's accounts of sexual problems associated with diabetes. The aim of this chapter is to further illustrate the importance of considering how experiences are shaped both by sexual identity and the relational context.

To conclude, Chapter 7 will summarise my findings and discuss how the thesis contributes to critical health psychology and LGBTQ psychology. I suggest implications for practice arising from my research, reflect on some of the limitations of my research and also suggest some future directions for the field.

Chapter 2: Methodology

Qualitative methods have been enthusiastically adopted within critical health psychology and (particularly British) LGBTQ psychology. As Murray (2004) notes, a key component of ‘criticality’ within critical health psychology has been to question the underlying assumptions and implications of traditional research methods. Mainstream health psychology has largely built its legitimacy and value around the premise that through the scientific study of human behaviour, psychologists may predict and control ‘unhealthy’ behaviours and increase adherence to medical regimens (Murray and Chamberlain, 1999; Crossley, 2000). Murray and Chamberlain (1999) suggest that by adopting ‘objective’ methods that resemble the natural sciences, health psychology has been able to integrate itself within the medical establishment dominated by biomedical science. In its emulation of the natural sciences however, mainstream health psychology is left wanting. Crossley (2000) suggests that psychology relies heavily on biomedically defined problems and taken for granted models of health and illness. Furthermore, in an attempt to identify independent variables and isolate them within ‘controlled’ studies, the social and cultural context of health and illness is obscured. By contrast, Crossley suggests that a ‘central feature’ of critical health psychology has been ‘to explore the qualitative nuances of meaning and value inherent in human experiences of health and illness’ (2000: 8).

As noted in Chapter 1, health psychology has been influenced by epistemological debates within psychology and social constructionist critiques of the positivist-empirical paradigm dominant within the discipline. Social constructionists contend that it is impossible for researchers to conduct ‘objective’ value free research, which is not constrained by the social and historical context in which research is conducted (Gergen, 1985). Furthermore, the taken for granted categories and concepts used as a starting point for research are themselves products of the culture and historical moment in which the research is embedded. For social constructionists, knowledge is viewed as a social process constructed between people, rather than something ‘out there’ to be discovered (Burr, 1995; Gergen, 1985).

Qualitative methods are also increasingly being adopted within certain quarters of LGBTQ psychology. A number of commentators have suggested that while LGBTQ psychology in the US remains highly invested in positivist-empiricist methods, British LGBTQ psychology is increasingly developing within a critical psychological framework and embracing qualitative approaches (D'Augelli, 2002; Kitzinger and Coyle, 2002; Peel et al., 2007)¹⁹. LGBTQ psychology in the UK has much in common with other social science and humanity disciplines (such as history, sociology and cultural studies) within, what has become known as, *gay and lesbian or queer studies*.

While the psychology of sexuality was traditionally pre-occupied with essentialist concerns regarding the aetiology of homosexuality, the French philosopher Michel Foucault (1978) and British historian Jeffery Weeks (1985), among others, drew attention to the historical and cultural contingency of the idea that homosexual behaviour is confined to a 'type' of person (i.e. a 'homosexual'). This has led to a central debate within lesbian and gay psychology - whether to pursue an essentialist or a social constructionist view of sexuality (see Kitzinger, 1995 for an overview). As Dowsett (2007: 421) notes 'Gay and lesbian studies, queer theory, and the new *critical sexuality studies*, not only challenged the prevailing understanding of human sexuality, its origins, and elaboration in science but also raised the possibility of studying sexuality with new methods' (emphasis in original). He further observes that a legacy of oppression from earlier scientific (particularly biomedical and psychological) research on lesbians and gay men, together with AIDS activism which challenged the lack of democracy in health research (see also Epstein, 1995) may have led to greater engagement with qualitative research methods.

This development within LGBTQ psychology also follows in the footsteps of feminist psychologists who were quicker to embrace critical and qualitative approaches (Clarke and Peel, 2005). Indeed feminist psychologists have been at the forefront of debates about epistemology and the relationship between researchers and the researched (Harding, 1987; Holloway, 1989). Moreover, a number of

¹⁹ This is also true of much LGBTQ psychology within Australasia (e.g. Braun et al., 2009; Riggs, 2007).

LGBTQ psychologists have explicitly positioned themselves as *lesbian* feminists. For instance, Celia Kitzinger's (1987) *The Social Construction of Lesbianism* takes a radical lesbian feminist position and has become a classic within British LGBTQ psychology (see Peel and Clarke, 2005 for appraisals of its influence on the field).

Experiential and discursive approaches within critical psychology

Wilkinson (2004) identifies three traditions within feminist health research. The first is a feminist version of the traditional positivist empiricist paradigm, which criticises gender bias in mainstream health research. For instance, chronic health conditions that predominantly affect women (e.g. osteoporosis, ovarian cancer) have traditionally been under researched (Travis, 1988). This approach aims to develop 'better' forms of science and address women's concerns in the pursuit of feminist goals. The second is a tradition of 'experiential' approaches, which seek to 'listen to women's voices', positioning women as 'experts' about their own lives and giving priority to their experiences and understandings of health and illness. As an example of this kind of research, Wilkinson draws on her own research with lesbians diagnosed with breast cancer as a group of women whose experiences have largely been ignored. The third is a discursive tradition which aims to examine how power relations are (re)produced through language. This tradition is aligned with social constructionism or post-structuralism and is concerned with how we talk about our lives, how we construct our world through the language we use, and what our choice of language functions to do. For example, Horton-Salway and Locke (2010) demonstrate that although talk about parents' childbirth decisions in antenatal classes are embedded within the rhetoric of 'choice', cautionary tales in the form of extreme horror stories function as a regulatory mechanism of coercion which discursively reproduces the moral superiority of medical intervention.

Much LGBT health research outlined in the introduction, while operating within a positivist-empiricist paradigm (and largely conducted within the US), can be considered 'critical' in its critique of (and its attempt to address) the way in which LGBT people's health has been systematically ignored. In this thesis I draw on a mixture of the latter two research traditions identified by Wilkinson using qualitative methods, both of which are increasingly also being adopted within

British LGBTQ psychology (Peel et al., 2007). Wilkinson suggests that one of the central tenets of feminist experiential approaches is to 'give voice' to women and argues that this principle can be extended and applied to a wide variety of marginalised groups. I draw on this approach particularly in Chapter 3 which presents LGB people's experiences of a range of chronic illnesses using a qualitative online questionnaire and Chapter 6 which draws on interview data and focuses on gay and bisexual men's experiences of sexual difficulty related to diabetes. I also draw on the discursive tradition within Chapters 4 and 5. In Chapter 4 I examine how sexual identity is constructed and discussed within an online discussion about diabetes. In Chapter 5 I apply discourse analysis to transcripts of interviews with LGB people with diabetes. I explore how their accounts are informed by discourses of gender and sexuality, how these multiple identities are negotiated and how the roles of partners are discussed. In the remainder of this chapter I will outline two analytical approaches adopted throughout this thesis before considering the particular methods of data collection adopted.

At this point, it is important to acknowledge that these two approaches to research may be viewed as incompatible and based on epistemologically incommensurable frameworks – realism versus social constructionism. Experiential approaches may be considered 'realist' as they are based on the assumption that people can self-report their 'experiences' in a relatively unproblematic way and thus treat language as a window to people's inner worlds. Social constructionist scholars have characterised the idea that qualitative researchers can simply 'give voice' to their participants as 'naïve' (Braun and Clarke, 2006: 80) and from a constructionist perspective, sociocultural contexts are viewed as giving rise to the accounts that individuals provide (Burr, 1995). Kitzinger (1994: 42) asserts that 'experience' 'cannot be posited as unproblematic authentic 'fact'', but rather should be viewed as embedded within a web of social norms, structured within, or in opposition to dominant cultural discourses. On the other hand, discursive approaches have been criticised for robbing participants of their voices, for having little to offer the study of subjectivity and for rarely offering specific recommendations for action. For instance, Willig (2004) argues that while discursive approaches have much to offer health psychology, they can also undermine the status of 'illness narratives as a form of self-expression' (p.116). Similarly, Crossley (2000b) has argued that with

their focus on culture, context and discursive acts, discursive approaches risk ‘losing the subject’ and offering little to our understanding of personal experience. A third criticism levelled at discursive research is that the relativism associated with social constructionist approaches makes it difficult to suggest practical recommendations and interventions (c.f. Willig, 1999).

The adoption of different epistemological positions, however, need not be viewed as inherently problematic. A ‘pragmatist’ approach to knowledge emphasises respect between different research paradigms and views knowledge as a tool for solving particular problems or answering particular questions. Pragmatism can be traced back over a century to philosophers such as William James, John Dewey and George Herbert (Morgan, 2007), however, Cornish and Gillespie (2009) have recently made a compelling case for such a pragmatist approach as a way of moving beyond a realism-constructionism divide within health psychology. They suggest that pragmatism is pluralistic in its acceptance of a variety of competing forms of knowledge and that rather than asking if knowledge accurately reflects an underlying reality, ‘for pragmatists, the only yardstick by which to judge a piece of knowledge is whether that knowledge is useful for a given interest’ (p.802). This is not to suggest that a pragmatist approach is the same as a utilitarian approach, which argues that knowledge should always serve some immediate practical purpose. Rather, according to Cornish and Gillespie, a pragmatist approach can acknowledge the wide range of ‘interests’ researchers may have. As Braun and Clarke (2006: 80) argue ‘What is important is that the theoretical framework and methods match what the researcher wants to know, and that they acknowledge these decisions, and recognise them *as* decisions’ (emphasis in original).

Realist research may be deemed ‘useful’ in that it can be used to ‘give voice’ to under researched and otherwise marginalised groups such as LGBTQ people (e.g. Braun et al., 2009), while constructionist research can be deemed ‘useful’ for interrogating the heteronormativity and cultural understandings about sexuality demonstrated in those voices (e.g. Peel, 2001b). As Wilkinson (2004) contends, either may be used to further the political interests of marginalised groups. The acknowledgement of political interests is typically viewed as ‘bias’ within scientific research, however within a critical qualitative paradigm, the recognition of such

factors is considered honest and enriching for the analysis (Gough, 2003). So here I acknowledge that my use of experiential and discursive approaches have been selective, based, in part, on politics. For example, in Chapter 3 I use thematic analysis to 'give voice' to LGB people living with chronic illness, while in Chapter 4 I adopt discourse analysis to examine how heterosexism operated within online interaction in a diabetes discussion forum.

When aiming to 'give voice' to my participants, I do so within a critical realist framework. Critical realism has been advocated as another way to move beyond this constructionist-realist divide when examining individual experience. Critical realism is an epistemological position that maintains the presence of a knowable reality independent of our perceptions, whilst acknowledging that such knowledge is imperfect and shaped by social and cultural discourse (Willig, 1999). This approach attempts to reconcile the epistemological insights of social constructionism with an acknowledgement of the material and embodied reality of people's lives (Willig, 1999). It treats subjective experience as legitimate and as important as expert knowledge (Pilgrim and Rogers, 1997). When applied to the topic of health and illness it represents a way to reconcile the biomedical with the psychosocial (Ussher, 1999a). It affirms the existence of a biomedical reality of illness while recognising that any representations of it are mediated by language and culture (Pilgrim and Rogers, 1997). For example, in Chapter 6, which considers gay and bisexual men's experiences of sexual difficulties, I accept the symptoms of erectile difficulties as 'real'. I recognise the physiological role diabetes may have in these problems; however the ontological status of 'erectile dysfunction' is not taken-for-granted but treated as a medical construct. Therefore any account of erectile dysfunction will be shaped by culturally available ways of understanding and talking about the problem. For the remainder of this chapter I shall outline the two main methods of analysis used throughout the thesis and introduce the three methods of data collection. Specific detail about the participants, procedure and ethical considerations for each method shall be presented in the chapters in which they are used.

Thematic analysis

Thematic analysis is a widely used qualitative analytic method to report the views and experiences of research participants (e.g. Braun et al., 2009). Braun and Clarke (2006: 79) describe thematic analysis as ‘a method for identifying, analysing and reporting patterns (themes) within data’. This form of analysis is sometimes also referred to as ‘thematic content analysis’ (Green and Thorogood, 2004) or treated as similar to (and occasionally even referred to as) content analysis (e.g. Meehan, Vermeer and Windsor, 2000; Wilkinson, 2000). While content and thematic analyses are both methods used to identify patterns across qualitative data, we may wish to make the following distinction. Content analysis is generally concerned with summarising the content of a dataset numerically, in the form of frequency counts, in order to provide a *quantitative* analysis of qualitative data. By contrast, thematic analysis is a *qualitative* form of analysis which (minimally) seeks to summarise themes within the data set and often to go beyond the content of the data to explore meaning in more depth (Braun and Clarke, 2006). Unlike content analysis, prevalence is not of primary importance. Braun and Clarke suggest that although there should be a number of instances across the dataset if something is to be considered a ‘theme’, what is of primary importance is that a theme should capture something of analytic importance with regards to the research question(s). Others have suggested it may even be misleading to provide frequency counts within thematic analysis, particularly if a semi-structured form of interview is used where the same questions may not arise in each interview or when the analysis is conducted across questions, rather than for each question individually (Kitzinger and Willmott, 2002).

Madill and Gough (2008) note that many qualitative methods could be described as a form of ‘thematic’ analysis, albeit with slightly different coding techniques and theoretical orientations (e.g. Grounded Theory, Interpretative Phenomenological Analysis). For this reason, some have regarded thematic coding as a generic process conducted within other analytic traditions, as opposed to specific method of analysis (Boyatzis, 1998; Ryan and Bernard, 2000). However, Braun and Clarke (2006) suggest that the technique deserves to be considered as a method in its own right. Although analyses ‘branded’ as thematic have at times been vague and inconsistent

(Madill and Gough, 2008), Braun and Clarke attempt to develop the method into a flexible and transparent form of analysis. They suggest that thematic analysis should be viewed as a ‘foundational’ method, which can be applied using a variety of epistemological and theoretical standpoints. I adopted a critical realist, inductive (data-driven) approach and the process I used for coding was based on that outlined by Braun and Clarke (2006) (which I describe in Chapters 3). I do not attempt to describe the content of the entire data sets but rather the data were coded in accordance to my research questions and how their experiences were shaped by their (non-hetero)sexual identity.

Discourse analysis

Discourse analysis (DA) is an umbrella term for a variety of discursive approaches to analysing texts. The term ‘discourse’ has a number of meanings. It can refer to any form of talk or texts. It can also refer to patterns of meaning evident within spoken or written language. A distinction is often made between two types of DA - discursive psychology (DP) and Foucauldian discourse analysis (FDA)²⁰ (Willig, 2004; 2008). What these different versions of DA have in common is that they are all interested in how accounts/texts are constituted rather than viewing them as a route to accessing cognitive states of speakers (unlike other qualitative approaches such as Interpretative Phenomenological Analysis [Smith, Flowers and Larkin, 2009]). They also both take a social constructionist approach and are interested in how accounts *descriptively* construct particular versions of reality (Burr, 1995; Edwards, 1997).

DP is concerned with the immediate interactional work in which speakers are engaged, similar to conversation analysis (Hutchby and Wooffit, 1998). It is also centrally concerned with what actions we perform through our talk – referred to as the ‘action orientation’ of talk (Edwards and Potter, 1992). DP was originally a reconceptualising of psychological topics such as emotions, attitudes and identities. For example, instead of accepting that emotional expressions are reflections of an

²⁰ This is alternatively referred to as ‘post-structuralist’ or ‘critical’ discourse analysis. I refer to it as ‘Foucauldian’ as this is the most commonly used term (Willig, 2004; 2008; Wiggins and Riley, 2010).

underlying cognitive state, Edwards (1999) suggests that invoking emotion can be used as an interactional resource²¹. Of particular interest to both critical health psychology and LGBTQ psychology, is DP's re-conceptualisation of identity (Potter and Wetherell, 1987). From a DP perspective, identity is not a stable entity that an individual develops over time, but rather it is produced in interaction to meet the needs of the local conversational context. So discursive psychologists are interested in how people present themselves through their talk. For example, discursive psychologists have examined how people with diabetes account for eating 'unhealthy' foods (e.g. chocolate) in ways which present themselves as compliant with dietary advice (i.e. accomplishing a 'compliant identity') (Peel et al., 2005) and how people make seemingly prejudiced statements in ways which present themselves as liberal minded (i.e. accomplishing a 'non-prejudiced identity') (Gough, 2002; Speer and Potter, 2000)

FDA views accounts of the world as constructing objects and subjects and is concerned with broader patterns of cultural meaning making. To illustrate this, Wiggins and Riley (2010) note that to describe someone as 'heterosexual' is to draw on the cultural understanding of our sexual partner choice as determined by what people are (e.g. 'heterosexual' or 'homosexual') as opposed to sexual desire for a particular person (irrespective of gender)²². Another example would be that to describe oneself as 'addicted' to chocolate is to invoke medicalized discourses of physiological and/or psychological dependency, as opposed to discourses of pleasure and personal choice (Benford and Gough, 2006). So FDA is concerned with identifying the social and cultural understandings drawn upon within the accounts that people provide. Discourses are also said to set up 'subject positions' which Davies and Harré (1990: 48) describe as 'the discursive process whereby selves are located in conversations'. Subjectivity is understood as being constituted through discourse and we, as speakers, take up certain positions within those discourses (e.g. as a 'gay man' or as a 'chocoholic').

²¹ See Chapter 5 page 135 for an example of what invoking an emotional state can achieve interactionally.

²² This is a particularly fitting given that it was Foucault (1978) who is credited as tracing a shift from understanding homosexuality as immoral sexual behaviour ('sodomy') to a type of person (the homosexual) in the late 19th century.

Broadly speaking, these two approaches differ in their focus of enquiry. DP tends towards a more conversation-analytic style which concerns itself solely with activities within the interaction - what is a particular account 'doing' within the conversation and what 'discursive devices' are being used (Edwards, 1997). The FDA style of analysis by contrast examines wider cultural understandings. Speakers are said to 'draw upon' discourses that have a wider existence within a culture. However, there are those who advocate a more synthetic approach, which focuses on the immediate interaction at hand *and* the wider social context which informs that interaction (Wetherell, 1998; Edley, 2001; Seymour-Smith et al., 2002). Wetherell (1998) suggests that a pure DP approach fails to address the political and ideological consequences of particular ways of talking about social issues. On the other hand however, she suggests that it is important to acknowledge that wider discourses are (re)produced in highly specific local contexts. By combining these approaches Wetherell (1998) and Edley (2001) suggest that we can examine why a particular version of the world is being presented and for what purpose.

Within this synthetic approach, the culturally familiar and recognisable ways of talking are referred to as 'interpretive repertoires' (Potter and Wetherell, 1987; Wetherell, 1998). Nigel Edley (2001: 198) describes interpretive repertoires as 'part and parcel of any community's common sense, providing the basis for shared social understanding'. This synthetic version of discourse analysis is ultimately concerned with mapping how shared cultural understandings are used in the local context (Wetherell and Potter, 1992). Gough (2006a: 2479) refers to this synthetic version as 'an eclectic approach which focuses both on discursive practices (how discourse is used to perform specific functions within a text) and discursive resources (how texts are informed by wider cultural norms)'.

I adopt this synthetic approach to DA in Chapter 4 with an archived online discussion and in Chapter 5 with interview data. Although discursive approaches have only recently begun to be applied to computer mediated communication (Lamerichs and Te Molder, 2003; Antaki et al., 2006; Horne and Wiggins, 2009; Veen et al., 2010), archived online discussions provide a wealth of 'naturally

occurring' conversations²³ which tend to be favoured by discursive psychologists (Potter and Hepburn, 2005).

There are an increasing number of helpful texts which outline 'how-to-do' discourse analysis (e.g. Wiggins and Riley, 2010; Willig, 2008), with much space often devoted to describing the coding process. While coding is an important initial stage of analysis used to transform an 'unwieldy body of discourse into manageable chunks' (Potter and Wetherell, 1987: 167), discourse analysis has been described as essentially '*a way of reading a text*' (Willig, 2008: 165, emphasis in the original) informed by a particular conceptualisation of language. So when adopting a discourse analytic approach, coding is focused on features of the interaction, what participants were 'doing' in the interaction and the identification of how talk is shaped by wider cultural norms. I was particularly interested in how chronic illness and sexual identity intersect in interaction, how chronic illness and sexual identity were constructed and how non-heterosexuals negotiate their gendered and sexual identities within talk (see Jowett, 2010). I will provide more detail on this process in each chapter which uses discourse analysis.

The analysis shifts from being more fine grained conversation analytic at some points, while more broad and critical at others. For example, in the first extract of chapter 4 I focus more on the conversational structure of the online post as this sets up the discussion and influences the way in which the subsequent 'speakers' respond. At other points I take a more 'critical' approach. For example in chapter 4 I interrogate how wider cultural discourses are drawn upon to heterosexist effect and in Chapter 5 I particularly focus on how discourses related to gender and individualism are used. In any piece of discourse analysis, the analyst will inevitably focus on some features of the discourse while paying less attention to others. This was based on what aspects of the discourse I felt were most pertinent to the research question(s) and which I found of particular analytic interest.

As Harper (2003) suggests, any analysis of data involves the researcher actively making *choices* at every stage of the research process. I chose to focus my analyses

²³ By this I mean conversations which would have taken place irrespective of myself or my research.

largely on social support and relationships and therefore focus on relational aspects of ill health. This is perhaps unsurprising given that sexual identity may be viewed as an inherently relational topic and as Flowers (2009) notes, relational understandings of health provide a critical contrast to biomedical approaches which locate 'health' within the individual and their body.

Methods of data collection

In this thesis I use three qualitative methods of data collection; a qualitative online survey (Chapter 3), observations of online support groups and an online discussion (Chapter 4) and interviews (both face-to-face and online) (Chapters 5 and 6). The use of multi-methods is becoming increasingly utilized within qualitative research (Darbyshire, MacDougall and Schiller, 2005). A distinction between the terms 'multi' and 'mixed' methods is often made within social scientific methodological literature. The former is typically used to describe the use of multiple methods of data collection and analysis within a single research 'paradigm' (i.e. qualitative *or* quantitative approaches), while the latter utilizes *both* quantitative and qualitative methods of data collection and analysis (Teddlie and Tashakkori, 2003). As my methods all fall within a qualitative (and critical) 'paradigm' of research, here I will use the term multi-methods. A multi-methods approach was not intended as a form of 'triangulation' in order to verify the 'validity' of the findings from each method, as is often advocated in (positivistic) mixed-method designs (Denzin, 1970). Rather, in this exploratory research, it was intended to 'cast the net' of my inquiry as widely as possible (Reinharz, 1992). Ussher (1999b) conveys this using a jigsaw metaphor in which different methods might be thought of as different pieces of a jigsaw, which together allow us to view a broader and more complex picture of our research topic.

The use of the internet in the research process features prominently throughout the thesis. Seale et al. (2010) note that the internet provides researchers with many opportunities including the recruitment of study participants, administering online questionnaires, conducting online interviews and observing online communities. I have used the internet for each of these purposes within this thesis, in combination with more traditional approaches such as advertising for participants in a diabetes

magazine and the more conventional face-to-face interview. I will now outline each of the methods used in chronological order of their use within this thesis.

Online qualitative questionnaire

Qualitative questionnaires (online or otherwise) are a minority method in qualitative psychology compared with the orthodox method of the research interview (Gough, 2006b). Some have even questioned whether open-ended survey questions should be deemed qualitative research at all (Dixon-Woods et al., 2006). Ignorance of qualitative research is also present in many texts on survey methods which often offer little guidance on how qualitative data gathered from open-ended questions should be analysed (Marsden and Wright, 2010). When open-ended question formats are discussed, it is usually as a supplement to quantitative questions and analysis, which are deemed to be the main element of the research (Marsden and Wright, 2010). Indeed most survey research collects predominately quantitative data, perhaps ending with an open-ended question allowing respondents to add any additional comments.

There are a number of limitations to using open-ended questions in survey research which may have deterred qualitative researchers from their use. Firstly, given that the vast majority of surveys primarily collect quantitative data, there may be an expectation that closed questions will mainly be used. Questionnaires following an open question format require more time and thought from the respondent, increasing risk of them becoming fatigued and failing to complete the survey. Secondly, the amount of data qualitative researchers can gather from individual respondents is limited. Unlike in interview research, there is no means by which the researcher can prompt respondents and encourage them to elaborate on their responses. Furthermore, the act of typing is more time consuming than speaking. Researchers are also neither able to rephrase their question to ensure that it is understood by the respondent nor correct any misinterpretation of the question.

Nevertheless, there are a number of advantages for the qualitative researcher. Surveys allow for a much larger sample than is generally practical using other qualitative methods. They thus provide a quick and effective way of collecting a

large number of diverse views and experiences in participants' own words (Harding, 2006; Harding and Peel, 2007). Toerien and Wilkinson (2004), who used a qualitative questionnaire to examine the meanings of women's body hair removal, suggests that the method is particularly suited to obtaining what they refer to as a 'wide-angle' picture, as it allows for a wider variety of responses to be captured than in either quantitative survey research or typically used qualitative methods. Thus, according to Toerien and Wilkinson (2004: 71), qualitative questionnaires are 'well suited to providing breadth in new areas of investigation'. It is for this reason that a qualitative questionnaire was used as the first study within this thesis; as an initial foray and exploration of how sexual identity may shape one's experience of chronic illness. I also hoped that by allowing respondents to indicate willingness to participate again in the future and supply a contact email address, the survey might act as a method of recruitment for in-depth research interviews. In turn it was thought that this might allow for a purposive sample of interview participants who could be selected based on their survey responses.

LGB people have historically been difficult groups to access for researchers and have been described as a 'hidden' or 'hard to reach' population (Clarke et al., 2010). With the rise of the internet, online surveys have become a popular and expedient method for researchers trying to access this population (Riggle, Rostosky and Reedy, 2005; Harding and Peel, 2007a). The rapid increase in computer-mediated communication and an explosion of online LGBT groups, social networking sites and listservs has provided researchers with a quick and effective way to publicise their studies and collect data from groups of people not easily identifiable 'off-line'. As well as being difficult to access, LGBT people may also be reluctant to take part in research, in particular, for fear of being 'outed'. Online surveys may go some way to addressing this problem as they enable individuals to participate anonymously (Harding and Peel, 2007a). Researchers have expressed some concern about the difficulty of ensuring that participants are who they say they are within research that utilizes the internet for data collection (Nosek, Banaji and Greenwald, 2002). These are not, however, problems solely for researchers using the internet. Paper surveys are equally open to deception and even the physical co-presence of the researcher does not ensure that respondents answer honestly (for example with regards to questions about sexual identity).

In sum, an online qualitative survey was used to conduct exploratory research; to gather participants' perspectives in their own words, while maximising the number of participants, the speed of data collection and the anonymity of respondents.

The use of pre-existing online material

As already noted, in recent decades there has been a rapid increase in computer-mediated communication. Not only has this provided researchers with opportunities to recruit their participants and conduct their research online, the internet also offers qualitative researchers a wealth of pre-existing texts which can be collected for analysis (Stainton Rogers, 2009). Online discussion forums, support groups and blogs have provided a proliferation of discourse about health and sexuality as people share their experiences and construct new identities in cyberspace. Importantly for critical psychologists, the internet is a major site for the cultural contestation of meaning (Stainton Rogers, 2009). It also provides new forms of communication for discursive psychologists to examine (Lamerichs and te Molder, 2003). In line with the preference of many discursive psychologists for naturalistic data (Potter and Hepburn, 2005), the internet provides a novel source of naturally occurring interaction. Although the term 'naturalistic' might seem an odd one when applied to data from the virtual world, archived online discussions meet Potter's (2004: 612) 'dead social scientist test' in so far as they would have taken place irrespective of the researcher.

In this thesis I use pre-existing online material in two ways. Firstly, I survey the diversity of online support groups available for LGBTQ people affected by chronic illness. During the recruitment stage of my questionnaire study, I became aware of a number of such online groups and several respondents wrote about their involvement in these groups in their survey responses (see Chapter 3). In line with a growing interest in the role of online support communities within health psychology (Davison, 2000; Coulson, 2005), I sought to document the range of such groups specifically for LGBT people available within one of the world's largest collections of online groups (Yahoo! Groups). In addition to documenting the range of health conditions for which such groups have been created, I also collected the moderator's

descriptions of their groups (available on the groups' homepages) to ascertain their purpose. The second way in which I use pre-existing online material is to conduct a discourse analysis of one discussion 'thread' on a (generic) diabetes support forum. Having established that a key purpose of *LGBTQ* online groups was to provide a safe haven from heterosexism within their generic counterparts, I sought examples of interaction in which non-heterosexuality featured in the discussions of generic health-related online support communities.

However, the collection and analysis of existing online material has its limitations. As with survey research, the researcher is unable to request clarification or elaboration on what has already been written, giving rise to ambiguity and a greater potential for misunderstanding (Seale et al., 2009). This can be exacerbated by missing words, spelling errors and strange punctuation which characterise this form of informal communication (Seale et al., 2009). The researcher does not have access to demographic information about those who have written online, other than that which they include within the posts themselves, and has no way of knowing if people posting on the internet are who they say they are. This problem of 'identity' however, can be averted to a certain degree by taking a discursive approach which is primarily interested in textual representations rather than 'people' and by treating identity categories as only relevant to the analysis when treated as such within the interaction itself (Kitzinger, 2000).

In-depth Interviews

Interviewing is the most commonly used method of data collection within qualitative psychology (Gough, 2006b) and has been described as 'a conversation with a purpose' (Burgess, 1984: 102). The specific purpose will depend on the particular research questions and to a certain degree, the analytic or theoretical tradition adopted by the researcher (as I will explain below). However, what all qualitative interviewing has in common is that it aims to engage participants in a dialogue to explore the topic of a given research project (Taylor, 2005). The form of interview used in this thesis can be described as a semi-structured interview (Smith, 1995). Semi-structured interviews are guided by an interview schedule, listing topics with possible open-ended questions that the researcher feels are important in

relation to the subject matter under investigation. In contrast to a structured interview format, the schedule is designed only as a guide allowing for a flexible and adaptable approach (Robson, 2002). Questions may be omitted, or additional ones added, the order and wording of questions may be changed and interviewers can ask for clarification and prompt participants to elaborate on their responses. In this respect, semi-structured interviews may be viewed as guided conversations (Kvale, 1996) which allow the researcher to let the interview flow more freely, exploring topics as and when introduced by the interviewee.

Although interviewing is similar in many forms of qualitative research, there are some differences between the experiential and discursive research traditions²⁴. Within experiential research the interviewee is often viewed as an ‘informant’ (e.g. Braun et al., 2009) and the aim is to ‘give voice’ to their experiences (Wilkinson, 2004). While in discursive research, interviews are generally viewed as ‘an arena in which one can identify and explore the participants’ interpretative practices’ (Potter, 1996a: 134-135) and ‘an opportunity [for participants] to rehearse the taken for granted’ (Seymour-Smith et al., 2002: 265). As mentioned previously, naturalistic data is often preferred by discursive psychologists (Potter and Hepburn, 2005) however, the advantage of interviews is that ‘they enable the researcher to deliberately question an entire sample of people on the *same* issues’ (Potter and Wetherell, 1987: 163 emphasis in the original). They also allow the researcher to elicit discourse on topics for which naturalistic data would be difficult to find.

With experiential research the interviewer adopts the role of an ‘empathetic listener’ (Leininger, 1985), while in some forms of discursive research the role of an ‘active interviewer’ is advocated (Holstein and Gubrium, 1997). The former requires the researcher to minimise their control over the interview and be as neutral as possible (Bowling, 1997). In the latter, some discourse analysts have advocated a more interventionist approach in order to activate a wider range of constructions and elicit a diversity of accounting practices (Potter and Wetherell, 1987; Holstein and Gubrium, 1997). As my research is situated in both experiential and discursive traditions, I aimed to strike a balance between these two approaches. The sensitivity

²⁴ There will also be differences within these traditions. The distinctions made between these two ‘traditions’ are meant as a useful heuristic.

of my research topic led me to largely adopt the position of an empathetic listener, however at times I also took a more ‘active’ approach when probing particular things said within the interviews.

Semi-structured interviews were used in this thesis as the aim was to *both* examine non-heterosexual experiences of a particular chronic illness in-depth *and* to explore how talk about illness management is informed by wider cultural discourses. Diabetes was chosen for a number of reasons based on earlier data collected. Firstly, diabetes was one of the most commonly reported health conditions in my sample of survey respondents, and the condition for which the largest number of respondents indicated that they would be willing to be interviewed. Secondly, diabetes (jointly with MS) attracted the largest number of online support groups in my search of Yahoo! Groups. These two studies provided intriguing data on diabetes in non-heterosexual contexts; however neither provided the opportunity to explore individual experiences in-depth. An advantage of collecting both pre-existing texts (such as online forum discussions), together with interviewing is that it allows for a fuller (or a more diverse) picture to emerge compared to one source alone (Potter and Wetherell, 1987).

Survey respondents who had indicated that they had diabetes and were willing to take part in a follow up interview were interviewed online; while participants recruited through an alternative means were interviewed face-to-face (a full description of the recruitment process shall be outlined in the Method section of Chapter 5). The main reason for using the internet to interview these participants was that they resided in the USA. Interviewing online thus eliminated the barrier of geographical distance and was in keeping with the online (and anonymous) nature of their previous participation. Online interviews can be divided into two main types; asynchronous and synchronous (Mann and Stewart, 2002; Alying and Mewse, 2009). Asynchronous online interviews are those that do not require both researcher and participant to use the internet at the same time and are usually conducted via email (Hunt and McHale, 2007). Synchronous online interviews involve both parties using the internet simultaneously to engage in a (text based) ‘real time’ conversation (Volda et al., 2004). For this research, instant messaging

(IM) software was used to conduct synchronous online interviews (a full description of the procedure will be provided in Chapter 5).

As already mentioned, the main advantage of online interviewing is its ability to overcome the barrier of distance (Chen and Hinton, 1999; Mann and Stewart, 2000; James and Busher, 2009). The medium also allows participants a greater degree of anonymity which may result in less inhibited responses when studying sensitive topics. Using IM also eliminates the time consuming need for transcription of the data, as a verbatim transcript is dynamically-generated in the process of conducting the interview, which can be copied and pasted into a word processing document (Chen and Hinton, 1999). It also has the added advantage of reducing the transcriber's potential 'bias' when translating an audio recording into a textual transcript (Ayling and Mewse, 2009).

Despite this, online interviewing also comes with considerable limitations. Participants need to have internet access and need to be literate. Online interviews also lack the audio-visual qualities of face-to-face interviews, typically used by interviewers to judge the participant's emotions and interpret what the participant is saying. For instance, facial expression, body language and tone of voice are absent. This makes it incredibly difficult to know if a participant is uncomfortable with a particular line of questioning and certain forms of expression (e.g. sarcasm) may not translate well in written form. Researchers also have little control over the research encounter as interviewers cannot respond to distractions in the participant's environment and may not even be aware of them (Volda et al., 2004). Another drawback is that unlike face-to-face interviews where an answer is formed out loud and initial statements are revised, IM allows participants to edit their responses before making them visible to the researcher, resulting in data which is less 'worked up'. From my experience of conducting both forms of interview it would also appear that online interviews take much longer and produce much less data (again see Chapter 5 for more detail).

Shaw (2010) suggests that the context of the research encounter and the relationship between the interviewer and the interviewee are important factors to consider when taking a reflexive approach to qualitative interview research. So here I will briefly

discuss the influence of myself and the medium of interviewing on my relationship with participants. All interviewees identified as lesbian, gay or bisexual and had been diagnosed with diabetes (see Chapter 5 for more information about the participants). As such, I held both 'insider' and 'outsider' positions as the interviewer. As a gay man, my non-heterosexuality may have conferred an insider status, however I have not been diagnosed with diabetes and may variably been considered an outsider based on my gender, age, nationality and so on. Early second wave feminist researchers such as Ann Oakley (1981) have commented on the benefits of being an insider when interviewing and LGBTQ researchers have also pointed to the benefits of having a shared non-heterosexual identity with participants (LaSala, 2003). Gillian Dunne (1997), for example, argued that her lesbian identity was crucial in establishing the trust that is necessary when conducting sensitive research with other lesbians. In particular, a key benefit of having an insider status is a sense of empathy, based on shared experience that can facilitate a rapport with interviewees (Lee, 2008). Establishing a shared identity in order to gain trust may be even more important when conducting interviews online, where the researcher is invisible and there is little opportunity for the interviewee to 'get to know' the researcher prior to the interview as illustrated in the following excerpt:

Vanessa:

Hey, do you mind me asking if you are 'family'?
Are you interested in doing research in the LGBT community because you are one of us or because you are coming from an academic interest?
if I have crossed the line, no prob
"feel free not to answer any questions"

Adam:

Oh yes, I'm gay.
[omitted text]

Vanessa:

Well, we don't have to worry about understanding each other on that score

Adam:

Yeah sure

Vanessa:

I appreciate your openness...it can be a little spooky wondering if there is homophobia lurking around

Adam:

Yeah totally. Sorry if I didnt make it clearer before. I have been trying to be up front with people about it

Vanessa:

It's not always easy. I am out everywhere but really we make the decision to come out in every new situation, don't we.... never really ends

It is clear here that my insider status as a non-heterosexual was important in establishing Vanessa's trust, allaying any fears that the motives of my research may be driven by homophobia. Her use of the words 'spooky' and 'lurking' might also allude to my invisibility within this context, indicating that developing trust may take on an added poignancy within this medium. Furthermore, by engaging in mutual disclosure and answering Vanessa's question, I am transformed from a faceless interviewer to 'family' (LaSala, 2003). Similarly, several other participants I met in person commented that they would not have taken part in the research had I not been openly gay.

On the other hand, my outsider positions are also likely to have influenced the kind of rapport built and the interaction produced. Unlike my sexual identity, which was deliberately disclosed in order to help build a sense of sameness with the participants, I did not disclose in advance my lack of personal experience of diabetes. Despite this there did not appear to be a presumption that I would have the condition²⁵. This may be because unlike LGBTQ research which is commonly undertaken by researchers who identify as such (Gabb, 2004), research about illness or disability is often conducted by researchers with professional knowledge of illness (e.g. health professionals) rather than experiential knowledge (Olkin and Pledger, 2003). My outsider position in relation to the condition, while likely a disadvantage in some respects may have enabled me to position the interviewees as the 'expert' in the research encounter, as advocated in experiential approaches (Wilkinson, 2004).

This chapter has located my research within a qualitative (and critical) paradigm of psychological research. It has explained that the research within this thesis can also be located within both experiential and discursive traditions of qualitative research and outlined my epistemological framework as being either social constructionist or

²⁵ Neither did I conceal the fact that I did not have diabetes. Several participants asked if I had diabetes, what my level of knowledge was regarding their condition or why I chose to interview LGB people with diabetes. The fact that I did not have diabetes invariably came to light during the interviews, if not explicitly discussed.

critical realist, depending on the particular aims of each study. I have outlined two analytic methods used within this thesis, thematic and discourse analysis and provided a rationale for the use of a multi-methods approach. Finally, I have introduced each of the methods of data collection used. I have outlined how the use of each method was informed organically by the research that preceded it and highlighted the advantages and limitations of using the internet in various ways throughout the research process. I have also been reflexive by providing information about the choices I have made throughout the research process and reflected on how the medium of the research, and myself as the researcher, impacted on the relationship formed with my participants. In each of the analytic chapters that follow, I provide more information about the participants and materials sampled, the exact procedure used and ethical considerations of each method.

Chapter 3: Exploring non-heterosexual experiences of chronic illness: an online questionnaire study

Background

This chapter will present the findings of a qualitative online questionnaire which explores the experiences of lesbian, gay and bisexual people living with a range of chronic illnesses. Currently, the education that health professionals receive routinely excludes a discussion of patient sexuality, rendering LGB people with chronic health conditions invisible and marginalised (Dibble, Eliason and Christiansen, 2007)²⁶.

To date, much of the literature about LGB people and chronic illness has sought to address this by presenting generic information about this population and considering its implications for health care (e.g. Dibble et al., 2007; Garnero, 2010). Alternatively, scholars have written from personal experience of living with chronic illness as an LGB person (e.g. Wilkinson, 1997) or from professional experience of working with non-heterosexuals (e.g. Lipton, 2004). For example, drawing largely on his clinical experience as a psychotherapist working with gay men in the United States, Benjamin Lipton (2004) asserts that HIV has become a ‘litmus test of health’ (p.5) within gay male communities and that other illnesses may be trivialized. According to Lipton, gay men with chronic illnesses other than HIV are placed to the margins of both a heteronormative mainstream healthcare system and a HIV-centric gay community.

There remains, however, a dearth of empirical research which examines LGB experiences. In one of only a handful of studies in this area, Sara Axtell (1999) conducted interviews with lesbian and bisexual women with a range of chronic illnesses including multiple sclerosis, diabetes and fibromyalgia. Axtell’s aim was to understand the ways in which these women integrated their sexual and chronic

²⁶ This likely reflects a general lack of education regarding social and cultural aspects of health within the formal training of health professionals (Loudon et al., 1999).

illness identities. Axtell reported that some participants felt that their sexuality and chronic illness intersected, while others felt that each aspect of their identity was independent of others. Participants also spoke about how their illness had strengthened their relationships with their partners. On a community level, Axtell's participants talked about lacking inclusive communities where they could be their 'whole self' and felt that they would have to create their own supportive networks. Elizabeth Walden (2009) also primarily employed qualitative methods to explore the experiences of lesbians living with chronic illness. Walden's research focused on a community support service for lesbians living with illness which Walden herself helped to create. Her research drew upon archived intake interviews, questionnaire responses from service users, in addition to research interviews with members of their support group. Many of the people using the service reported that they were not 'out' to or had a strained/non-existent relationship to their family of origin. Furthermore isolation and loneliness were identified as major motivating factors for individuals contacting the organisation. Walden concluded that the community support service provided for needs sometimes left unmet by families and health and social services as well as acting as a point of contact with the lesbian community.

So while there have been several pioneering qualitative studies conducted with LGB people living with chronic health conditions, they have relied on small samples and have thus been unable to provide a wide range of experiences. As a result, what is needed is an exploratory study that can accommodate a larger number of diverse perspectives. For this reason, I adopted a qualitative questionnaire in order to capture a wider breadth of experience (Toerien and Wilkinson, 2004) that would contextualise the more in-depth forms of analysis presented in subsequent chapters of the thesis.

Research question

The aim of the qualitative survey was to 'give voice' to LGB people living with chronic illness and was guided by the following research question; how does living with a non-heterosexual identity shape people's experiences of living with a chronic health condition?

Method

An online qualitative questionnaire was used to collect responses to open ended questions in order to collect a large number of diverse experiences and perspectives in participants' own words (Toerien and Wilkinson, 2004; Harding, 2006).

Participants

A total of 190 respondents with a chronic condition (approximately 60% of whom had more than one) took part in the study. Half ($n = 94$) of these identified as female and 44.1 percent ($n = 83$) identified as male (see Table 1). Most described their sexual identity as either lesbian (44.1%, $n = 83$) or gay (39.4%, $n = 74$) while 10.6 percent ($n = 20$) identified as bisexual (see Table 2).

Table 1: Gender of survey respondents

Gender	<i>n</i>	%
Male	83	44.1
Female	94	50
Trans male (FTM)	4	2.1
Trans female (MTF)	1	0.5
Other (e.g. 'intersex')	6	3.2

Table 2: Sexual identity of survey respondents

Sexual Identity	<i>n</i>	%
Lesbian	83	44.1
Gay	74	39.4
Bisexual	20	10.6
Other (e.g. 'queer')	11	5.9

The majority of respondents were aged over 30 years (80.8%, $n = 152$ – see Table 3). Respondents mainly resided in the USA (57.5%, $n = 107$) and the UK (36.6%, $n = 68$) with other responses from Canada ($n = 5$), Ireland ($n = 2$), Denmark ($n = 1$), Spain ($n = 1$), Australia ($n = 1$) and New Zealand ($n = 1$). The majority classified their ethnicity as 'White European'/'White other' (84.7% $n = 160$ see Table 4)

Table 3 – Age of survey respondents

Years of Age	<i>n</i>	%
18-24	14	7.4
25-30	22	11.7
31-40	43	22.9
41-50	44	23.4
51-60	48	25.5
61-70	16	8.5
71+	1	0.5

Table 4 – Ethnicity of survey respondents

Ethnicity	<i>n</i>	%
White	160	84.7
Black	2	1.1
Pakistani	1	0.5
Chinese	1	0.5
Asian other	1	0.5
Other (e.g. 'Hispanic')	20	10.6

Over half described their current occupation as ‘professional’ (51.9%, $n = 97$) while 8 percent ($n = 15$) indicated that they were retired and a further 10.2 percent ($n = 19$) specified that they were retired because of ill health or disability. It was specified that a chronic illness meant a ‘long term condition’. Overall, 52 different illnesses were provided by respondents. The five most commonly reported physical chronic illnesses in the sample were arthritis (20%, $n = 38$), hypertension (20%, $n = 38$), diabetes (15.3%, $n = 29$), asthma (14.2%, $n = 27$), and chronic fatigue syndrome (7.9%, $n = 15$ - see Table 5).

Table 5: The 10 most commonly reported illnesses by survey respondents
(see Appendix 1 for a full list of illnesses reported)²⁷

Illness	<i>n</i>	%
Arthritis	38	20
Hypertension	38	20
Diabetes	29	15.3
Asthma (moderate/severe)	27	14.2
Mental illnesses	19	10
Chronic fatigue syndrome (CFS/ME)	15	7.9
Multiple sclerosis	14	7.4
Cancer	12	6.3
HIV/AIDS	12	6.3
Osteoporosis	10	5.3

Procedure

The questionnaire (see Appendix 2) was divided into three sections. The majority of questions allowed respondents to write as much or a little as they wished (e.g. ‘In what ways, if any, has your illness affected your personal life?’). The survey was designed to allow respondents to skip any questions they did not wish to answer in order to allow people to take part without having to report anything they did not feel comfortable disclosing. Following University ethical approval, the questionnaire went live on 14 May 2008 and remained online for eight weeks. SurveyMonkey.com was used to collect the data. The qualitative responses

²⁷ The sum total of these percentages is greater than 100% because many respondents indicated that they had more than one chronic illness.

collected were typically brief, as online surveys are a limited method of collecting qualitative data because of the inability to ask participants to elaborate on their responses and the expectation that closed or quantitative questions will mainly be used (Riggle, Rostosky and Reedy, 2005). To mitigate this expectation, it was explained at the outset that they would be open-ended and that respondents could write as much as they liked. The free text response boxes were also made much larger than the standard SurveyMonkey boxes to indicate that long responses were welcome. The data collected from the open-ended questions amounted to approximately 90 A4 pages of data.

Two methods of sampling were used: strategic opportunistic sampling and snowball sampling. The strategic opportunistic sampling consisted of (1) sending a recruitment email to 22 LGBT-related online mailing lists and (2) placing an online advert on the social networking site, Facebook for five days. The email lists ranged from general LGBT-related groups (e.g. regional LGBT community electronic mailing lists) to groups with a clearer interest in the topic (e.g. LGBT health and disability lists). The majority of such lists were UK based although a number had an international membership. For email lists of which I was not a member, a message was sent to the moderator asking if they would consider forwarding on the call for participants so that they could decide on the appropriateness of the message for the list. Participants were told that the purpose of the study was to examine the views and experiences of LGB people in relation to chronic illness. The online advert placed on a social networking site was designed to target men whose online profiles indicated that they were 'interested in men' and women whose profiles stated that they were 'interested in women'. The snowballing method consisted of emailing 96 personal contacts who were asked to circulate the email among their networks as well as including a link to the survey in my email signature.

Ethical considerations

In order to ensure that respondents were fully informed, the survey began with an information page (see Appendix 2). This information was deliberately presented as concisely as possible in order to maximise the likelihood that it would be fully read by respondents. Included in this was information about myself, what the project was about, what taking part in the research would involve and details about how the

respondents confidentiality would be ensured. Information provided regarding myself included my name, my position (as a research student) and the institution which my research was affiliated with. It also stated that I am a gay man. This was included in order to allay any fears that my research might be motivated by homophobia and to suggest that they could trust that I would treat the data provided in a way that was sensitive to LGBTQ communities. It was explained to participants that the purpose of the project was to explore LGB people's views and experiences related to living with chronic illness(es). Respondents were informed that the questionnaire would consist of both multiple choice and open-ended questions. It was estimated that the questionnaire may take approximately fifteen to twenty minutes, but that this would depend on how much they wished to write. This estimate was based on a pilot survey response by an lesbian acquaintance with severe asthma. It was evident both from comments made in the final section of the questionnaire (which enabled the respondent to provide feedback on the survey) and from the detail of some of the responses that many respondents spent much longer than this completing the survey. While a more extensive piloting phase may have enabled me to provide a better time estimate, the detail provided by some demonstrates the interest these respondents had in having their voices heard.

Respondents were asked to create an identification code and to make a note of this for their own records. It was explained that should they wish to withdraw their data retrospectively, they would be able to do so by emailing me with their identification code within two weeks of submitting their responses. Respondents were assured that no explanation for withdrawal of their data was required. In terms of ensuring confidentiality, the information page stated that any responses would be recorded against a respondent number and that the full survey responses would only be viewed in their entirety by my supervisor and I. During the process of gaining ethical approval from the University ethics committee, a number of issues were raised. Firstly, concerns about the potential for data to be intercepted by third parties were raised. In order to address this, encryption software available to professional subscribers to SurveyMonkey was used to ensure a secure channel for data collection and retrieval. Secondly, the ability to guarantee confidentiality was questioned given that the data was to be held on the server of an external organisation (surveymonkey.com). For this reason, it was explained in the

information page that data would be held on SurveyMonkey's server but that SurveyMonkey guarantee that the data will be kept private and confidential. Respondents were referred to SurveyMonkey's privacy statement for further information. My email address was provided in order for respondents (or potential respondents) to contact me with any questions they may have. A separate consent page provided three statements to which respondents were required to indicate agreement with before proceeding to the survey proper. Respondents were required to indicate that they had read and understood the information provided on the first page, that they understood how to withdraw their data retrospectively if required and that they agreed to take part in the study.

Method of analysis

The qualitative questionnaire responses were analysed using thematic analysis, following Braun and Clarke's (2006) comprehensive guide comprising of six stages: 1) Familiarisation with the data; 2) Generating initial codes; 3) Searching for themes; 4) Reviewing themes; 5) Defining and naming themes; 6) Producing the report. Familiarisation was achieved by collating all responses for the open-ended questions within a word processing document and conducting multiple readings of the data corpus. The data was then coded to identify features that appeared important in relation to the research question. So here the data were coded around how sexual identity shaped experiences of chronic illness. This involved systematically making notes (key words and phrases) in the margins of the document, with the aim of being as inclusive as possible. The search for themes involved looking for connections between the codes generated and collating the coded data into provisional groups (i.e. themes). Rather than looking for themes within the responses to individual questions, themes were searched for across the data set. Again the aim was to arrive at a set of themes which identified the ways in which respondents were suggesting that their sexual identity affected their experience of illness. Once provisional themes were identified these were checked against the dataset. The extracts within each theme were re-read to ensure that there was a sufficient similarity between the extracts. At this stage, themes with considerable overlap were combined into one theme. For example, perceptions of LGBT communities as supportive and beliefs that they are prejudiced were combined into one theme as these responses were considered to be two sides of one

coin. Moreover, at times both of these perceptions were expressed within the same extract. The themes were then given names with the aim of concisely capturing the essence of the theme. At times this involved using terminology not explicitly used by the respondents themselves. For instance no respondent specifically referred to the support they received as ‘heteronormative’, yet this concept was felt to concisely sum up what was being described.

The analysis takes a critical realist epistemological standpoint as respondents’ written accounts are taken as representative of their lived ‘reality’, while acknowledging that the meanings given to these experiences are mediated by the sociocultural context (Willig, 1999). Braun and Clarke suggest that researchers should identify their research as either focusing on the ‘semantic’ or ‘latent’ level. The semantic level is described as being concerned with the surface meaning of the data, while latent level analyses aim to examine the underlying assumptions and ideologies within the data. Given that the aim here is primarily to ‘give voice’ to the respondents experiences and the responses provided were often brief, the analysis here is at a semantic level.

Analysis

In the following analysis respondents are referred to by their respondent number, sexual identity, country of residence and the illnesses the respondent specified that they were living with.

This study is based on the assumption that, while there are many issues that will be specific to individual diagnoses and specific to those who identify as either lesbian, gay or bisexual, chronically ill people who identify as LGB will also have much in common (Dimond, 1983; Anderton, Elfert and Lai, 1989). The themes that I will highlight in the following analysis are: (1) ableism within LGBT communities; (2) isolation from LGBT communities and other LGB people living with chronic illness; (3) heteronormativity within sources of information and support; and (4) homophobia from healthcare professionals.

LGBT communities: ableist or more accepting of differences?

A number of respondents expressed the view that the only illnesses that lesbian and gay communities have responded to are HIV/AIDS (and other sexually transmitted infections) among gay and bisexual men and breast cancer among lesbian and bisexual women:

In these [LGBT] communities if you don't have AIDS or Breast Cancer you don't get no respect. They are not aware or inclusive of others with disabilities in my experience! [...] they need to realise that neuroimmune disease is eating up our lesbian communities and provide the same kind of support and activism that AIDS and Breast Cancer has gotten. ME, MS, Lupus, Lyme, Arthritis, and other progressive inflammatory conditions are so very common and so ignored. (R249, white lesbian, Canada, arthritis, CFS)

Some felt that LGB people, like themselves, with illnesses other than HIV/AIDS or breast cancer were ignored within their communities and in the above statement, the respondent appears to try to frame her own illnesses as 'lesbian health issues', emphasizing a sense that in order to gain community support, a health issue must be seen as unique in some way to that community. As Epstein (2003) indicates, however, as long as LGBT communities view themselves as having distinct 'health issues' they will fail to attend to illnesses that affect a substantially large number of people within, but that are not necessarily restricted to, or more common within, those communities.

Respondents' accounts about how supportive LGBT communities are of those with chronic illnesses were mixed. Some felt that LGBT communities mirror the prejudices surrounding illness and disability found in society generally:

LGBTI communities are wilfully ignorant about chronic illness – they mirror society's attitudes that we are malingerers, whiners, people who don't take care of ourselves, or otherwise people of no value whatsoever. To become disabled by chronic illness is to cease to exist. I have been abandoned by virtually all of my LGBTI friends (including former partners) and communities. (R269, white lesbian, USA, arthritis, diabetes, liver disease +7 other health conditions)

Others commented that LGBT (although predominately gay male) communities particularly stigmatized those with chronic illness because of a culture that emphasizes bodily perfection, idealizing ‘slim’, ‘fit’ and able bodies. For example, one respondent commented about how stereotypes of gay men had presented him with difficulties:

Having to battle the cultural stereotypes that queers (especially gay men) are supposed to be the fit, buff model of health, and that “these things don’t happen to us” has been a difficult mental barrier. (R101, black gay man, USA, diabetes, sleep apnea)

Gay men in particular are bombarded with images of highly toned male physiques within the gay media and research suggests that gay men suffer greater body dissatisfaction than their heterosexual counterparts (French et al., 1996). Hanjorgiris, Rath and O’Neill (2004) have suggested that narrow concepts of physical beauty within gay male cultures may result in illness, particularly conditions which have disfiguring symptoms or treatments, being more distressing for gay men. Furthermore, Genke (2004) suggests that ageism may be more pronounced within gay male communities, further exacerbating the difficulties older gay men living with chronic illness face. A number reported feeling the need to be ‘perfect’ to be accepted within LGBT communities:

the LGBT community, feels that if you are not “perfect” then you are not worthy of their taking the time to get to know you. (R201, white gay man, USA, type 1 diabetes, kidney disease)

While many of these comments focused on gay men in particular, lesbian communities were also described as ableist:

If you aren’t able bodied, slim, athletic, and go go go, lesbians just don’t know what to do with you. (R268, white lesbian, USA, asthma, CFS, degenerative disk disease)

Such comments echo O'Toole's (1996; 2000) findings of ableism within lesbian communities. In her exploration of lesbians living with physical disabilities O'Toole suggests that disabled lesbians often feel isolated from lesbian communities, not only due to ableist prejudice, but also due to an emphasis on self-reliance and independence within lesbian communities.

In contrast to this were accounts of LGBT communities being more understanding of chronic illness than society in general. In particular, some felt LGBT communities are more accepting and inclusive of 'difference' and diversity, including differences relating to health and (dis)ability. For example:

Probably the most support that I get from the LGBT community is a sense of belonging. I identify as being a member of the LGBT community more than I identify with being a member of my chronic illness community. One thing I have found, however, is that within the LGBT community there tends to be a more compassionate understanding of individuals who are 'different' than I tend to find in mainstream society. (R387, white bisexual man, USA, arthritis, Arnold chiari malformation, degenerative disk disorder)

Contact with other LGB people has been cited as an important factor in the development of non-heterosexual identities (Markowe, 1996) and Frable, Wortman and Joseph (1997) found that having networks with LGBT community was positively correlated with lower levels of psychological distress. This sense of belonging to a community of LGBT people is often identified as a positive aspect of being LGB (Riggle et al., 2008). Similarly, Wilton (1997) suggested that lesbian communities may be better able to recognize, understand and challenge stigma associated with chronic illness given their experience of stigmatized sexual identities.

There was a sense among some respondents that LGBT communities in general are more accepting of 'difference', perhaps as a result of being treated as 'different' based on their sexuality, as suggested by Wilton (1997). Some respondents reported feeling, however, that certain sections of LGBT communities are more accepting and inclusive than others:

I think being bisexual – and identifying as such ... has put me in contact with people and attitudes that are more inclusive and supportive of differences. Bisexuals are not necessarily more knowledgeable about illnesses or disabilities but it has been my experience that when told about them they're more likely to accept and advocate ... The LGBT community is very mixed in their attitudes ... It's also broken up by gender and orientation – most gay men (with a few exceptions) seem to be very fatphobic and very nerdphobic, and to basically not give a shit about anyone but themselves. Lesbians and transmen are either very politicized and attempting to be inclusive, or apathetic and hating everyone who is different from them. Bisexual women are the most likely to be accepting of difference, although there are of course quite a few who aren't. Most of my friends are bisexual women ... And my one asexual friend (who has chronic illnesses herself and is a disability activist) has been tremendously supportive in all kinds of ways. (R213, white bisexual woman, USA, hashimoto's thyroiditis)

Here this respondent appears to suggest that she finds bisexual women as well as 'politicized' members of lesbian and trans communities in particular to be more inclusive. While lesbian and gay communities have both often socialised together, Ellis (2007) suggests that lesbians in particular have also organised politically around a feminist agenda. This respondent may be suggesting that the more politically engaged sections of the lesbian and trans community influenced by feminism and trans activism may be more committed to challenging stigma attached to chronic illness.

Isolation

Respondents commented on the many different ways their illness had impacted on their social life including relationships ending as a result of their illness, difficulties in dating and finding new relationships or sexual partners. A number of respondents with debilitating illnesses also reported, as Wilton (1997) suggested, a sense of social isolation from other LGB people and LGBT communities:

My former LGBTI communities and friends have completely abandoned me. Once you are forced to go back home to live with Mommy, you no longer exist, apparently ... The physical and social isolation are the worst aspects of being chronically ill ... An LGBTI person who has to live with his/her heterosexual family is more socially isolated than a heterosexual person in the same situation. I am completely cut off from any local community. (R269, white lesbian, USA, arthritis, diabetes, liver disease +7 other health conditions)

This respondent suggests that living with her ('heterosexual') family of origin is more socially isolating for a non-heterosexual. Much of the LGBT health literature highlights the lack of social support many LGB people receive from their families of origin and suggests that partners and friends are depended upon more for support (Aronson, 1998; Kurdek and Schmidt, 1987). Indeed Walden (2009: 565) describes this as 'characteristic of the lesbian (and gay male) experience'. By contrast, the above extract suggests that, in some cases, chronic illness may result in a disengagement from families of choice and a return to one's family of origin. Walden herself comments that estrangement from families of origin was by no means the rule among those using her organisation's support service and in some cases users of the service lived with and were dependent upon their parents, siblings or children. Although support from family members, when available, is generally considered to be positive, the extract above illustrates how an enforced dependency on one's family of origin may be socially isolating for an LGB person. Such respondents felt 'abandoned' or 'cut off' from the communities to which they once felt they belonged as their health deteriorated. This has also been highlighted by Wilkinson (1997) who, after devoting many years to AIDS work felt abandoned by the LGBT community when she developed chronic fatigue syndrome.

Another respondent commented on the difficulties of finding someone ('gay/straight') to assist them in maintaining contact with LGBT communities:

I have no social life at all, cannot go to the city without assistance cannot get to the gay area of the city ... and am totally unable to get any volunteer gay/straight to assist me to the queer quarter even to pick up a pink paper ... be gay and disabled and you find out who your friends aren't, I have NO support at all you become so very isolated, in all ways. (R273, white lesbian, UK, MS)

Again dependence on others here is described as resulting in isolation from LGBT communities. Similarly, Walden (2009) observed that visits from their lesbian volunteer care team were at times the only contact that clients would have with the lesbian community. Inaccessibility was raised by a number of wheelchair users who reported that: ‘many gay and lesbian venues are not wheelchair accessible’ (R123, black lesbian USA, hypertension, MS). Others with illnesses such as diabetes, asthma and epilepsy reported avoiding LGB venues such as bars and nightclubs for health reasons. Gay bars and nightclubs are important in the maintenance of LGBT communities. With few alternative social spaces dedicated to LGB people, such commercial venues often act as defacto community centres providing opportunities for LGB people to socialise and meet one another. Those excluded from these venues or those who wish to avoid the behavioural norms of such social spaces (e.g. alcohol consumption) may feel particularly isolated from the LGBT community (Ellis, 2007).

As well as expressing a sense of isolation from LGB people generally, some reported that their illness made them feel like a minority within a minority and felt isolated from other LGB people with their illness (see also Bennett and Coyle, 2007). For example, one respondent commented: ‘I feel like the only person with this condition amid the LGB community’ (R156, white lesbian, UK, Crohn’s disease).

A number of respondents expressed a desire to affiliate with others who shared both these aspects of their identity: ‘I have felt extremely isolated because it is very difficult to find gay people with my illness’ (R222, white lesbian, USA, autoimmune disease). Here, not knowing others who both have a chronic illness and identify as LGB was described as adding to feelings of difference and isolation. Those who had other LGBT friends with a chronic illness reported this as being particularly helpful. For example, one gay male respondent commented: ‘I receive invaluable support from LGBT friends who are diabetic and LGBT friends who are partnered with diabetics’ (R255, white gay man, USA, diabetes). A bisexual woman wrote: ‘I know many lesbians and transgendered men with PCOS, and we have provided support to each other’ (R204, Hispanic bisexual woman, USA, PCOS).

Another respondent wrote about how he and his partner's shared experiences of living with chronic illness formed a positive part of their relationship together:

My new partner is understanding about the ED [erectile dysfunction]. In fact, he has a chronic illness himself, being a Type I diabetic since the age of 9 ... I think the fact that we both have to deal with our bodies not being the way they were when they were more completely healthy is part of our bond. (R153, white gay man, USA, prostate cancer)

A number of respondents reported having used the internet to find other LGB people with their condition (or simply other LGB people with a chronic illness) and reported these networks as good sources of support: 'I am part of an online support group, of other lesbians with similar problems and they are a wonderful emotional support system for me' (R268, white lesbian, USA, asthma, CFS, degenerative disk disease). This parallels Axtell's (1999) study, in which one participant expressed desire for a community where she could be her 'whole self' and testifies to the persistence of this issue over a decade since Axtell's research. These respondents similarly desired such a network and used the internet in order to make such connections. For some, however, these groups were not as active as they would have liked:

Through the internet I have contacted a number of LGBT people with ME. We have formed our own support group online. Personally I have received a good deal of emotional support from the group and have tried to give such support in return. The group has been very inactive recently though. (R198, white gay man, UK, asthma, CFS, type 2 diabetes)

The lack of opportunities for LGB people to integrate their non-heterosexual identities with chronic illness identities has been previously noted (Axtell, 1999; Lipton, 2004; Walden, 2009). Lipton (2004: 13) comments that 'the opportunity for locating a social space that promotes identity integration and offers affirmation of both of these fundamental aspects of identity *at the same time* is generally absent for this population' (emphasis in original). While some respondents reported that they

felt no need for LGB specific support and that local support groups provided for their needs, others felt that such groups did not cater for them as LGB people as the next theme will make clear.

Heteronormative support

Few respondents (with exception to some in the USA) had access to face-to-face groups for other LGB people with their illness. While some did not feel the need for such groups, others described general illness-related support groups as groups of predominantly heterosexual people and potentially homophobic environments. Some reported that they felt unable to disclose their sexual identity for fear of homophobia. One respondent stated that this was because of the age of many people with her illness: 'I find many people with my condition are older and have therefore not felt very comfortable in being out to them' (R53, white lesbian, UK, colitis, hypothyroidism). Another stated that the perceived need to conceal her sexual identity meant that, for her, such groups were:

just another oppressive atmosphere that adds to my stress, and doesn't help enough to counteract it. So unless they are lesbian/gay focused, they are not helpful to me. (R268, white lesbian, USA, asthma, CFS, degenerative disk disease)

For others, perception of support varied depending on the particular group. For instance, one respondent reported that she had felt comfortable in a previous local support group, but feels uncomfortable in the group she currently attends:

I am also part of a support group at my hospital. I was part of another group there that recently folded. I was comfortable in the old group and was free to come out even though I was the only queer person in the group. I'm not comfortable at all in this new group. (R163, white lesbian, USA, arthritis, cardiovascular disease, coronary heart disease, diabetes, hypertension, liver disease, congenital generalized lipodystrophy).

For those who perceive support groups as presumed heterosexual and potentially hostile environments, the intended aim of fostering feelings of being understood and relating to each others' experiences are unlikely to be achieved. Some reported that

the predominantly heterosexual membership of support groups did not share the same concerns as themselves, which made such groups unappealing and limited their ability to address their needs: ‘PCOS communities are full of straight women who discovered they have PCOS when they were trying to get pregnant. Totally unappealing to me’ (R204, Hispanic bisexual woman, USA, PCOS).

Other distinctions that respondents made included female partners’ supervision of men’s health within heterosexual relationships and female partners being more vocal than men within ‘straight’ or ‘mixed’ support groups²⁸:

The culture difference between gay and straight makes it hard for us to mix with them in support groups. For instance many Straight men with diabetes don’t cook for themselves so they aren’t really involved in their own dietary needs and view their ‘wife-mommy’ as the one who feeds them and selects their diet. Gays and lesbians don’t live in these kind of gender role play acting ways. (R157 white gay man, USA, arthritis, asthma, diabetes, hypertension, chronic pain)

Interestingly, in the network in which my [gay specific] support group met, we found that when any of us went to the straight or mixed support groups, the straight men generally seemed much more reticent to speak in the groups. Their wives were generally the vocal ones, asking questions and sharing. In the gay group, we, the patients, were much more active for ourselves. (R153, white gay man, USA, prostate cancer)

A number of respondents also described other forms of support, such as written information in books, magazines and illness-related charity websites as heteronormative in their assumption that the reader is heterosexual. This was most commonly reported about sources of information addressing sexual problems related to illnesses, for example:

Most of the books I read were not very inclusive. Sexuality was presumed to be hetero, and, of course, many special issues were thus not even contemplated

²⁸ Issues raised here regarding differences between same and different sex relationships will be elaborated on in Chapter 5.

(e.g. the additional degree of hardness one needs to penetrate an anus, as opposed to a vagina, the nonprocreative meanings of semen, etc.). (R371, white gay man, USA, prostate cancer)

Others also commented that they felt that LGB people were invisible within written resources. For example, one respondent with asthma stated:

I read Asthma UK magazine and to be honest I have never seen info specific to LGBT people. It seems sadly that only diseases/medical conditions associated with gays etc such as STDs/AIDS are inclusive or target sexual identity. This is very negative and not supportive for those of us LGBT with chronic conditions. (R127, white gay man, UK, asthma)

Lipton (2004: 9) suggests that illnesses, other than HIV, tend to be 'heterosexualized'. By this he means that the language and iconography used by mainstream medical services and illness charities routinely marginalise non-heterosexuals. Culturally available illness narratives, for instance those available in the genre of illness (auto)biography, are also invariably heterosexual narratives (Wilkerson, 2003)²⁹. One respondent highlighted that 'minorities' are only catered for by mainstream support organizations and charities if those minorities have a higher incidence of the illness while others are ignored. He specifically pointed out that while diabetes charities target support at ethnic minorities and cater for them specifically there is no such support available for LGB people with the illness:

A large diabetes support community does exist, but they do so to the exclusion of other types of identity (such as sexual identity) UNLESS there is a higher incidence of diabetes, as within ethnic groups. (R245, white bisexual man, USA, type 1 diabetes, hypertension).

Heterosexism and homophobia from healthcare professionals

As well as reporting heteronormativity from sources of support, a number of respondents recounted experiences of homophobia from healthcare professionals.

²⁹ Audre Lorde's (1980) *Cancer Journals* is a notable exception which also illustrates how support for people with illnesses (in this case breast cancer) is shaped by a dominant white and heterosexual culture.

One such respondent stated that: ‘homophobia is still an ever present reality’ (R80, white Queer, UK, arthritis, hypertension, dermatitis, diverticulosis).

These experiences mainly took the form of healthcare professionals informing the respondents of their anti-LGB views. For example, one respondent described negative experiences with a number of nurses, stating that they had: ‘felt entitled to pronounce judgementally about my lifestyle at a point when I am feeling physically unwell and, therefore, vulnerable’ (R386, white gay man, UK, arthritis, colitis, kidney disease).

Such experiences took place in a number of contexts, including doctors’ surgeries, hospitals and for one respondent, in their own home:

Homophobic doctors are a nightmare! I always disclose my sexual identity to my medical community and healthcare professionals who have not dealt with their homophobia make me very uncomfortable. I also had an agency appointed homecare worker for almost six months and it was a terrible and very disempowering experience. This homecare worker constantly made disparaging remarks in my home and it was difficult for me to finally make a complaint against her. I was afraid I might lose my homecare benefits or get someone else who was worse. (R279, white lesbian, Canada, arthritis)

Such statements concur with the findings of other studies that suggest that despite wider changes in attitudes to LGB people, homophobia in healthcare provision is still a reality (Beehler 2001; Eliason and Schope, 2001). The above extract also draws attention to the fact that while most research has focused on LGB people’s experiences of healthcare professionals within healthcare settings (e.g. doctors’ surgeries and hospitals), those with chronic illnesses who require home care may also experience homophobia in their own home. Another issue raised by a lesbian with 11 different illnesses (R269, white lesbian USA) was that unlike LGB people generally, those living with a number of chronic illnesses have contact with a greater number of healthcare professionals, which she described as ‘upping the odds’ of coming into contact with professionals with anti-LGB views.

Even those who have not experienced homophobia from healthcare professionals, may have concerns about such a possibility. Indeed a small number of respondents reported not disclosing their sexual identity to healthcare professionals for fear of a homophobic response and its possible implications for the care they receive, for example:

I have not discussed my sexual identity with any healthcare official associated with my diabetes care. This is because I fear their reaction and how it might affect my care. (R255, white gay man, USA, diabetes)

Of those who had chosen to actively disclose their sexual identity to healthcare professionals, some reported doing so specifically to ‘test’ that a healthcare professional would be comfortable with this and to evaluate their risk of encountering discrimination:

It’s very important that I’m sure they will be ok with my orientation ... The only way to test them is to come out right away and watch them. Otherwise you’re not safe. (R157, white gay man, USA, arthritis, asthma, diabetes, hypertension, chronic pain)

There were, however, also comments about respondents’ positive experiences with healthcare professionals who knew their sexual identity, for example: ‘Most of my gynecologists [related to her PCOS treatment] have been very supportive and have been helpful when I tell them I’m queer’ (R204, Hispanic bisexual woman, USA, PCOS). A number specifically made a connection between their positive experiences and their geographical location:

I’ve had a lot of positive experiences with healthcare professionals. We live in a queer area, I’ve had surgeries here and my partner has always been welcomed and treated as my partner and we did not need to ‘prove’ our relationship status. (R160, white Queer, USA, hypertension, endometriosis)

One respondent also referred to gender, ethnicity and affluence as reasons for his positive experiences of healthcare:

All of my experiences with healthcare professionals have been positive. I am an affluent white male, and so am privileged to be able to afford adequate health insurance, and can choose my doctors. (R364, white gay man, USA, hepatitis C)

So while positive experiences were not uncommon among the sample, many of such respondents positioned themselves as 'privileged'. Another reason provided for positive experiences were as a result of having sought or happening to have healthcare professionals who themselves identify as lesbian, gay or bisexual:

I was able to find a gay male GP in the last few years and that was an incredibly positive experience. (R279, white lesbian, Canada, arthritis)

I have been treated by a man who is a gay physician and he is sensitive to the issues that are faced by LGBT individuals. However, many of my other physicians are not and often discussing general health issues becomes uncomfortable. (R387, white bisexual man, USA, arthritis, arnold chiari malformation, degenerative disk disorder)

A few also described belonging to 'LGBT health practices' or finding doctors that advertised themselves as 'queer friendly'. So while experiences were both positive and negative, respondents were often able to articulate ways in which concerns about heterosexism influenced their views of the health care they receive.

Summary

In this chapter I have highlighted some of the ways that sexual identity may shape one's experience of living with a chronic illness. Despite the respondents living with a myriad of different illnesses, being of different genders, identifying their (non-hetero)sexual identity in various ways and living in different countries, their experiences have much in common. What unites them is not 'epidemiological similarity', but common experiences of oppression, invisibility and isolation (Epstein, 2003). Respondents expressed differing perspectives as to how supportive LGBT communities are of people living with chronic illness. Respondents

highlighted the way in which LGBT movements frame health and illness and felt that those whose illnesses are not currently considered ‘gay/lesbian health issues’ feel invisible within and ignored by LGBT communities. Respondents in this study described feeling isolated from other LGB people with their condition, did not feel that support groups with a primarily heterosexual membership adequately addressed their concerns and many expressed a desire to affiliate with others like themselves. The responses presented in this chapter also highlight that some LGB people feel that their concerns are not represented in published information about their illness, and continue to experience or fear homophobia within healthcare services. The next chapter will continue with the themes of seeking support from others who share these two identity positions as people who are not heterosexual and are living with chronic illness, as well as heterosexism within sources of support. In particular, the focus turns to online forms of support.

Chapter 4: Online support seeking

In the previous chapter we saw how survey respondents reported using the internet to find other LGBTQ people with their illness(es). This chapter is concerned with non-heterosexual people seeking support online from other non-heterosexual people affected by a chronic health condition. First I provide some background on the topic of online support seeking, which has become a fast growing area of research in health psychology (Coulson, 2008). I then introduce a form of health-related online support seeking that has been significantly under researched – health-related support groups specifically for LGB(TQ) people. I then examine in-depth, using discourse analysis, one thread of an online discussion in which a ‘gay diabetic’ seeks the support of other gay diabetics within a generic diabetes discussion forum.

Background

For over a decade increased access to the internet has led to a proliferation in the number of online networks for individuals living with similar health concerns (Wright and Bell, 2003). These networks have taken the form of bulletin boards, newsgroups, online discussion forums and electronic listservs. For instance Yahoo! Groups, which is one of the world’s largest collections of online groups (and a hybrid between email lists and online forums), currently has 12,024 ‘support’ groups³⁰ within its category of ‘Health & Wellbeing’. Such groups allow individuals to engage in ‘supportive’ computer-mediated communication with those living with similar health conditions. There is also a growing body of research which examines health-related ‘online support groups’ (see Wright and Bell, 2003 for an overview). It has been noted that some chronic illnesses are better represented among available online support groups than others (Davison, Pennebaker and Dickerson 2000; Ferguson, 1997). For instance cancer in particular appears to attract the largest number of support groups (both online and face-to-face), followed by illnesses such as CFS, MS, and diabetes (Davison et al., 2000). A number of advantages in this form of support have been noted (Wright and Dorman, 2001; Wright and Bell, 2003). These include their ability to overcome geographic and temporal limitations

³⁰ Of course some such groups will be more ‘active’ than others.

of face-to-face support groups and the anonymity that the medium affords individuals when discussing sensitive issues related to health and illness. It has also been suggested that the lack of social status cues fosters more heterogeneous supportive relationships. To date, within the research literature there has been a greater emphasis on the strengths and potential benefits of such computer-mediated support groups than their weaknesses and potential problems (Pitts, 2004). One problem identified is that such online groups tend to be, what has been referred to as 'weak-tie' networks, rarely fostering long term supportive relationships (Wright, 2000)³¹. Another problem associated with the medium is that the lack of physical presence, social obligations and the greater potential for misunderstanding may lead to a more inflammatory and hostile interaction (known in internet slang as 'flaming') (Alonzo and Aiken, 2004; Oegema et al., 2008).

Just as computer-mediated groups have developed with the aim of providing support for those with health-related concerns, so too have online networks developed to provide support for LGBTQ people (Correll, 1995; Haag and Chang, 1997; Shaw, 1997; Burke, 2000; Campbell, 2004). LGBTQ people may similarly not be readily identifiable to one another and meeting in person may be particularly difficult for those residing in rural areas or those too young to attend social spaces typically catering for LGB people such as bars and nightclubs (Burke, 2000). The anonymity offered by computer-mediated communication may also be particularly desirable for those who are not open about their sexuality or who are in the process of coming out (Haag and Chang, 1997; Burke, 2000). Although it would appear that people join online LGBTQ groups and websites for a wide variety of reasons, existing research has largely focused on gay men's (and to a lesser extent lesbian women's) use of the internet to find sexual partners (e.g. Horvath, Bowen and Williams, 2006; Bolding et al., 2007). There are however, a plethora of online LGBTQ communities that cohere around a wide variety of topics.

A search of Yahoo! Groups revealed that 42 groups existed for LGB(TQ) people affected by chronic health conditions other than HIV with a combined membership

³¹ Wright and Bell (2003) also note a number of benefits in having 'weak-tie' forms of support. For instance, disclosing certain information with stronger ties (e.g. family members) may be more risky (e.g. it might have unwanted consequences for the relationship) when compared to disclosing the same information to a relative stranger.

of 1872 members³². In total, 18 groups were related to various forms of cancer. In terms of specific conditions, diabetes and multiple sclerosis attracted six groups each, closely followed by breast and prostate cancer which both attracted five groups (see Table 6).

Table 6: Illness-related Yahoo Groups for LGBTQ people

<i>Illness</i>	<i>n</i>	<i>%</i>	<i>Women only</i>	<i>Men only</i>
Diabetes	6	14.3	1	3
Multiple Sclerosis	6	14.3	3	2
Breast Cancer	5	11.9	5	-
Prostate Cancer	5	11.9	-	5
Cancer (general)	5	11.9	1	1
Chronic illnesses (general)	5	11.9	4	1
Chronic Fatigue Syndrome	3	7.1	-	2
Chronic pain	2	4.8	1	-
Testicular Cancer	1	2.4	-	1
Lung Cancer	1	2.4	-	-
Colon Cancer	1	2.4	-	-
Renal disease	1	2.4	-	-
Polycystic ovarian syndrome	1	2.4	1	-

These illnesses mirror those for which online support groups are most prevalent generally (Davison et al., 2000). However, to my knowledge, no research to date has examined such specific health-related online support seeking, nor any has any research examined non-heterosexuals' experiences of the conditions which attracted the largest number of groups (i.e. diabetes and MS).

The descriptions provided by the moderators of these groups, on their homepages, are intriguing and may provide some indication as to why such specific support seeking occurs. Some contain brief descriptions of the intended membership and purpose of the group, for example; 'Online discussion and support group for queers with cancer'; 'Gay men who identify as bears discuss diabetes and diet'. Others provide more extensive descriptions which include information as to why the group

³² The terms 'gay', 'lesbian' and 'bisexual' were used in combination with the 52 chronic health conditions reported in the online survey to search for such groups.

was created, details of associated organisations and information about the creator themselves. Not all are exclusively for LGB(TQ) people with these conditions but also those whose lives have been indirectly affected; for example, one group exists for LGBTQ parents of children with cancer and two exist for partners of gay men with cancer. Many are single sex groups (31 out of 42), in particular those for gendered conditions such as breast cancer, PCOS, prostate cancer and testicular cancer. However this does not necessarily preclude same sex partners of those with these conditions using the forum, and some actively welcome such participation.

While research on the nature of online social support remains in its infancy, some have suggested (often based on content analyses of online messages) that the main forms of support given or received are informational and emotional support (Ravert Hancock and Ingersoll, 2004; Coulson, 2005; Gooden and Winefield, 2007). Interestingly, several of the LGBTQ groups actively discourage informational support, for example one group description stated that the group was ‘not a place for medical advice’ and advised men to ‘consult with your medical consultant or clinician for proper treatment and health advice’. Such a statement resonates with concerns about the dissemination of inaccurate medical information within patient-led online support groups and is in contrast to those who believe that online groups have a self-correcting mechanism for misinformation and welcome the democratisation of medical information as empowering (Ferguson, 1997; Burrows et al. 2000). It is not clear from group descriptions that LGBTQ people felt that they had specific informational needs with regards to their conditions. Although a number of groups spoke of LGBTQ people having ‘unique’ or ‘special’ needs, exactly what these might be remain unspecified, for instance; ‘Gay men with testicular cancer have special needs and need a special place to discuss those needs’.

Rather, the groups are generally described as intended to provide emotional support and to discuss the social aspects of illness. For example one MS group describes itself as a ‘discussion group for gay and bisexual men with MS who wish to discuss matters beyond diagnosis and medication but how MS is affecting their gay lifestyles or related matters whether world affairs or relationship problems’. Relationship issues are commonly suggested as a possible discussion point; for instance one description states ‘we help one another with questions about treatment,

lovers, partners and life'. Another group for prostate cancer focuses exclusively on sexual dysfunction, describing itself as a 'place for gay and bi males to express their inner feelings about their inability to get an erection'. Other topics mentioned include, finding 'good doctors', illness management when socialising on the commercial gay scene, and 'coming out' to partners about their illness. Others suggest that being non-heterosexual creates 'additional challenges' to those already faced when living with a chronic health condition.

As conveyed by survey respondents in the previous chapter, many of the group creators express a sense of isolation in their group descriptions and emphasise the need to 'connect' with others like themselves. Several descriptions tell of the creators' unfruitful search for a support group which specifically caters for LGB(TQ) people living with their condition; 'Once diagnosed with breast cancer I set out to find a support group that would represent myself, a lesbian with breast cancer. None existed hence this support group's creation'. These groups are often also described as safe spaces where chronically ill LGBTQ people can be themselves and speak freely, without fear of homophobia. For example one moderator describes their group as a place to 'share with others the challenges faced in relationships and other areas of life as a result of living with a chronic illness, without homophobia and other prejudices'.

This last point, led me to wonder if there are LGB people who seek support from other non-heterosexuals within generic online support groups (i.e. those not specifically for LGB people) and the possibility of a negative reception from other group members.

Research questions

In examining the single online discussion thread that is the focus of the remainder of this chapter, my analysis was guided by a number of research questions. Firstly, how is sexual identity being policed within this diabetes discussion thread? Secondly, how is the (ir)relevance and (in)appropriateness of (non-hetero)sexuality to a discussion forum about diabetes worked up and challenged? And thirdly, in

doing so, how is sexual identity and diabetes socially constructed within the discussion?

Method

Procedure

The terms ‘gay’, ‘lesbian’, ‘bisexual’, ‘sexual orientation’, ‘sexual identity’ and ‘queer’, in combination with chronic illness terms generated from the online survey, were used as search terms and were entered into the internet search engines such as Google and Yahoo. The selection criteria for the material were that the discussions involved interactions about (non-hetero)sexual identity and a chronic health condition other than HIV and that they occurred in an openly accessible newsgroup or discussion forum³³ (I shall discuss the ethical considerations of this below). A number of instances were found where sexual identity was a topic of discussion within newsgroups for people with a particular illness; however a single case (i.e. a single discussion) was chosen for detailed analysis. A single case approach is well suited to a fine-grained discursive analysis as well as to exploratory qualitative research (Antaki et al., 2006). Furthermore, Veen et al. (2010: 27-8) suggest that a single case analysis is ‘best suited to providing the groundwork for revealing participants’ understandings of the norms and rules that are at play in interaction’. The thread selected for analysis was chosen for a number of reasons. Firstly, and perhaps most pragmatically, this thread contained the largest number of messages (306 posts, by 41 authors). Secondly, the thread captures a ‘naturally occurring’ discussion about the relevance and appropriateness of sexual identity for an online discussion group for people with diabetes, which closely related to my research question. The discussion was copied into a word processing file, with the formatting as well as spelling, grammatical errors retained. At this point, posters³⁴ were given pseudonyms³⁵ and anything within the content of the posts which could be used to identify them or the particular newsgroup were changed.

³³ Although a ‘newsgroup’ and a ‘discussion board/forum’ are technically different, they are functionally very similar, and therefore for I shall use these terms interchangeably.

³⁴ In this chapter I refer to the people posting messages online as ‘posters’ rather than participants as they were not intentionally participating in my research, nor was their consent obtained.

³⁵ Pseudonyms were chosen to reflect the gender, or gender neutrality of their online names. Signatures which composed of a combination of letters (perhaps initials) were replaced for different letters.

Material used

A 'thread' refers to a collection of posts on a specific topic within an online discussion forum. Anyone participating in online forums who wish to introduce a new topic for discussion can do so by starting a new 'thread' and providing the first message. The discussion thread selected for this analysis was created in the year 2000 within a publicly accessible newsgroup for people with diabetes and was entitled 'gay diabetics'. The nature of this kind of research is such that socio-demographic information of those involved in the discussion is largely unknown. However it was clear from posts that the discussion included individuals both from the US and the UK. The newsgroup was a mixed-sex group for people with any type of diabetes. The gender of posters was largely indicated by their online names (of which there were approximately equal numbers of men and women), although gender-neutral nicknames were at times used. Their type of diabetes was sometimes indicated within their posts or as part of their online signature (e.g. Beryl, type 1). A small number of those involved in the discussion identified themselves as gay within their posts, while others indirectly indicated a heterosexual identity or heterosexual behaviour (as discussed in more detail within the analysis itself).

Ethical considerations

While online interaction occurring in online discussion forums are a rich source of data for qualitative health researchers, the ethics of observing and using such interactions as data has been hotly debated among social scientists (King, 1996; Eysenbach and Till, 2001; Sixsmith and Murray, 2001). The use of the internet certainly presents qualitative researchers with new ethical considerations. For instance, some researchers believe that using pre-existing online interactions from discussion forums may be considered a violation of privacy and that informed consent should be gained by those who contributed (King, 1996). Others, such as Seale et al. (2010: 598), however vehemently disagree and 'take the view that these messages are in the public domain and that their research use does not require informed consent or ethical review'. At the heart of this debate is what counts as 'public' and what is 'private' online. I took the view that online material, which is accessible without any need to sign up or subscribe and could be viewed by anyone

browsing the internet could be deemed public³⁶ and therefore does not require informed consent.

The BPS's (2009: 9.1) *Ethical Principles for Conducting Research with Human Participants* states that 'observational research is only acceptable in situations where those observed would expect to be observed by strangers'. The multi-party and anonymous nature of internet forums means that posters can indeed expect their posts to be read by strangers. In fact, when reading internet posts, it becomes clear that posters orient towards addressing a group of strangers. Even when replying to a particular post, this is done within a context whereby it is normatively acceptable for others to read and respond to it. However, as the public/private nature of such material is a matter for debate among social scientists I did subject my research plan to ethical review by the University ethics committee (as advocated by Coulson, 2005). In addition, I chose a thread which had been inactive for a prolonged period of time (since 2000)³⁷. In line with other psychologists using online discussion as data, I have also chosen to give posters pseudonyms and not identify the particular newsgroup under discussion (Gavin, Rodham and Poyer, 2008; Horne and Wiggins, 2009).

Method of analysis

To analyse this material I use a form of discourse analysis which combines the insights of conversation analysis (CA), discursive psychology and Foucauldian discourse analysis. Most research using, and theories about, computer-mediated communication have been based on realist and cognitivistic frameworks. However, Lamerichs and te Molder (2003) have argued that these previous approaches do not fully recognise the 'social' nature of online interaction and offer a discursive psychological approach to computer based communication. While some forms of interaction are more commonly used for discursive analyses than others, in principle discourse analysis can be applied to any form of text (Wetherell and Potter, 1987). There has also been a proliferation of research within health psychology which has

³⁶ This is indeed the distinction that Yahoo! Groups appears to make, with those groups which do not require the user to sign up being explicitly labelled 'public'.

³⁷ This decision was made in light of such a suggestion being made by the ethics committee that reviewed Coulson's (2005) research.

adopted discourse analysis (e.g. Radley and Billig, 1996; Wilkinson, 2000a, 2000b; Wilkinson and Kitinger, 2000; Wiggins, Potter and Wildsmith, 2001; Burns and Gavey, 2004; Seymour-Smith and Wetherell, 2006) including its application to computer-mediated communication (e.g. Lamerichs and te Molder, 2003; Snejder and te Molder, 2004; Kokkonen, 2009; Veen et al., 2010).

I describe my approach here as a combination of ‘discursive’ approaches as I pay analytic attention to the sequential qualities of the posts as with conversation analysis (Hutchby and Wooffit, 1998; Antaki et al., 2006), the rhetorical features of interaction as with discursive psychological analysis (Billig, 1991; Edwards, 1997) and also the wider cultural constructions within discourse as with Foucauldian discourse analysis (Parker, 1992). As already mentioned, my original interest was how sexuality might be ‘policed’ in generic online support groups and how heterosexism might manifest itself. When reading the specific thread selected, I also became interested in the way in which seeking support specifically from other ‘gay diabetics’ was treated as an accountable matter, which becomes evident when examining the sequential structure of the interaction (Antaki, 2006). The thread selected for analysis is an example of argumentative discourse (Billig, 1991) and I was also interested in the way in which posts appeared designed to undermine alternative versions of what the original poster wanted or was ‘doing’. I was interested in the various explanations offered for why specific support seeking is, or is not, necessary and the various ways in which sexuality was constructed within the discourse.

Analysis

‘Gay diabetics’: the thread

The thread selected for analysis was entitled ‘Gay Diabetics’ and begins with a poster enquiring if there were other gay diabetics reading the thread. The post resulted in considerable discussion and debate with the thread containing a total of 306 messages. It is worth noting from the start that it is not always possible to discern the gender or sexuality of the contributors to the thread. Some of the discussants chose gender neutral nicknames (or did not provide a name at all) and only a minority of the posters explicitly identify their sexuality within the posts

themselves. This is not problematic if we take the stance of a conversation analyst; that identity categories such as gender or sexuality should not be treated as relevant by the analyst unless treated as such within the interaction itself (Kitzinger, 2000). I thus adopt this position and only make analytic reference to a poster's gender or sexuality when made relevant by the poster themselves.

The opening post: a request for other gay diabetics

To begin, let us examine the opening post which sets the scene for the rest of the discussion³⁸:

Extract 1

1. Are there any other gay diabetics out there? There doesn't seem to be
2. _any_ info out there concerning issues specific to us. I'd be
3. interested in talking with others.
4. Thanks.
5. Rbz
6. For the flamers: I've been reading this newsgroup on and off
7. since 1992, I work in a computer business, I've edited Netiquette FAQs,
8. I have a shelf of Miss Manners books, and we're simply _not_ going to
9. agree on the appropriateness of this post. I think it is appropriate
10. for this newsgroup, and I ask you to extend the courtesy to the other
11. members of not posting a series of flames.

From discursive psychological and conversation analytic (CA) perspectives, there is a lot that could be said about this opening post alone³⁹. I would like to highlight a number of features. Firstly, we can see that the initial message opens with the first part of what a conversation analyst would describe as an 'adjacency pair' (Sacks, Schegloff and Jefferson, 1978; Hutchby and Wooffitt, 1998). These are turns that require a particular kind of response; for example an invitation requires an acceptance or a rejection. Here we have a question, and questions call for answers.

³⁸ Posts are presented as originally displayed, including spelling errors and formatting.

³⁹ Antaki et al. (2006) devote their entire analysis to an initiating message and a single response in their application of CA to online forum communication.

This question alone achieves a number of interactional activities. In asking if there are ‘any *other* gay diabetics out there’ (line 1) the poster identifies him/herself as a ‘gay diabetic’ and addresses the question to the thread’s unknown readership (‘out there’). The desired next speaker is also implicitly nominated. The question is formulated as requiring a yes/no response. We would therefore expect a ‘yes’ response to come from someone also identifying themselves as a gay diabetic. Alternatively, a lack of response should be sufficient for an answer in the negative. We would not anticipate, for example, someone to respond by stating that none of the readership (who by the nature of the medium is unknown) identifies as gay. The relevant speaker to the next part of this adjacency pair should then be, we would assume, a ‘gay diabetic’.

The writer of this post then addresses other gay diabetics by stating that there appears to be no information available which is specific to ‘us’ and states that they would like to talk to other people who identify as such. However, after signing off with a gender ambiguous online nickname (lines 4-5), the writer offers a postscript addressed to ‘the flammers’ (line 6). A ‘flamer’, within internet slang, is someone who ‘flames’ – that is, posts hostile messages (Alonzo and Aiken, 2004). In lines six to eight, Rbz provides a four part list of credentials functioning to position him/herself as qualified to determine the ‘appropriateness’ of the message, about which it is stated that the flammers and him/herself are ‘simply not going to agree’ (lines 8-9). This is an ‘end of story’ type formulation which appears designed to foreclose any debate, suggesting that to engage in such further discussion would be futile (Speers and Potter, 2000). Thus, within this postscript, Rbz displays an orientation that others may potentially deem the post inappropriate. Rbz also orients to the writing of such a post as an accountable activity within this environment and attempts to forestall criticism before it occurs pre-emptively providing a negative category (a ‘flamer’) for any undesired response.

The first response: contesting the relevance of sexuality

Extract 2

In response to Extract 1

1. What in the hell does being Gay have to do with diabetics, Does your
2. sexual preference in someway increase/decrease the effects of diabetes??
3. What next??
4. Are there any other diabetic pedophiles out there??
5. Are there any other diabetic necrophiliacs out there??
6. How about are there any one legged, red haired, blue eyed, diabetic,
7. hermaphrodite out there??
8. What possible diabetic problems are specific to Gays that are not a concern
9. to us all no matter out sexual preference??
10. Personally I think this is a troll (Yes I took the bait) by someone wishing
11. to push his/her gay agenda..
12. What a crock of crap.
- 13.
14. OtherOne

The writer of this post can be seen as undermining the relevance of the original poster's sexuality through ridicule. He does this by providing alternative hypothetical versions of the original question (lines 4-7). The first two of which substitute 'gay' with paraphilias (paedophilia and necrophilia) and the third with a person non-normatively sexed⁴⁰, drawing on heterosexist discourses of lesbians and gay men as sexual and gender deviants (Peel, 2005). This hypothetical framing works on the assumption that the reader accepts these alternatives as being of a similar nature to the original while at the same time unthinkable and/or unacceptable. The third combines this with a list of other attributes to position the original post as being highly specific (lines 6-7). By providing three of these hypothetical alternatives, repetition is used to emphasise the argument (and double question marks are used to similar effect).

⁴⁰ It is worth noting that the term 'hermaphrodite' is a term which intersexed people themselves commonly find offensive.

The message ends by attending to the interactional business of accounting for this response. The non-conformity of this reply to the required yes/no response structure of the original post (Raymond, 2003) together with its hostile tone immediately lays itself open to being characterised as one of the ‘flamers’ of which Rbz anticipated. Moreover, the post shares another feature of what Rbz pre-emptively suggested a flamer might do – disagree about the appropriateness of the post. OtherOne’s pre-emptively characterised position as a ‘flamer’ is responded to in the form of a reciprocal insult exchange by characterising Rbz’s post as a ‘troll’. Herring et al. (2002: 371) explain that a ‘troll’ is a post⁴¹ that ‘baits and provokes other group members, often with the result of drawing them into fruitless argument and diverting attention away from the stated purposes of the group’. By positioning the original post as a ‘troll’ OtherOne provides a counter negative characterisation and re-positions the response as exactly what the original poster wanted (‘yes I took the bait’⁴², line 10).

Note that in line one, OtherOne addresses the response to the original poster. However, by line 10 the post addresses the wider readership of the forum in speaking *about* the original poster (referred to as ‘someone’). Billig (1991) has observed that anti-Semitic conspiracy theorists rarely direct their arguments at the ‘conspirators’ themselves, as they should already know about the conspiracy. Similarly, Herman (1998) has noted the conspiratorial quality of the ‘gay agenda’ discourse drawn upon here⁴³. So here we see that this reply is designed to undermine the original post to anyone else who reads it. While both of these two posters adopt gender-neutral/ambiguous nicknames, with the exception of Extract 2 in which the unknown gender of the poster is highlighted (‘his/her’, line 11) other forum participants, as we will see, orient to both of these people as being male.

⁴¹ Herring et al. (2002) note that the word ‘troll’ is often used interchangeably to refer to a person who ‘trolls’ or to the posts of a ‘troller’. Here I use the word ‘troller’ to refer to the person category in line with Herring et al. although it is not immediately clear in which way OtherOne uses the term.

⁴² The term ‘troll’ purportedly originates from the method fishing in which bait is attached to a line which is drawn through water behind a boat (Herring et al., 2002). Rather ironically (particularly considering OtherOne’s subsequent accusations in Extract 5b lines 14-15), the term ‘troll’ was also once gay slang meaning to cruise for sex (Online Etymology Dictionary, 2010).

⁴³ Alan Sears and Craig Osten, conservative Christians and authors of the book *The Homosexual Agenda* (2003), have described the first aim of this said agenda as being to ‘talk about gays and gayness as loudly and as often as possible’ (Winn, 2003).

Re-establishing relevance: the use of ‘Second Stories’

Let us now consider the subsequent post in the thread, which does not occur until three months later:

Extract 3

In response to Extract 2

1. Well this was a thread from many months ago, but I see the poster's point
2. in that he might want to find support from other gay diabetics. I can
3. empathize because when I was first diagnosed the only other people I
4. found in a diabetic support group were all overweight middle aged people
5. Went to another support group, the people there were ancient! Left me
6. wanting to find others in their teens and early twenties going through the
7. same thing. At that time, I felt like a weirdo, I didn't know anybody my age
8. with diabetes save for my best friend. It can be lonely give the guy a
9. break
10. Beryl, Type I (Humalog and Ultralente)⁴⁴

Within a face-to-face conversation, a lack of uptake by other speakers or a topic change would usually indicate the end of a discussion. Although an online discussion operates in a very different time frame, Beryl's opening reference to the period of time between the last post and her own contribution orients to an understanding that adding to the discussion after such a considerable period of inactivity is in some way non-normative and the discussion may be deemed over. The post is not a response to the original message, but is a counter to the first reply (Extract 2) and is designed to re-establish the original post as relevant and appropriate to the forum.

Firstly, I would like to draw attention to the way in which Beryl selects a different relevant item of the original post to OtherOne. While OtherOne focuses on the original post's mention of 'specific' concerns (Extract 1, line 2; Extract 2, line 8), Beryl selects their desire to talk to other gay diabetics and formulates this in terms of general 'support' seeking (Extract 3, line 2). Moreover, she suggests this is

⁴⁴ Humalog is the trade name for an insulin analog. Ultralente is a long-acting form of insulin.

something with which she can ‘empathize’ (line 3) and demonstrates this with a ‘second story’ (Arminen, 2004).

Second stories are a device by which one does not merely claim to empathise with a previous speaker but *demonstrates* understanding by providing a parallel experience which is designed to resemble the first (Arminen, 2004; Veen et al., 2010). Arminen (2004) suggests a number of functions of second stories including providing support for first speakers, offering new perspectives and interpretations as well as helping other group members make sense of what the first speaker has said. Veen et al. (2010) observed the use of second stories in online forum interactions and suggested that within this medium, where the original speaker may fail to elaborate or repair their previous turn (as was also the case in this instance), second stories can be used by other group members to contextualise posts.

The particular second story used here involves Beryl’s (previous) experience of attending support groups whose members were ‘overweight’, ‘middle aged’ or ‘ancient’ (line 5). She suggests that this led to a desire to find others in their adolescence or early twenties ‘going through the same thing’ (lines 6-7), and that this situation led her to feel ‘like a weirdo’ (line 7). Beryl concludes in line eight with the statement; ‘It can be lonely give the guy a break’. This statement links her own experience with that of the original poster, suggesting that they are of a comparable nature. Furthermore, this statement addresses the post to OtherOne and orients to his/her post as unfairly hostile. Here Beryl thus re-characterises the original post, by way of a second story, as a reasonable request in contrast to OtherOne’s characterisation of it as a discountable troll. Furthermore, she provides a candidate answer to OtherOne’s question (‘what the hell does being Gay have to do with diabetics’ Extract 2, line 1) without directly discussing ‘specific’ concerns regarding sexuality per se.

Associating diabetes and HIV

By comparison the next message in the thread attended directly to the original post’s mention of specific issues, suggesting that HIV may be a particular shared concern for gay diabetics:

Extract 4

In response to Extract 2

1. (At the risk of engaging in a dialogue with OtherOne) one concern that
2. is much more specific to gay diabetics (also to heterosexual female
3. diabetics--though they are significantly lower risk) is the risk of HIV
4. transmission posed by frequent blood testing. If you have 50 puncture
5. wounds on your fingers, all in various stages of healing, what risk is
6. there from contact with any bodily fluids?
7. There are several more issues that are indeed specific to gay
8. diabetics; they are fairly obvious, but you must carefully read your
9. copy of The Gay Agenda. Unfortunately, I cannot give you specific page
10. cites since The Gay Agenda is, of course, under continuous revision.
- 11.
12. <grin>

Here the poster counters OtherOne's claim that there are no 'specific concerns' which gay diabetics experience. Here, a hypothetical risk of HIV transmission from puncture wounds associated with blood glucose testing is offered as one concern which is 'much more specific to gay diabetics' (line 2). The notion that gay men are at a higher risk of HIV is not accounted for here. It is thus treated as taken-for-granted knowledge that HIV concerns are indeed much more specific to gay men. The poster does however take care to limit this claim (it is 'much more' specific as opposed to exclusively a gay concern). There is also a parenthesised acknowledgement that this is also a concern for other people, however it is stated that 'they are significantly lower risk' (line 3). Risk of HIV is thus constructed in terms of degrees of risk and in terms of different social groups in a lay epidemiological style. This claim is also hedged in another way. By posing a possible question that a gay diabetic may have (lines 4-6), the poster does not suggest that finger wounds from frequent blood testing *does* pose a significant risk of HIV transmission within this group, but simply offers it as one possible concern (among others) about which gay diabetics may wish to seek information. The delicate way in which this proposed specific concern is presented thus displays orientation to the possibility of being challenged on constructing HIV as a 'gay

issue'; which is precisely the challenge which is subsequently brought (as we shall see in Extract 5a).

In the second part of the post it is suggested that there are other specific concerns which are 'fairly obvious' (line 8), thus discounting a need to articulate them. Note also, that these other issues are described simply as 'specific' to gay diabetics, as opposed to the softened '*more* specific' used earlier. OtherOne's suggestion of a 'gay agenda' is also satirically responded to here. By capitalising 'The Gay Agenda' as a proper noun (line 9) and suggesting that OtherOne must 'carefully read' his 'copy', it is ironically constructed as a printed manifesto. OtherOne then responded to this post as follows:

Extract 5a

In response to Extract 4

<quotes Extract 4 lines 1-6>⁴⁵

1. Oh only Gays have to worry about HIV transmission via the finger stick
2. route. Do heterosexuals have some kind of innate ability to defend against
3. hiv transmission via the finger stick route that isn't available to the Gay
4. diabetic?? Don't think so. Heteros and gays from what I am led to believe
5. both enjoy manual stimulation of the sex organs, so I don't think this is
6. something only gays have to worry about.

Upon quoting the first half of Extract 4, OtherOne provides a receipt and reformulation of what the previous poster had written (lines 1-2). In common with much argumentative discourse, OtherOne selectively targets and repeats particular features of the previous speaker's turn before launching a counter to it (Billig, 1991). The delicate way in which HIV transmission was constructed in terms of degrees of risk is here ignored. This counter argument is perhaps made possible by modern constructions of HIV from a 'gay plague' to an 'equal opportunity' virus (Kitzinger and Peel, 2005). We can see how OtherOne here constructs HIV as an equal concern for gays and heterosexuals alike. In their CA study, Kitzinger and Peel (2005) illustrated how trainees within lesbian and gay awareness training often

⁴⁵ To prevent repetition quotations are not reproduced here.

describe risk of HIV infection in this way and speak from a position in which the 'de-gaying of AIDS' is treated as representing a non-prejudiced stance. In fact, here OtherOne subsequently attends to the business of presenting a non-prejudiced self explicitly in the second part of this post:

Extract 5b

In response to Extract 4

<quotes Extract 4, lines 7-12>

7. I have no problem with the sexual orientation of anyone, and personally
8. have "whatever floats your boat attitude as long as it involves consenting
9. adults." What I do object to is the apparent need of some people to define
10. themselves via their sexual orientation.. I personally don't think the
11. original poster of this message was looking for diabetic information as
12. much as he was looking for another gay person.. Is this newsgroup in the
13. process of changing from a source of information about diabetes to a
14. dating newsgroup.

By denying being prejudiced, OtherOne orients to the (quoted) satirical mocking of the gay agenda in Extract 4, as an accusation of prejudice (Speer and Potter, 2000). To ward off such an accusation, OtherOne produces the idiomatic formulation, 'whatever floats your boat' (line 8) which is placed within quotation marks to indicate its clichéd nature. In line with many 'idiomatised ways of talking' (Sacks, 1992), it is both characteristically vague and has a commonplace quality (Drew and Holt, 1998; 1995). It is not a direct rebuttal of the perceived criticism in the previous turn, but rather it is stated in general terms that he/she does not have a problem with the 'sexual orientation of anyone' (thus dismissing that it is *non-heterosexuals* who commonly face prejudice). It is sufficiently vague to function as a general response to an accusation of prejudice. Furthermore it ties OtherOne individually to a liberal individualist position with regards to sexuality and a taken-for-granted cultural norm against prejudice (Billig, 1991).

This idiomatic expression also functions as a disclaimer for what is to follow, in which an objection to the original post is expressed which itself risks being

perceived as heterosexist. In line nine, OtherOne professes an ‘objection’ to people defining themselves in terms of their sexual identity, thus again implying that such categorisations are of no relevance. This implies a disapproval of public declarations of sexuality, and at another point in the thread OtherOne claims to have ‘never seen a married diabetic looking for another married diabetic’. While criticisms are commonly made that lesbians and gay men ‘flaunt’ their sexuality, such arguments overlook the taken-for-granted and already-assumed status of heterosexuality (Peel, 2001).

As such, heteronormativity enables heterosexuals to incidentally disclose their heterosexuality, for example through referring to their heterosexual relationships, without this being treated as something out of the ordinary or talking about one’s sex life (Land and Kitzinger, 2005). For instance, Kitzinger (2005a; 2005b) has illustrated using CA, how heterosexuality is routinely made apparent within everyday conversations, without speakers orienting to this as an announcement of one’s sexual identity. It is this routine presumption of heterosexuality which may result in non-heterosexuals deploying their own membership categories in ways which appear more obvious (Land and Kitzinger, 2005). Thus we find, as with the original poster and within a number of other responses, the indexing of oneself as a ‘gay diabetic’ in a way which heterosexual speakers (whose sexuality is unmarked) would not label themselves as a ‘straight diabetic’.

In this post, OtherOne contests the notion of HIV as a ‘specific’ concern for gay diabetics and instead offers an ulterior motive for the original post. Diverging from the previous accusation that the original poster may be wishing to push a ‘gay agenda’, here there is a suggestion that Rbz was seeking a partner. While OtherOne aims to undermine HIV as a ‘gay issue’ in this post, HIV was also mentioned by other contributors as a common concern for gay diabetics. Consider for instance part of a longer post, which while coming much later in the thread was written as a response to the OtherOne’s first post (Extract 2):

Extract 6

In response to Extract 2

1. With this, on two occasions, when before a meal i took out my pill case
2. and took my Amaryl, Vit E, Mutli, Alpha-Lipoc Acid, and Q-10 pills, i
3. have been asked by friendly, ignorant persons, "How long have you had
4. AIDS?" I don't have AIDS. I don't have HIV. Not that they'd know the
5. difference. What I do have is a requirement to tell anyone who knows i am
6. gay, seeing me take a handful of pills, that i have diabetes, not HIV, or I
7. live with the consequences of the stereotype otherwise. Usually i say
8. nothing and let people assume what they like. It makes them more afraid
9. of me. I know that, if need be, i can chase them off with the threat to
10. bleeding on them.

This post also constructs HIV as a gay issue, however it is better guarded against the possibility of being challenged in a number of key respects. Firstly it makes no suggestion that gay men *are* differentially affected by HIV but is based on others' assumptions about gay men and HIV and how gay diabetics may be affected by such stereotypes. Secondly, presenting this argument in the form of personal experience makes it additionally difficult to challenge. Stating that this has happened on two occasions, further functions to give the impression that this is not simply an isolated incident and so may be an experience shared by others.

Speaking as a gay diabetic: invoking category entitlements

In Extract 6, by disclosing a gay identity (line 6), the poster was able to claim experiential authority (Kitzinger, 1994) regarding how gay experiences of diabetes may differ. I now wish to turn to two further posters who indexed their sexual identities as 'gay'. In particular I wish to consider the consequence of this for the interaction itself:

Extract 7

In response to Extract 1

1. This is not a flame; so to speak, okay maybe I flame a little. But I am gay
2. and I can't imagine what specific issues would address us? What issues are

3. you going through that you think diabetic hets aren't going through as
4. well? I'm a bit curious 'cause I can't think of anything.
- 5.
6. Jim

Jim begins this post with a disclaiming formulation; 'This is not a flame...But...', similar to the commonly used disclaimers 'I'm not homophobic/racist/sexist but...' (van Dijk, 1987). He is signalling here that his message is not likely to be the response Rbz desired. By indexing his identity as gay, Jim invokes a category entitlement – who would know better about the concerns of gay diabetics than a gay diabetic himself (Potter, 1996b). Note it is only his sexuality which is indexed ('I am gay'), his identity as a diabetic is to-be-assumed within a diabetes newsgroup.

Again he targets the original poster's reference to 'specific' issues (line 2) as relevant, and asks what 'issues' they are experiencing that a heterosexual would not. This is despite a number of other posters offering their own suggestions (e.g. concerns about HIV, general feelings of isolation). A distinctive feature of such online discussions is that it is unclear whether or not contributors have read previous posts in the thread other than that to which they directly respond (Veen et al. 2010). By describing himself as 'curious', he positions himself as genuinely enquiring as opposed to dismissive. This post received only one direct response, from someone who had not previously contributed to the discussion, also identifying themselves as a 'gay diabetic':

Extract 8

In response to Extract 7

1. Jim,
2. I'm new here and haven't posted before, but I am also a gay diabetic so
3. thought I would throw in my 2cents. I don't know that we have any specific
4. issues, but maybe it would be easier to talk to others who may have
5. similar experiences. If we talk about our experience with our life partners,
6. it may be more comfortable with other gay/lesbians than with the whole
7. group. I'm not sure. But if someone wants to start any subgroup or e-mail,
8. I would probably join in
9. Tom

By indexing himself as a 'gay diabetic', Tom constructs the thread as directly relevant to himself. He also claims a category entitlement to speak with experiential authority in his response to Jim. However, at the same time, he also downgrades the status of his comment as only a personal opinion by formulating it as throwing in his '2cents' (line 3). He acknowledges the original poster's reference to 'specific issues' and aligns himself with Jim in his assessment that he does not know of any (lines 3-4). However, as with Beryl in Extract 3, he then targets the original poster's stated desire to 'talk to others' as the most relevant item in the post and reformulates the notion of 'specific issues' to that of 'similar experiences' (line 5). His use of 'maybe' here (line 4) and later 'I'm not sure' (line 7) further avoids a direct challenge of Jim's previous post. In particular, he suggests that gay (and presumably lesbian) diabetics may wish to discuss their relationships with their partners and may feel 'more comfortable' doing so with other non-heterosexuals.

Resisting narrow constructions of diabetes and sexual identity

The question of whether sexual identity has any relevance to the topic of diabetes, of course depends upon how both are socially constructed. Consider the following post which (similar to OtherOne's post in Extract 2), questioned the relevance of Rbz's sexuality to a newsgroup about diabetes:

Extract 9

In response to Extract 1

1. Unless you want to know how many carbs in sperm why in the hell does
2. your life style have to do this this newgroup.

Widdicombe (1998) has suggested that membership categories are associated with particular activities. We can see in this message, how diabetes and being gay are constructed in terms of category bound activities. Carbohydrate counting is treated as an activity bound to the category 'diabetic', while oral sex is associated with the category 'gay' (described euphemistically as the original poster's 'lifestyle'). In doing so, the diabetic is reduced to dietary management and a gay identity is

reduced to sexual acts⁴⁶. We see in the following extract that Mary challenges precisely this reduction of diabetes to management activities on the one hand and sexual identity to sexual activities on the other:

Extract 10

In response to Extract 9

<quotes Extract 9>

1. We talk about a LOT of different things having to do with diabetes
2. management and living with diabetes here, not just metabolism, bgs levels,
3. and carb counts. We talk about how our disease effects our relationships
4. with our partnres. We talk about insurance issues. We talk about being
5. discriminated against because of the ignorance of others. We talk about a
6. LOT of stuff. Because you do not see a connection between diabetes and
7. being gay doesn't mean that it isn't there. It only means that you don't
8. know about it.
- 9.
10. If you're a guy, would you seriously outlaw any conversation among
11. women about diabetes because "unless you want to know how many carbs
12. in sperm" it bears no relation to diabetes? I mean, some of us engage in
13. oral sex with men, but we also have a much, much, MUCH larger life than
14. that, much of which is not familiar to men and yet is an integral part of our
15. experience with diabetes. The same is true for gays and lesbians -- their
16. lives are not limited but they may include life experiences you've neither
17. had nor understand.
- 18.
19. If it's not a thread that interests you, as always, you have the option of
20. skipping it.
- 21.
22. Mary

Mary suggests that discussion within the newsgroup revolves around two things; 'diabetes management *and* living with diabetes' (lines 1-2). She contests the implication that discussion narrowly focuses on diabetes management; encapsulated

⁴⁶ Peel (2005) similarly notes that slang terms for lesbians and gay men routinely reduce these identities to sexual acts in a way which heterosexuality is not.

by a three part list of such topics ('metabolism, bg levels and carb counts', lines 2-3). She then provides a list of discussion topics which fall outside of the category of 'diabetes management' but under the title of 'living with diabetes' such as relationship problems, problems with health insurance and discrimination. The repetition of 'we talk about' five times within lines one to five and capitalisation of 'a LOT' (lines 1 and 6) help to emphasise the range of topics discussed within the newsgroup. So here Mary challenges the narrow construction of diabetes as a medical condition which is only related to matters of biology and blood glucose management as well as challenging constructions of (non-hetero)sexual identity as being exclusively concerned with matters of sexual behaviour.

In the next paragraph of the post, Mary turns her attention to the narrow construction of gay men. She does this by asserting that oral sex is not exclusively an activity of gay men (i.e. it is not 'category-bound') and that one would not reduce (female) heterosexuality to such an activity in the same way. We can also see here an example of embedded disclosure of heterosexuality by Mary ('I mean, some of us engage in oral sex with men' lines 12-13). By speaking about lesbians and gay men in the third person ('their lives', lines 15-16) again Mary positions herself as the empathetic heterosexual. She makes a comparison between the original poster wishing to talk with people of the same sexual identity and women wishing to discuss diabetes with those of the same gender. She also questions the previous contributor's epistemological entitlement to knowledge of its relevance. She suggests that (heterosexual) women's experiences 'is not familiar to men' (line 14) and then similarly states that lesbians and gay men may have experiences which the previous poster has 'neither had nor understand(s)' (lines 16-17). In doing so, Mary can be seen as questioning the poster's experiential authority to talk on the subject.

Summary

In this chapter I have further explored how chronically ill non-heterosexuals utilise the internet to seek support from other LGBTQ people affected by their illness. This chapter demonstrates the way in which heterosexism and heteronormativity may prevent LGBTQ people seeking such support within generic online support and may police what can be said and by whom within them. In the online discussion

documented, some constructed (non-hetero)sexuality as inappropriate and/or irrelevant to a diabetes newsgroup, thus silencing non-heterosexual users of the forum. I have therefore contributed to critical health psychology by casting a critical eye on the power relations that may exist within online 'support' communities. This is in stark contrast to the health psychology literature which has tended to celebrate the 'empowering' potential of online support groups for those living with long term illness. I have also contributed to social constructionist approaches to health and LGBTQ identities. I demonstrated how the relevance of sexuality to this diabetes newsgroup was a contested issue and paid particular attention to how and in what ways sexual identity was constructed as (ir)relevant within the discussion. Those who constructed sexuality as irrelevant to the condition suggested that non-heterosexuals did not experience 'specific issues' which did not also apply to heterosexuals. They also drew on discourses which reduced sexual identity to matters of sex and biomedical discourses which reduced diabetes to biological processes. In contrast, others suggested that diabetes affected social aspects of life and that sexuality was relevant in terms of isolation, stigma and the need for appropriate support. In doing so, I have also contributed to the application of a discursive approach to analysing computer-mediated communication. In the next chapter I continue to adopt a discursive approach and apply this to interview data with self-identified lesbians, gay men and bisexuals with diabetes.

Chapter 5: Gender, sexuality and support

In this chapter I use discourse analysis to explore how LGB people with diabetes talk about the support they receive from others in managing their chronic condition. In particular, I consider the culturally available ways of talking about the support that partners provide and the social discourses that my participants drew upon when discussing the management of their diabetes.

Background

Social support is certainly portrayed as important within the diabetes literature. The involvement of supportive others is claimed to improve adherence to diabetes regimens (Matire et al., 2004; Ohman and Soderberg, 2004). Gallant (2003: 172) asserts that:

Certainly, a supportive other may directly influence self-management by providing hands-on help with self-management tasks, like administering insulin or managing medications. A supportive other may also provide an indirect influence by facilitating self-management activities with verbal encouragement, advice, or other kinds of tangible help (like serving as an exercise partner), or by providing an environment that facilitates proper self-management.

In her review of the literature, Gallant claims that there is evidence for a positive relationship between social support and good chronic illness management, and that this appears to be particularly the case for diabetes and dietary behaviours. However she notes that studies rarely specify their conceptualisation of ‘support’ or the mechanisms by which support operates. Furthermore, she contends that support can be a double-edged sword, with well intentioned partners, friends or family members acting in ‘unsupportive’ or ‘inappropriate’ ways. In this way, significant others can be both a help and a hindrance (Gallant, Spitze and Prohaska, 2007).

Here I will briefly outline three studies of partner support within diabetes management. These particular three were chosen to draw attention to different theoretical approaches within qualitative health psychology. All three papers were

published in 2005. The first two adopt (different) realist approaches, while the third draws on a social constructionist, discursive psychological approach.

Miller and Brown (2005) interviewed twenty (heterosexually) married couples, of which one partner had type 2 diabetes about their dietary management of the condition. This study adopted a 'family systems theory' approach with the stated aims of providing a description of the 'processes' associated with dietary change 'at the couple level' and to categorise couples according to 'marital adaptation patterns' (p. 227). Adaptability was conceptualised as consisting of four components:

Flexibility (the extent to which spouses made diet changes), roles (assigning and implementing jobs for diet management, such as meal planning), rules (setting guidelines around the diet), and communication (open or closed verbal exchange between the spouses about the diet). Miller and Brown (2005: 228)

Couples were then categorised in terms of marital adaptation as either 'cohesive', 'enmeshed' or 'disengaged'. Cohesive couples were described as those in which both partners 'worked together as a team' (p. 228); both were flexible, diet management roles were shared, rules were 'negotiated' and communication was open. In 'enmeshed' couples, the non-diabetic partner was described as taking most of the responsibility, the diabetic partner was inflexible, roles were not shared, the non-diabetic spouse would attempt to enforce rules and diet was not freely discussed. Finally, 'disengaged' couples were those in which the diabetic partner was described as solely responsible for their own dietary management. In these relationships either one or both partners were described as inflexible, roles were not shared, rules were either inconsistent or nonexistent and communication was predominantly closed.

While Miller and Brown note that it was the male partner who had diabetes in five of the seven couples described as 'enmeshed' (i.e. responsibility lay with the non-diabetic partner), and it was the female partner who had diabetes in five of the eight 'disengaged' couples (i.e. responsibility lay with the diabetic partner), very little is made of this gender difference. Rather the theoretical focus, as with much mainstream psychological theory, is the 'processes' of relational adaptation to chronic illness.

By contrast, Wong et al. (2005) explicitly examined the gendered pattern of partner support in the dietary management of type 2 diabetes. They interviewed 12 heterosexually married people with diabetes (six female, six male), and seven of their partners (three female, four male) from which three trends were found. Men with diabetes were described as being ‘actively supported’ by their wives. Active support was defined as ‘tangible’ assistance such as meal preparation and food shopping⁴⁷, as well as ‘significant appraisal support in the form of verbal encouragement to eat healthily’ (p. 218). Women, on the other hand, were described as more often receiving ‘passive’ support from their husbands, in the form of acceptance of meal changes. The men with diabetes in the study, reportedly, more often ate the same meals as the rest of the family. By contrast, women with diabetes more often adjusted their own meals, for instance by reducing their portion size or preparing a separate meal for themselves. They concluded by suggesting that men are ‘more often the beneficiary of this arrangement’ (p. 219).

This analysis certainly is not alone in commenting on this gendered pattern of dietary management among couples where one has diabetes (see also Maclean, 1991; Gallant et al., 2007). These findings also fit well with much research on the relationship between gender and health behaviour generally. Such research has suggested that heterosexual women often encourage their male partners to seek health care and exert ‘control’ over their health behaviours (Lewis and Lewis 1977; Umberson 1992; Norcross, Ramirez and Palkinkas, 1996). However, Kemmer (2000) cautions against making such assertions regarding gender and food preparation, claiming there to have been a considerable shift in domestic roles in recent decades, with a ‘traditional’ gendered division now far from universal.

These two social scientific ‘accounts’ of partner support in diabetes management have both convergences and dissimilarities. Both studies incorporate qualitative methodology and both suggest that partners are influential in the management of diabetes. However, Wong et al.’s (2005) focus is primarily on gender while Miller and Brown (2005) focus on ‘types’ of relational adaptation. Although a focus on

⁴⁷ Wong et al.’s (2005) study also included a quantitative component in which a significant gender difference was found in the division of household labour; with women more often taking responsibility for meal preparation and food shopping irrespective of which partner had diabetes.

relationship types and adaptation patterns avoids portraying gender differences as universal and inevitable, feminists have criticised family systems theory for downplaying gender inequality and overlooking the social and cultural contexts in which families exist (Yllo, 1993). Both also adopt a realist approach – taking what is said within interviews as a window to the attitudes and behaviours of couples.

Peel et al. (2005: 781) interviewed 40 type 2 diabetes patients and adopted a discursive psychological approach, which they contend represents a ‘radical departure’ from much realist research as illustrated above. The focus here was on the participants’ accounts themselves - how dietary management was socially constructed through such talk and on the actions that different accounts accomplish. Peel et al. reported that the women in their study tended to construct their diet as an individual concern, often in conflict with their responsibilities as wives and mothers to cater for their families’ food preferences. Men by contrast, generally constructed the management of their diet as a family matter, implicitly placing responsibility on their female partners. In addition, they illustrated how women more often constructed dietary ‘non-adherence’ in terms of their ‘cravings’ and ‘addiction’ to sweet foods.

Although Peel et al. adopted a very different approach to analysing their data, their findings resonate to some extent with Wong et al.’s (2005) study, in so far as traditional gender discourses were found to shape talk about diabetes management. A further similarity with the previous two studies is that non-heterosexuals are rendered invisible. Heterosexuality is here again, the unmarked norm.

Understanding same sex relationships

As noted in Chapter 1, when research is conducted about non-heterosexuals, this generally takes the form of comparative studies which aim to determine similarities and differences with heterosexual relationships. And just as there has been a strong impulse within ‘gay affirmative’ psychology to demonstrate the mental health of LGB people, so too have LGBTQ psychologists often concerned themselves with countering heterosexist stereotypes by demonstrating similarities between same and different sex relationships (e.g. Kurdek 2004; 2007). Such stereotypes have

traditionally portrayed LGB people's relationships as unstable, with gay men and bisexuals particularly depicted as promiscuous and unable to live up to the (heteronormative) 'ideal' of a monogamy. However, in line with the ascendance of more liberal discourses around homosexuality within western societies, same sex relationships have predominantly been constructed as 'just like' heterosexual relationships, both within the media (Riggs, 2005b; Jowett and Peel, 2010) as well as social scientific literature (Clarke, 2002).

Kitzinger and Coyle (1999) however have criticised this trend within the literature, calling for greater consideration of how same sex relationships may differ from heterosexual couples (potentially for the better!). Particularly relevant to us here, is the way in which research has tended to portray differences in relation to the division of household labour. It has been suggested that lesbians tend to have a commitment to egalitarian values within their relationships (Dunne, 1997) and that gay and lesbian couples divide domestic chores more equally than their heterosexual counterparts (Kurdek, 2007). On comparing lesbian and gay male couples, Kurdek (2007) noted that lesbian partners were more likely to do all tasks equally, while gay men were more likely to divide and specialise in particular tasks, based on personal interests and efficiency. Such findings would suggest that the dietary management of diabetes could well be different within same sex relationships (and also differ by gender of the couple). However, Carrington (1999) conducted both interviews and ethnographic observations of same sex couples and suggested that although many of the couples did indeed report a commitment to egalitarianism within interviews, his observations led him to believe that, in many cases, one partner often did more household labour than the other. Such discrepancies highlight that accounts given within qualitative interviews may not necessarily map onto behaviour. In the analysis which follows, I explicitly adopt a social constructionist approach which does not rely treating what is said in interviews as being a 'true' reflection of one's attitudes or behaviour. I use discourse analysis in order to examine LGB people's talk about support and diabetes management.

Research question

My aim in this chapter is not to develop a grand theory about how partner support for chronic illness management works within same sex relationships. The goal of discourse analysis is not to determine if certain claims are true or false (Potter 1996b). Neither is it my aim to reveal how support within same sex relationships compares to that of different sex relationships. Rather my aim here is to examine the discursive frameworks within which 'support' is discussed. By this I mean that the focus is on LGB people's *talk* about support within their relationships. So in this chapter I ask how discourses of gender and sexuality are drawn upon and how partner support and their relationships are constructed within LGB people's accounts of their diabetes management.

Method

Participants

Twenty non-heterosexual people with diabetes consented to be interviewed. This comprised of six women and fourteen men, including four lesbian women, two bisexual women, eleven gay men and three bisexual men. Twelve had type 1 diabetes and eight had type 2 diabetes. Their ages ranged from 25 to 69 with a mean age of 47 years and none came from an ethnic minority background. Although type 1 and type 2 diabetes are clinically different in a number of important ways, my rationale for including participants with both types was based on the findings outlined in the previous chapter. In Chapter 4, I noted that people with both types of diabetes shared online support groups and those seeking support from other 'gay diabetes' did not specify a diabetes type. Moreover, it was social issues rather than specifically medical issues that were suggested topics of discussion within online LGBTQ diabetes groups. Furthermore, Campbell et al., (2003), who include qualitative research on both types of diabetes in their meta-synthesis, suggest that qualitative health research should not necessarily be driven on the basis of medical classifications. All participants were informed that their partners were welcome to

be present and participate in the interviews if this was desirable, however only one participant chose to include their partner⁴⁸.

Seven of the participants were recruited through the online survey, and were interviewed online. Online interviewing allowed me to interview those survey respondents from outside of the UK⁴⁹ (all seven were from the USA) and was in keeping with the anonymous nature of their previous participation. Interviewing these survey respondents also enabled me to follow up on issues raised by these participants. The remaining thirteen interviewees were recruited through a call for participants placed in Diabetes UK's *Balance* magazine. This is a bi-monthly magazine that all members of the charity receive and is also sold in selected high street retailers.

Procedure

The interviews followed the commonly used 'semi-structured' format (Smith, 1995). An initial interview schedule was drawn up as part of a research proposal to be considered by Aston University's ethics committee (see Appendix 3). This was informed by a review of the literature and covered the broad topics of day-to-day management of diabetes, how diabetes affected their relationships and social life as well as their interactions with health professionals. This was intended as a flexible guide for the interviews and although these broad topics were covered in all interviews, the focus of the interviews was, to some extent, determined by the participants themselves and sensitive to the individual. This resulted in interviews which were substantially different from one another. Despite this, all interviews began in the same way by asking the participant to say a little bit about how they came to be diagnosed with diabetes.

Interviews conducted via the internet used instant messaging software of the participants' choosing allowing participants to use software with which they were already familiar. This resulted in three different forms of free IM software being utilized (MSN/Windows Live Messenger, Yahoo Messenger and Google's Gmail

⁴⁸ In this instance, their partner was also asked to read and sign the consent form given to participants.

⁴⁹ The use of free online chat software was also less costly than the alternative of telephone interviewing.

chat). Participants were emailed a consent form in advance to provide more information about the study and were encouraged to ask any questions they may have about the study via email. Due to the protracted nature of reading and typing (as opposed to listening and speaking) online interviews were substantially longer than those conducted face-to-face. Participants were asked after an hour and a half if they would like a break and were also informed that the interview could be broken down into a number of shorter interviews and continued at a later date. None of the participants chose to do this resulting in all online interviews being one-off research encounters of approximately three hours.

Participants taking part in face-to-face interviews came from various regions of England and Wales and interviews took place at a location of the participants' choice. This included at Aston University, in interviewees' homes or workplaces as well as in neutral and public locations such as cafés. When using public spaces, locations were chosen which were quiet (e.g. a relatively unoccupied café) both to ensure confidentiality and allow for a good quality recording. Interviewees were asked to complete a brief questionnaire before the interview which provided socio-demographic information (see Appendix 4) and helped to avoid any irrelevant line of questioning.

All face-to-face interviews were audio recorded and transcribed verbatim using a simplified version of the Jeffersonian (2004) transcription notation (see Appendix 5). Verbatim transcripts were dynamically produced in the process of conducting the online interviews which were copied and pasted into word documents. Features of the verbal interaction such as hesitations, pauses and false starts were included in transcripts of face-to-face interviews and all spelling and grammatical errors were preserved within online transcripts.

Ethical considerations

The research was conducted in line with BPS ethical guidelines for conducting research with human participants and a research proposal was subject to review by Aston University's ethics committee. All participants were emailed a consent form (see Appendix 6) in advance, in order to provide more information about the study

and to ensure that they were happy to proceed. For online interviewees, informed consent was obtained prior to the interview via email as advocated by Eysenbach and Till (2001). In the absence of a signature participants were instructed to type their name and the date and that the emailing of the consent form would be taken as confirmation of their consent. Face-to-face interviewees were asked to sign two copies of the consent form, one of which the participant was given for their own records.

Participants were informed that the interviews would be tape recorded and that transcribed excerpts from their interview may appear in published material arising from the study. All participants were given pseudonyms and any identifying information was altered or omitted from the transcript. All audio recordings, transcripts and socio-demographic questionnaires were stored securely in a locked filing cabinet and labelled against their pseudonym and interview number. The contact details of participants were stored separately from the data and held securely on a password protected computer. Interviewees were informed that given the research topic, some questions may be of a sensitive nature but that they were under no obligation to answer particular questions and could terminate the interview at any time. Participants were also made aware that they could withdraw their participation retrospectively without explanation up to two weeks after the interview had taken place. The contact details of my principal supervisor were also made available had participants wished to make a complaint or had not wanted to contact me directly when withdrawing their participation. Given that it is possible that participants may not have read the consent form in its entirety these issues were raised before the beginning of each interview. I also made myself aware of sources of information and support regarding diabetes and support services available within the LGBT community, should participants request it.

I chose to inform participants that I identified as a gay man within the call for participants in order to alleviate any possible fears that the research may be used in a heterosexist way. While this carried a small risk of attracting homophobic correspondence, this risk was considered minimal. A decision was taken in advance that any such correspondence would not be responded to and would be forwarded to one of my supervisors. When conducting face-to-face interviews precautions were

taken to ensure my personal safety. When meeting participants, a designated person was always informed of the destination, time and expected duration of the interview. I carried a fully-charged mobile phone at all times and the designated person was contacted after I had left the location.

Method of analysis

Following (when necessary) transcription of the interviews, the transcripts were read and re-read in order to identify features of the data which were of particular interest. These will be explored in this and the following chapter. The feature which I focus on in the present chapter was the ways in which participants talked about the management of their condition in the context of their personal relationships. A synthetic approach to discourse analysis was used to analyse the data. I systematically coded all of the transcripts, identifying all relevant data to this topic. After the data were collated I read and re-read the extracts to identify patterns and tropes in relation to discourses of health, gender and sexuality. As well as identifying broad discourses of health, gender and sexuality within the text, when presenting specific examples I examine how these discourses may perform specific functions within the interaction.

Analysis

My analysis will focus on three themes found within the participant's talk about support. The first identifies interpretative repertoires in which men and women were at times contrasted in terms of gender roles and at others gay men were contrasted with heterosexual men. The second theme illustrates how participants presented themselves as relatively 'independent' (sometimes in contrast to heterosexual couples) and constructed their relationships as equal. I then examine talk in which participants negotiated their own and their partner's responsibility for dietary management of diabetes.

Gender roles and gender inversion

In this theme I highlight the ways in which participants contrasted the kind of support that men and women offer based on dichotomous notions of masculinity

and femininity and how these were related to lesbians, gay men and their relationships. In Extracts 1 and 2 this is evident by the way in which women are constructed as more 'sympathetic' (Extract 1, lines 8-10) and 'caring' (Extract 2, line 19) than men.

Extract 1

Andy – type 1, bisexual trans man (single, living with his ex-partner)

1. Adam says: yeah. Would you say you receive any support from friends and
2. family
3. Andy says: Hmm, I get sympathy from my mother and one of my sisters,
4. who has lupus. But I don't talk about my health with anyone
5. except my parents. My dad (not step but biological) lives close
6. to me and he asks about my health, but he's more concerned
7. with his own. Not that he doesn't care about mine or show
8. interest in what's going on, but I don't elicit sympathy from
9. most guys, esp. if they don't have diab[etes]
10. Andy says: they aren't taught to offer that the way women are. I know I am
11. sort of in the middle in my behavior on things cause I can fully
12. understand how it feels to be sick and disabled. My friends are
13. sympathetic, men and women so I like that. I guess some guys
14. are able to show sympathy without feeling weird or girly. I still
15. tend to talk more about health stuff with women though.
16. Adam says: yeah thats interesting
17. Adam says: do you think that applies to lesbians and gay men in the same
18. way. About being able to talk about health and offer sympathy
19. I mean
- [3 lines omitted]⁵⁰
20. Andy says: I don't know about lesbians and gay men. I don't know many
21. of either these days. Most gay men I guess are like straight
22. guys. They will listen a bit but aren't really interested or
23. invested in hearing about sickness or disease. I think but I
24. could be wrong that for gay men the key is to be healthy and

⁵⁰ The omitted lines here were an online 'overlap' of speech in which Andy finished his previous turn after the next question had been asked (line 17-19). Line 20 is thus the beginning of Andy's response to this question despite the omitted part of the transcript.

25. good looking and young to get someone. With dykes it's a bit
26. different.

Extract 2

Becky – type 2, lesbian woman (lives with her partner Jo)

1. Becky: I mean you wouldn't have had the support I give you from
2. Matthew [Jo's ex husband] would you?
3. Jo: No
4. Becky: But Phil [a heterosexual friend's husband] would give that
5. support to Sally
6. Jo: But you don't know that (.) men are different don't forget
7. Becky: I could see him doing that
8. Jo: Some men don't show their feelings do they (.) they're not very
9. understanding of any illness (.) that a woman has (.) are they?
10. Becky: I can't comment on that
11. Jo: When he's got a cold, he's got the flu
12. Adam: ((laughs))
13. Becky: Yeah but-
14. Jo: When a woman has a cold y'know she's just got to get up and
15. get on with it whereas a man will lie down (.) if a man's got
16. diabetes he'll play on it
- [27 lines omitted]
17. Becky: Thinking of it now (.) looking into it deeper yeah I think you get
18. more support female to female (.) because generally women are
19. more caring (.) so I think I think you would
20. Jo: I think it does too
21. Becky: But then I'm not saying it wouldn't be in a heterosexual
22. relationship (.) it depends on those individuals

In Extract 1, Andy positions his father as representative of men in general who are not 'taught' to offer sympathy as women are (line 10). Andy then positions himself as an exception to this rule. With prior knowledge of Andy's history, his statement that he is 'in the middle' with regards to his own ability to offer sympathy (lines 10-

12), could be read as a reference to his trans identity. However, within the context of what follows, what is readable here is a claim that he is able to offer sympathy *in spite of* his (male) gender, due to his own experiences of illness. Andy thus deftly claims entitlement of membership to the category 'male', while avoiding the negative implications of constructing men as unsympathetic. Andy then presents some other exceptional cases, namely his male friends. However his use of 'I guess some guys' (line 13) reiterates their exceptional status, rather than revises or negates his previous constructions of men.

Following from this, I ask Andy if he thinks this gender difference is also true of lesbians and gay men. In so doing, I may be seen to invite the suggestion of difference as Andy does not imply in his previous statements that he was referring to *heterosexual* men and women. Andy responds by positioning himself as unqualified to make such a judgement before tentatively suggesting that most gay men are 'like straight guys' (lines 21-22). Andy can be seen as 'doing' tentativeness in his construction of gay men by beginning one sentence with 'I guess' (line 21) and another with 'I think but I could be wrong' (lines 23-24), signalling that he is negotiating a tricky subject here. In line 24, Andy switches from talking about gay men as being within a general category of men, to talking about *gay* men in particular. Here he draws on discourses of gay men being overly concerned with fitness, physical appearance and youth (a discourse also drawn upon by respondents within Chapter 3).

In Extract 2, Becky is responding to a question concerning whether she feels the support she receives from her female partner Jo differs from what she would receive in her previous heterosexual relationships. A co-constructed response is offered by Becky and Jo. Becky provides two contrasting examples of supportive and unsupportive heterosexual husbands (lines 1-5). In so doing, Becky implies that the kind of support she would receive from a man would depend on the man in question. Jo then challenges Becky's knowledge of her friend's (Phil and Sally's) relationship (line 6), which results in Becky downgrading her previous statement, to a more speculative; 'I could see him doing that' (line 7). Jo's assertion that 'men are different don't forget' in line 6, presents the idea of gender differences as a taken-for-granted fact and 'common sense'. To reinforce this position, Jo draws on the

cultural notion of 'manflu' whereby men are commonly believed to exaggerate the symptoms of the common cold. While this does not relate to the kind of support men provide within a relationship, it functions as 'evidence' that there are indeed differences between men and women with regards to how they respond to illness.

Approximately 50 seconds later, Becky alters her position in alignment with Jo's. Becky suggests this shift is due to 'thinking about it' on a 'deeper' level (line 17), a claim which is given weight by returning to the subject after a brief interlude. By adopting this new position and constructing women as 'more caring', Becky is able to present her lesbian relationship in a positive way. It is also worth noting that within couple interviews, there is a tendency to negotiate a unified position and accomplish shared assessments (Seymour-Smith and Wetherell, 2006). After congruence with Jo is achieved, Becky adds the caveat that this does not mean that heterosexual relationships are not caring and that 'it depends on those individuals' (line 22). Thus she is able to draw on cultural constructions of women as caring in order to favourably position her and Jo's relationship, while also offering a counter argument. Becky is engaged in a delicate balancing act here between two competing and contradictory discourses; one based on the notion that men and women are fundamentally different and the other consistent with individualist notions that we are all individuals and that it is the 'type' of relationship one has which counts.

In both of these extracts we saw the interpretive repertoire of women as caring being deployed. In Extract 2 we saw how such a construction can be used to position female same sex relationships in a positive way. But what implications does this have for gay men and their relationships? What interpretive repertoires or cultural resources are available for gay men with diabetes to talk about their relationships in a similarly positive way? Extracts 3 and 4 are taken from an interview with a man with type 1 diabetes who discusses his late wife's and his subsequent boyfriends' reactions to low blood glucose.

Extract 3

Gordon – type 1 gay man (currently lives alone, previously married)

1. Adam: Has there been any specific differences between how your wife
2. was about the diabetes and your boyfriends or=
3. Gordon: =oh yes oh absolutely big difference (.) my wife was panicky (.)
4. desperate sometimes (.) er anxious nervous (.) er kept on and on
5. and on to make sure I was doing the right things (.) boyfriends
6. just take it as it comes (.) if you have a bad time they notice it (.)
7. they point it out to you (.) and if you deny it they insist (.) they
8. say 'sit down you're gonna eat something' and you just do it be
9. because y'know they're not panicking and it's much easier
10. Adam: Yeah so less panicking
11. Gordon: Less panicking (.) I couldn't stand the panics she used to get into
12. Adam: But they still encourage you to eat and things like that?
13. Gordon: Oh yeah they still take control (.) make you sit down (.) make
14. you eat even though you're protesting (.) and a man can do that
15. (.) a man can do that without worrying about it
- [12 lines omitted]
16. Adam: And do you put that down to them being men and your wife a
17. woman or is it that your wife was a particular-
18. Gordon: I put it down to men (.) no I think all women would be like that
19. (.) most women would be panicky (.) that's my experience of
20. women (.) women just panic (.) whereas men don't panic (.) they
21. just take things much more rationally and easily (.) I could be
22. wrong about that because my wife was especially anxious and
23. nervous

Extract 4

1. Gordon: I had a guy called Tim who was just absolutely lovely with me
2. (.) he was the guy who moved in for a week after I came out of
3. hospital just to look after me (.) and he was in his forties (.) I
4. thought it was just perfect (.) absolutely lovely (.) but it's not for
5. me to question why they feel like that
6. Adam: And that kind of caringness, did that come as a shock?

7. Gordon: Well I always knew that gay men were very caring (.) generally
8. they went for the caring professions (.) they're male nurses,
9. they're flight attendants, they're social workers, they're housing
10. officers (.) they've got loads of gay men in [city name] city
11. council that do all these sorts of caring profession jobs so I knew
12. there was a thing about gay men in the caring professions
- [13 lines omitted]
13. Adam: Yeah so do you find that about y'know gay men in particular?
14. Gordon: I do I do (.) I find plenty of gay men who have got very good
15. caring professional jobs and I don't find them at all aggressive (.)
16. there's no macho stuff with them (.) there's no pretence about
17. them (.) trying to show that they're masculine

In Extract 3 Gordon contrasts men and women but in a different way to that seen in Extracts 1 and 2 outlined above. In lines three to nine, Gordon's wife is constructed as 'panicky', 'anxious' and 'nervous', while his male partners are constructed as calm, composed and controlling. His use of reported speech (line 8), which was spoken in a calm tone of voice, functions to illustrate such an approach to dealing with low blood glucose, which he suggests is a better form of support. In line 13, he further emphasises men's ability to 'take control' of such a situation in his repetition of they 'make you' (lines 13-14) and 'a man can do that' (lines 14-15). Here, rather than constructing this difference as a difference in individual personalities, it is accounted for as a gender difference drawing on wider cultural discourses of women as 'over emotional' and men as stoical and 'rational' (line 21). This is similarly noted in Seymour-Smith et al.'s (2002: 262) study in which they assert; 'it is worth noting how the binaries constructed [...] male versus female and positive (stoical) versus negative (overly worried) – work in tandem'.

Now consider Extract 4 in which Gordon constructs gay men as different from heterosexual men in general. Gordon states that he 'always knew' gay men were caring (line 7) presenting this as self-evident cultural knowledge. To bolster this statement, he deploys a four-part list of caring professions to which gay men are drawn. The use of such lists is persuasive as they help to convey a sense of generality (Jefferson, 1990). He also infers a degree of 'insider' knowledge through

his own professional involvement with the city council. He then constructs gay men as non-aggressive and not invested in 'macho' forms of masculinity (lines 15-17). While Gordon had previously drawn on traditional characteristics associated with hegemonic masculinity, such as stoicism and rationality, here gay men are constructed as different to heterosexual men in order to position them as caring. So Gordon is able to lay claim to masculine subject positions on behalf of his partners in Extract 3, while in Extract 4 he draws on notions of gay men's non-normative gender roles to adopt alternative subject positions. Heterosexual men displaying such 'feminine traits' would commonly be positioned as 'deviant' (Seymour-Smith et al., 2002), however by drawing on notions of gender inversion and gender non-conformity here being caring is constructed as a normative quality of gay men.

Asserting independence and claiming equality

Within the sample, few of the participants suggested that they *needed* their partner's support to manage their diabetes and many of the men, in particular, were careful to construct themselves as independent and self-reliant. In Extracts 5 and 6, this is done in different ways.

Extract 5

Justin – type 1 gay man (currently single)

1. Adam says: ok. You said in the survey that your ex partner was really
2. very over protective. In what way, did you mean?
3. Justin says: well I was with him when I went on the pump. He came to
4. all of the diabetes classes with me, came to my doctors
5. appointments and was constantly asking if I was OK. Did I
6. check my sugar? and when I did go low, he was always there
7. hovering. I appreciated it, but I'm a grown man. I can take
8. care of myself

Extract 6

Michael – type 1 gay man (lives with his male partner)

1. Michael: I think generally a gay relationship is not quite (.) quite the same
2. as a lot of straight relationships where there is this y'know
3. almost a change from mother to wife scenario for them because
4. that's- they're not independent they've been controlled by their
5. mother they've left home got married and now being controlled
6. by the wife and then the kids come along and they just end up in
7. drudgery and following what they're supposed to do (.) so I can
8. see that being a lot more of an issue
9. Adam: Yeah and in what way do you think a gay relationship is
10. different to that?
11. Michael: Erm (.) I think you find they're more equal (.) I mean I'm sure
12. there are some that are not >don't get me wrong it's not gonna
13. be everyone< but I just think in general in gay relationships you
14. tend to be two people- two independent people that live together
15. and do various things together

In Extract 5 Justin adopts the position of an independent man by constructing his ex-partner's attempts at support as undesirable. He uses a three-part list of things his ex-partner used to do to construct him as overly involved (lines 3-5). He also uses the extreme case formulations that his partner was 'constantly' (line 5) asking if he was alright and was '*always* there hovering' (lines 6-7), conveying his partner's surveillance as incessant. This device is commonly used to maximise a description's rhetorical force when attempting to accuse or argue a particular point (Pomerantz, 1986). He provides a disclaimer that he 'appreciated' his partner's concern, warding off possible readings of him as ungrateful, before constructing such behaviour as not only undesirable, but unnecessary. By his reference to himself as a 'grown man' who is capable of caring for himself, he implicitly contrasts himself with a child. The idea of a partner checking one's management of a chronic condition is thus here constructed as infantilising. In the process, he also manages to adopt a position consistent with hegemonic masculine ideals of self-reliance and independence.

In Extract 6 Michael also positions himself as independent, however he does this through a contrast of gay and heterosexual relationships ('they're not independent' in line 4 versus 'you tend to be two people- two independent people', lines 13-14). Here he constructs a rather derisory picture of heterosexual relationships (and wives in particular) whereby heterosexual men are under women's control. In order to lend weight to this assertion, Michael deploys a script formulation of heterosexual men leaving the maternal home, getting married and having children (lines 4-6). Script formulations are descriptions of actions or events which characterise them as predictable and sequential (Edwards, 1995). Here Michael adds credibility to his statement that heterosexual men undergo a transition from being controlled by their mothers to their wives, by embedding this claim within a (hetero)normative series of life events – getting married and having children. For instance, stating that 'the kids come along' (line 6), helps to endow this script with a sense of inevitability. Embedding claims in such scripts are convincing precisely because they sound familiar to the listener. Michael's use of the word 'drudgery' (line 7) to describe heterosexual men, here is both evocative and interesting as it is arguably an inversion of what would usually be associated with heterosexual women's traditional roles of wives and mothers. The claim that women have 'social control' over male partners' health was noted in the introduction to this chapter. Health professionals and wives have also been found to commonly position men as childlike, constructing them as unable to take care of themselves, thus conflating the roles of wife and mother (Seymour-Smith et al., 2002; Seymour-Smith and Wetherell, 2006). What is interesting here is that Michael draws on and interprets this understanding of heterosexual relationships in order to position his own relationship in more favourable and 'equal' terms (line 11).

The following extract shares a number of characteristics with the previous one. However, unlike Michael, whose account was told in an observational or 'documentary style' (Seymour-Smith et al., 2002: 259) in which the dynamics of his own relationship were merely implied, Martin constructs his relationship as equal and contrasts this with his previous relationship with his ex-wife.

Extract 7

Martin – type 2 gay man (lives with his civil partner James)

1. Martin: I think we're jointly responsible for what we eat and erm (.) I
2. suppose there are times when James will say "let's have this"
3. and I say "no hang on that's not as healthy as this alternative"
4. Adam: yeah
5. Martin: but I think generally speaking we try to take equal responsibility
6. (.) erm when you were talking about kids as I was saying earlier
7. I was married and I've got three children and when the marriage
8. broke down they used to come round for a meal and I would
9. cook
- [3 lines omitted]
10. Adam: And when you were married was it joint then?
11. Martin: No it was entirely my wife who used to plan the meals and I just
12. used to help her to buy the food (.) and it wasn't planned as
13. much or with as much care (.) it's probably difficult with
14. children anyway I think you probably do tend to buy more than
15. perhaps you need (.) but yeah that was the pattern we followed
16. Adam: Yeah so perhaps slightly different had you been with her today
17. do you think?
18. Martin: Yeah probably (.) I think she would exercise sterner discipline
19. than I exercise on myself I think (.) she was that kind of person
20. anyway
21. Adam: Yeah so your partner doesn't try to exert any control?
22. Martin: No no
23. Adam: Any encouragement or
24. Martin: Encouragement certainly and discouragement from buying the
25. wrong things or eating the wrong things but we both I think
26. accept that it's entirely up to each of us what we eat and what we
27. do really

Here Martin generally constructs his relationship with James as one of 'joint' and 'equal' responsibility, which is then contrasted with his previous wife who was 'entirely' responsible for meal planning. And again, in contrast to his stated equal relationship with his current partner, his ex-wife is described as controlling. While he does not suggest that this is a generalisable gender difference ('she was that kind

of person anyway', lines 19-20), he nevertheless positions his current same sex relationship as equal, one of individual responsibility and 'encouragement' (line 24). What is also of interest here is the way in which Michael does not orient towards the described situation with his ex-wife as requiring an explanation for why he did not take equal responsibility, simply stating; 'that was the pattern we followed' (line 15), perhaps intimating at traditional gender roles.

Negotiating responsibility for dietary management

As Peel et al. (2005) illustrate, 'roles' and responsibility for the management of diabetes is constructed within talk itself. As we ask participants to discuss the management of their condition, they are actively involved in negotiating blame and responsibility. For example, consider the following extracts taken from the same interview:

Extract 8

Amy - type 1 bisexual woman (lives with her partner Steve)

1. Amy: since he's been working at home he just bakes all the time (.)
2. and you can't refuse- well you can but ((laughs)) you feel bad if
3. you refuse to eat it and it's puddings and (.) I know I'm doing
4. the wrong thing but (.)
5. Adam: yeah

Extract 9

1. Adam: Yeah and do you think when he's cooking do you think he cooks
2. with your diabetes in mind or?
3. Amy: No ((laughs)) no the portion control is quite scary really
4. ((laughs)) I have been known to eat about three kilograms of
5. carrots at once and he does know about it and he understands I
6. mean (.) y'know he's got a chemistry degree and it's there and
7. he knows the principals but I think the two don't go together
8. really in his head
9. Adam: And what about the food shopping do you do that together or?

10. Amy: ((laughs)) We used to (.) erm but again he's- with having more
 11. time at home he's taken over that mostly and again its you
 12.. mention something and we've got four packets of it ((laughs)) I
 13. won't show you the freezer (.) biscuits and chocolate and (.)
 14. Adam: yeah
 15. Amy: I mean yes I can eat them but not in the quantities we've
 16. currently got sitting in the house
 17. Adam: yeah
 18. Amy: and I do get quite frustrated with him and I do take it out on him
 19. >and I know it's me and my will power< (.) yes he's bringing it
 20. into the house but he's not making me eat it and I can see from
 21. doing all the blood tests at the moment that it is the evenings
 22. that's sending my blood sugar through the roof

In both Extracts 8 and 9 we see how Amy delicately negotiates responsibility for doing the 'wrong thing' by eating unhealthy foods. In Extract 8 Amy uses the extreme case formulations that her partner bakes 'all the time' (line 1) and that she 'can't' (line 2) refuse. She then quickly repairs the turn, possibly in recognition that the extreme nature of this claim would risk her account not being taken seriously (also indicated by her laughter). The claim is then tempered with 'you feel bad if you refuse' (lines 2-3). From a discursive perspective, invoking emotions such as 'feeling bad', do not reveal underlying emotional states but rather are used as an interactional resource. In this case, guilt is invoked as a reasonable justification for not refusing her partner's puddings. Her use of 'you' instead of 'I' ('you feel bad if you refuse to eat it', lines 2-3), generalizes her statement to suggest that *anyone* would find it difficult to refuse something their partner had cooked, as well as positioning her behaviour (eating the pudding) as reasonable. She then attends to the imperative to appear morally accountable by stating that she knows it is 'wrong' (line 4). Responsibility is implicitly shared within this account. Amy's description of her partner as always baking foods which she can't refuse, works to attribute a degree of blame on him for making the puddings. However she then positions herself, as opposed to her partner, as ultimately culpable ('I know I'm doing the wrong thing', lines 3-4).

In Extract 9 I ask Amy if her partner considers her diabetes when preparing meals. Amy's laughter (lines 3 and 4) here lightens the negative implications of her response. Although she describes the portion sizes her partner serves as 'scary' (line 3) the subsequent laughter may signal that we are not to take this too seriously. This again happens in line 12 where she laughs after criticizing how her partner buys too much food. She provides an incomplete three-part list of the 'type' of foods he buys in excess (line 13). Jefferson (1990) noted that it is very common for lists to consist of three parts. While the lengths of lists can vary (above, we saw the deployment of a four-part list), a list of two lacks rhetorical power. The second 'and' which ends the list here may function as a 'generalised list completer' in the same way as one might use 'etcetera' to imply a third part to the list (Potter, 1996b). The list used here ('biscuits and chocolate and', line 13) is a list of archetypal unhealthy foods (Peel et al., 2005). At the end of this extract there is more explicit toing and froing of blame attribution ('yes he's bringing it into the house but he's not making me eat it', lines 19-20).

In the extract below, we return to Becky and Jo as another example of how one partner's responsibility over another's dietary management is negotiated and accounted for:

Extract 10

Becky – type 2 lesbian woman (lives with her partner Jo)

1. Jo: I THINK I CONTROL her:: diabetes better than what she does
2. Becky: Yeah if we go out for a meal-
3. Jo: I've adjusted to it better
4. Becky: If we go out for a meal (.) I say to Jo "can I have a dessert?"
5. Adam: ((laughs))
6. Becky: Because it's a big thing if I have a dessert isn't it?
7. Jo: Mm
8. Becky: y'know it's like I've been a really good girl to have a dessert and
9. if she says no I'll whinge but I won't have it
10. Adam: ((laughs))
11. Becky: so you're like my mother in that way aren't you?
12. Jo: Yeah (.) but I can control it better than she can

The first thing I would like to note here is that the extract above could be viewed as politically embarrassing for lesbians and gay men who would like to position their relationships differently to heterosexual relationships (as seen in the previous theme). My reason for including this extract is not as 'evidence' that the construction of same sex relationships as egalitarian is a 'false' one, rather it is to examine how a same sex partner's control over another's behaviour is negotiated within talk in the absence of gender roles.

In the first line of this extract Jo emphatically claims to 'CONTROL' Becky's diabetes (also in line 12) and is critical of Becky's self-management of her condition. Becky aligns herself with this assessment and positions herself as childlike. She has to ask Jo for permission to have a dessert⁵¹ (line 4), she must have been a 'really good girl' in order to have one (line 8) and she will 'whinge' if Jo's does not allow it (line 9). She also explicitly describes Jo as being like a 'mother' (line 11). This raises the question, what does adopting such a childlike position function to do within this account? Seymour-Smith et al., (2002) note that the common positioning of men as childlike and passive with regards to their health presents such behaviour as humorous. There is certainly evidence of this here, indicated by my laughter in lines five and ten. Broom and Whittaker (2004: 2378) similarly note that it is not uncommon within people's accounts of diabetes self-management to involve a 'parodic positioning of themselves as children'. To do so, they suggest, evokes playfulness and diverts blame. Thus it arguably functions to relinquish responsibility, while at the same time diminishing the perceived seriousness of this. Note also however, that Becky still attempts to present herself positively by indicating the exceptionality of her having a dessert in her emphasis that such an event is a 'big thing' (line 6) and that she will not have a dessert if Jo says no (lines 8-9). Becky's construction of herself as an obedient child, thus neither challenges Jo's account of her as not fully being in control, while avoiding the possible negative connotations of this.

Finally, consider the extract below in which Becky and Jo, at another point in the interview, continue to jointly work up Jo's position of control over Becky's dietary

⁵¹ Note that the dessert in question is unspecified here, but it is implied that a dessert is necessarily an unhealthy or indulgent part of a meal.

management. Here Becky and Jo attend to what Peel et al. (2005: 785) refer to as ‘the troublesome issue of consuming chocolate’:

Extract 11

1. Becky: I mean you know to buy my chocolate (.) to keep in the house (.)
2. but- I have to kind of justify it don't I?
3. Jo: Yeah
4. Adam: So you- so you buy the chocolate?
5. Becky: For me when I ask because if I go-
6. Jo: If she goes she'll buy a big bag
7. Becky: Yeah I'll go mad
8. Jo: When I just buy a block of chocolate and it's got to last her a
9. couple of weeks like (.) because if it hasn't then I wanna know
10. why
11. Becky: And I'm- I have such poor willpower I just think “oh bollocks
12. I'll have it anyway” so I know if I was to go and buy it I'd have
13. one in the car on the way home, I'd have one when- do you
14. know what I mean? So it's kind of (.) an unwritten agreement
15. isn't it
16. Jo: But I only buy her a bar of chocolate once a month (.) I don't
17. buy it her everyday

Here I request clarification that it is Jo who buys chocolate for Becky. This account is collaboratively produced by finishing and building on one another's turns. Jo explains that if Becky were to buy chocolate herself she would buy a big bag, while Becky builds on this with ‘Yeah I'll go mad’ (line 7). This again is an extreme case formulation, implying that her chocolate purchasing behaviour is uncontrollable. Preceding this extract, Becky had previously drawn on discourses of addiction describing herself as a ‘chocoholic’, which arguably functions much in the same way (Peel et al., 2005; Benford and Gough, 2006). As with Amy in Extract 9, Becky also draws on the notion of ‘willpower’ but to quite different effect. Amy drew on a discourse of willpower to emphasise individual responsibility with regards to her

diet and to excuse her partner's behaviour which could have been interpreted as unhelpful. Becky, by comparison suggests that she, as an individual, has very 'poor' willpower and puts this forward as a reason for Jo to control and supervise (but also to permit) her chocolate consumption. Jo's buying of the chocolate is constructed as a form of damage limitation and characterised by Becky as a mutually reached arrangement. Finally note Jo's minimisation of how little and how seldom it is bought (lines 8-9 and 16-17), highlights Jo's orientation to her buying the chocolate as being potentially viewed as inappropriate.

Summary

In summary, in this chapter I have built on previous work within discursive health psychology which has examined how diabetes self-management is constructed through talk (Peel et al., 2005) and how social support is negotiated within relationship talk (Seymour-Smith and Wetherell, 2006). I have extended this work by looking specifically at the talk of non-heterosexuals. Broom and Whittaker (2004) suggests that people's talk about the self-management of diabetes displays the negotiation of a moral identity through what are often contradictory discourses. People are fundamentally concerned with asserting a positive and moral identity. The talk analysed here focuses not only on their management of diabetes, but significant other's (particularly partners') involvement and 'support'. My participants drew on contradictory discourses surrounding gender and sexuality. Participants invoked traditional notions of gender, at times constructing women as more caring and sympathetic than men while, at others, positively portraying men as stoical and rational while women were depicted as overemotional and overbearing. Such discourses were often drawn upon in ways that were advantageous for the construction of their own relationships. They were used to imply that lesbian relationships were more caring by virtue of their gender or that gay men were more independent and their relationships more equal than heterosexual relationships.

The discourses drawn on here mirror those available within the literatures regarding support within heterosexual relationships and the nature of same sex relationships. While same sex couples are neglected within the social scientific literature of

partner support, non-heterosexuals are able to draw on discourses about 'what straight couples are like', in order to construct their own relationships favourably. However this had to be done tentatively and in a way which did not discount dominant liberal individualist discourses that we are all, more or less, the same and that the nature of a relationship depends on the individuals within it. We also saw how couples have to navigate tricky terrain when discussing responsibility within their relationships. In order to position themselves positively participants could not simply position their partner's as to blame (for example by cooking or buying 'wrong' foods). To do so would contravene dominant moral understandings of individual responsibility (Broom and Whittaker, 2004; Peel et al., 2005). Similarly when one partner was described as 'controlling' or supervising another's diabetes management, this was done in a way which presented themselves as a harmonious couple who had willingly come to this arrangement rather than this being imposed by gender roles. In talk about partner support, it would appear that people often attend to protecting both their own and their (current) partner's identities simultaneously. Here I have drawn attention to both the local embeddedness of interaction as well as the wider 'structural' factors which influence talk. The use of contradictory discourses is (in part) determined by the interactional business being attended to at any given moment. Essentially there may be a lot more 'going on' within participants talk than qualitative research about social support, which generally treats their data as disinterested descriptions of the roles and responsibilities within their relationships, might suggest.

In the next chapter I continue to explore how LGB people's relationships intersect with experiences of diabetes, however the focus shifts to (predominantly) gay and bisexual men's accounts of how diabetes has affected their sex lives.

Chapter 6: Sex and diabetes: gay and bisexual men's experiences

Background

Sexual dysfunction in men with diabetes is well documented, with the focus primarily being on erectile dysfunction (ED) (Penson et al., 2009). Studies have suggested that around half of all men with diabetes will experience ED at some point (Fedele et al., 2000) and that sexual dysfunction is common in even relatively young men with type 1 diabetes (Penson et al., 2009). While psychological factors (such as performance anxiety) can contribute to erectile problems, there are a range of physiological factors which directly relate to diabetes (e.g. nerve damage, narrowing of the arteries, endocrine disorders). De Berardis et al. (2002: 284) have characterised ED in men with diabetes as 'a serious problem too often overlooked'; a sentiment reiterated by participants in a study by Rance et al. (2003), which found that men with diabetes ranked ED as the third most important complication of diabetes after kidney disease and blindness. Despite this, there remains a dearth of qualitative research that considers the wide range of sexual difficulties related to diabetes and the socio-cultural and relational contexts in which they are experienced.

The few studies that have begun to address this issue have largely taken the form of 'quality of life' assessments and attempts to measure 'sexual bother' (e.g. De Berardis et al., 2002; Penson et al., 2003; Penson, et al., 2009). For instance, men with diabetes report more severe ED than men without diabetes and ED has a significantly worse psychological impact on men with diabetes than those without (Penson et al., 2003). However, as Bokhour et al. (2001) have argued (in relation to ED and prostate cancer), such studies tell us little about the lived experience of this problem and therefore do not explore the nature of the problem in a sufficiently meaningful way. Furthermore, these assessments do not allow for discussion of other issues related to diabetes and sexuality.

Such research typically applies quality of life scales to measure the psychological impact of biomedically defined sexual ‘dysfunction’. However, medical understandings of sexual function obscure the social, cultural and interpersonal context of sexuality (Tiefer, 1994; Potts et al., 2004; Wentzell and Salmerón, 2009). Moreover, they impose sexual norms by promoting the phallogentric and heteronormative idea that ‘sex’ necessarily involves the insertion of an erect penis into a vagina; and as such cannot, unproblematically, be applied to gay men (Boyle, 1993).

The very definition of ED is often, either explicitly or implicitly, framed in terms that are inappropriate for gay men (Blank, 2005). For example, a self help text by the American Diabetes Association (Roszler and Rice, 2007: 8) poses the following question: ‘have you been experiencing difficulty recently in achieving erections that you and your partner consider adequate for vaginal intercourse?’ Although one could argue that sexual problems such as ED are the same for both gay and heterosexual men, an erection adequate for vaginal intercourse may differ from that needed for anal or oral penetration (Goldstone, 1999; Blank, 2005) and insertive and receptive roles are potentially reversible in sex between men (Sandfort and de Keizer, 2001). Also if we look beyond the physical, to the psychosocial and cultural, the differences may be greater still.

Studies regarding diabetic men and ED do not usually specify the sexual identity of their participants despite often documenting other sociodemographic characteristics such as ethnicity, educational level and household income (e.g. LeMone, 1993; Penson et al., 2003; Penson et al., 2009). Relationship status is commonly recorded; however, the vast majority of participants are invariably married. Given that these studies are largely undertaken in the US where same-sex marriage remains widely unavailable, it may be reasonable to assume that the majority are in different sex relationships. The number of sexual partners is also often omitted, or when noted (e.g. Penson et al., 2003) the vast majority are in monogamous relationships. The result is that those who are gay, bisexual, single or in non-monogamous relationships are marginalised and rendered invisible within the research literature. Expectations and concerns about sex may differ between heterosexual and gay men

and the experience of sexual difficulties within an exclusive relationship may differ to that of casual encounters (Bancroft et al., 2005).

As Campbell and Whiteley (2006) assert, sexual problems occur within a social, relational and cultural context and understanding that context is key to providing adequate and appropriate support. In this chapter I turn my attention to diabetic gay and bisexual men's accounts of their sexual experiences. I therefore focus on the twelve gay and two bisexual men interviewed. However at the end of this chapter I will briefly pay attention to the sexual 'problems' that one female participant (and her partner) discussed.

Research question

This chapter examines how diabetes affects gay and bisexual men's sex lives, and asks how do social and personal contexts affect these men's experiences of diabetes-related sexual difficulties?

Method

Participants

As noted above, this chapter focuses primarily on the 14 men with diabetes who were interviewed. Of these, eleven identified their sexual identity as gay and two identified as bisexual. Ten of the men had type 1 diabetes (mean duration 27 years) and three had type 2 diabetes (mean duration 6 years). Their ages ranged from 28 to 69 (mean 48 years) and all participants were white. Nine participants resided in the UK and four in the US.

Procedure

The procedure for conducting the interviews was as outlined in the previous chapter. No direct question regarding sex or sexual dysfunction was asked during the interviews. However, questions such as 'in what ways has diabetes affected your relationship?' commonly resulted in men's accounts of how diabetes had affected their sex lives. All of the men discussed sex to some degree and from speaking to

the male participants after the interviews it was clear that there was commonly a prior expectation that this would be a topic of discussion. By contrast, only one of the female participants discussed sexual problems. In the spirit of the semi-structured interview, when this topic did arise in the participants responses, this was followed up with further questions in order to elicit elaboration from participants.

Ethical considerations

Ringheim (1995: 1692) suggests that ‘there are few social science research topics more difficult to study’ than sex, given its sensitivity. In addition, Gott and Hinchliff (2003) suggest the topic is more difficult still to research with older people as there is arguably an even greater potential to upset and offend. Therefore when this topic was raised during interviews, great care was taken to conduct questioning in a sensitive manner. When such personal information was disclosed, time was given for participants to share their stories. For some of the participants I was one of the few people with whom they had discussed their sexual problems and for one participant in particular (‘Colin’), it appeared to be the reason he had taken part. Indeed Colin’s account of his erectile problems dominated much of the interview and he later commented that he had taken part in order to share his story, in the hope that it would be of some comfort to others in his position. Despite the sensitivity of the topic, the men all appeared comfortable sharing this information and none appeared offended by any further line of questioning. Some have suggested that face-to-face interviewing may be seen as ‘threatening’ in sex research (Catania, McDermott and Pollack, 1986: 71), and the anonymity offered by online interviewing may well have helped the US participants ‘speak’ more candidly. While euphemism was used much more within the face-to-face interviews, they nevertheless produced rich accounts which were more extended and nuanced in character. Furthermore, many of the men in the face-to-face interviews commented afterwards that they had enjoyed the interview⁵². Given the sensitivity of this topic and Colin’s expressed desire to ‘share his story’, a more experiential form of analysis was used. As Willig (2004: 166) notes, while discourse analysis has much to offer critical health psychology, it can risk undermining the status of ‘illness narratives as a form of self-expression’. By adopting a critical realist standpoint I was able to preserve the experiential and embodied dimensions of

⁵² This was similarly observed in Gott and Hinchliff’s (2003) study of older people’s views of sex.

participants' accounts while also noting discourses at play or the subject positions that their narratives afforded.

Method of analysis

Thematic analysis, as outlined by Braun and Clarke (2006) and described in Chapters 2 and 3 was used to analyse collated data on the topic of sex and diabetes. Themes were identified which related to sexual difficulties associated with diabetes. The themes identified were 'problem-based' and within each theme I paid particular attention to the meaning given to the problem, as well as the sociocultural and relational context in which the problem was 'situated'. Here I adopt a critical realist perspective (Willig, 2001) as it affirms the (at times embodied) 'reality' of these problems for the participants while putting some critical distance between myself and the way in which my participants talked about their difficulties and the discourses they draw upon. In this analysis I aim to adopt a broad concept of 'sexual difficulty' (Richters et al., 2003; Hurley and Prestage, 2007) moving away from the narrower, medically defined concept of 'sexual dysfunction'.

Analysis

Three problem-based themes were identified: erectile problems; other 'physical' problems (thrush and hypoglycaemia); and disclosing diabetes to sexual partners.

Erectile problems

Erectile difficulties were the most commonly mentioned sexual problem among the participants. While all were aware that erectile difficulties were a possible complication of diabetes, the men typically found it difficult to determine whether their own poor erections could be caused by other factors such as age or stress. The perceived severity and psychosocial impact of such difficulties varied between the men. Many described the problem as 'manageable' with medication. None of the US participants suggested a lack of health insurance prevented them access to medication, but several UK participants suggested the quantity of oral prescription drugs available on the NHS for erectile dysfunction is inadequate for an active sex life. For others, erectile problems had a more profound impact on their life:

Extract 1

It [‘impotence’] had over the years killed my social life ...I can’t just chat to somebody in a pub...I remember on one occasion I went into a gay pub and there was a lad I’d been eyeing up for months, stunning from my point of view and erm...next thing I knew he was standing next to me. I couldn’t speak, I could not speak and he came to stand next to me, somebody he knew fancied him. I gulped it down and ran out the club. I can’t believe I did that now but I couldn’t even talk to him. I was too frightened because I wouldn’t want somebody on our local scene to know that erm, I couldn’t rise to the occasion. And that’s the one problem with gay life ...in heterosexuality, you meet on another occasion and you go out and you go for dinner or for whatever and you chat to them. It’s a long time before you actually got into bed, but the gay life was never like that, that was almost always the first time you meet. So that was terrifying me I couldn’t do it. (Colin)

In this extract, Colin’s account is contextualised by his identity as a gay man, attending commercial venues on a gay ‘scene’ and belonging to a culture which follows different relationship ‘rules’ or scripts than that of a heterosexual culture (cf. Mutchler, 2000). Before the interview, Colin commented that he did not consider himself to be a ‘typical gay man’ as he had had little sex during his life, which he attributed to the lack of confidence described above. His account not only suggests fear of embarrassment on an individual level with a partner, but his specification that he would not want somebody on the ‘local scene’ to know implies a fear of gossip spreading throughout his local gay community.

Colin also invokes the idea of two distinct and dichotomous cultures; ‘gay life’ in which gay men engage in sexual activity quickly after meeting a partner and ‘straight life’ whereby sex is preceded by a courting process. A key point raised within the interviews was that the context of sexualised norms within gay culture shaped and exacerbated their experience of sexual difficulties related to diabetes:

Extract 2

It can cause problems because, as a gay guy, obviously a major part of the gay culture is basically sex, y'know, it's very promiscuous, very sexually orientated, very physically orientated and if you suffer from impotence- if you're seventy odd then they don't care, but when I was in my thirties, when I was in my early thirties and I'm going what!? Well if you go to a bath house, like a gay sauna, y'know it can definitely be erm, not so much the physical side, but it stresses your- self worth, you lose your sense of self worth. You lose your confidence, it's a confidence thing. (Enzo)

The sexualised norms of the communities to which they belong were framed as highly problematic for these men. As Braun et al. (2009: 121-122) note, however, such an account of gay culture 'is a somewhat stereotyped portrayal of a homogenised gay community that does not reflect the diverse, complex and nuanced communities and contexts in which gay and bisexual men live'. This understanding of gay culture may nonetheless shape the way these men see themselves. Having sex thus becomes integral to the maintenance of a gay or bisexual identity (Mutchler, 2000; Braun et al. 2009). Above, Enzo suggests that experiencing erectile problems when attending gay saunas has resulted in a loss of confidence and self worth. Although he does not specify what exactly it is about this environment that makes such problems particularly difficult, the anonymous and depersonalised nature of such sex-on-site venues may not be sensitive to the emotional needs of men who experience sexual difficulties (Haubrich et al., 2004).

While 'erectile dysfunction' is generally defined in medical discourse as an inability to achieve or maintain an erection adequate for (assumed-to-be-vaginal) intercourse (Steidle, 2002), some of these men stated that they did not engage in anal intercourse at all, nor did they desire to do so. For instance, Colin candidly remarked: 'I've never given or received anal sex. I never wanted to'. Yet, erectile problems were spoken of in the context of other sexual activities:

Extract 3

If it's a one night stand then yeah even if it's only a hand job by them, you want a reason for it, and they might think that they don't turn me on, y'know,

and that would be rotten for me, if I really was attracted to them physically then I don't want it to look as if I wasn't. So again it's embarrassment I suppose in a way, but yeah I'd lose them for that reason. (Colin)

This extract highlights that the meanings ascribed to erections are wider than medical discourse of sexual 'function' imply. Within the medical model, the 'function' of an erection is its ability to penetrate and engage in intercourse. In contrast, it is the psychosocial impact that is emphasised here; the embarrassment experienced, as well as fear of losing a potential partner. This embarrassment is likely, at least in part, to be due to the relation between the erect penis and notions of hegemonic masculinity, however gay and bisexual men may resist the 'coital imperative' inscribed in the medical model of erectile dysfunction (Potts, 2000). The significance of an erection as suggested here is also about communicating sexual arousal and indicating pleasure to a partner. Rather than use prescribed medicine for erectile dysfunction in order to treat an inability to engage in intercourse, Colin suggested that he had only ever used erectile aids (e.g. 'Viagra') for masturbation. Similarly Enzo spoke about his erectile problems in relation to masturbation:

Extract 4

The only thing I resent, if you said to me 'is there anything you resent about diabetes?' it's erm because I'm a guy, I do things that guys do when they're on their own, and the mechanics don't work. There's many a time I lie in bed and it doesn't matter how hard I try, I'm on my own, and my body just will not cooperate and that gets me down. (Enzo)

Again, here, difficulties getting an erection were not described as an inability to engage in intercourse. The 'problem' is not even portrayed here as embarrassment, or the ability to 'perform' for a partner. Rather it is about his relationship with his own body and frustration with its non-cooperation. Just as the ability to have sex was part of Enzo's perception of being within the norms of the gay community, the ability to masturbate is also framed here as part of his identity as a man ('because

I'm a guy, I do things that guys do'). So rather than erectile dysfunction representing an impediment to the 'natural' function of penetrative intercourse, as the medical model suggests, within these accounts erectile difficulties were interwoven with and problematic for these participants' identities as men and in particular as gay or bisexual men.

Other 'physical' problems

While erectile problems are typically the sole sexual problem addressed within the literature about men with diabetes, these men reported a number of other more acute complications of their condition which affected their sex lives. For example, in the extract below, Ben describes his experience of thrush and its impact on sexual activity between him and his partner:

Extract 5

Ben: As a diabetic, I sometimes suffer from a Candidiasis in my buttocks. This makes it impossible to be the "bottom" in anal intercourse.

Adam: Ok. And is that a big issue for you? I mean do you adjust what you do in the bedroom because of that?

Ben: It hasn't been all that much of a concern. I do prefer to top and my partner is usually willing to bottom, but there are times we'd like to switch and haven't been able to...there have been 2 or 3 occasions in which a particularly bad Candidiasis infection has caused an odour which makes oral sex unpleasant. In those situations, my partner and I have been limited to mutual masturbation or have abstained from sexual contact altogether.

Although vaginal thrush is commonly reported as a problem for women with diabetes within the self help literature (e.g. Roszler and Rice, 2007), candida infections in the anogenital region are also common among men with diabetes, which may be particularly problematic for gay or bisexual men who engage in receptive anal intercourse (Goldstone, 1999). The above extract highlights the flexibility inherent in sex between men, where adopting certain roles can be used as a strategy to resolve particular sexual difficulties⁵³. Although it was not commented on within these interviews, gay and bisexual men experiencing erectile difficulties

⁵³ This may, however, be limited by the sexual preferences of the men involved.

may similarly choose to be the receptive partner in intercourse which does not necessitate an erection (Bancroft et al., 2005). Ben went onto explain that he was not 'out' to the health professional responsible for his diabetes care and visited a specialist sexual health clinic for gay men when being screened for sexually transmitted diseases (STD):

Extract 6

I feel that I'd have to discuss any sexual problems related to my diabetes with my endocrinologist. I did have to discuss the Candidiasis with him, but I did not disclose its affect on my sex life. If the impotence problems continue, I will also discuss those concerns with him. The gay health clinic in [city name] seems to operate exclusively for the testing of STDs and the counseling of those who find themselves testing positive for an STD...I have considered exchanging the care of my endocrinologist for the care of an internal medicine specialist in [city] who advertises as gay-friendly. If diabetes ever had a significant enough impact on my sex life as a gay man, then I almost certainly would make that change. (Ben)

Gay and bisexual men may be wary of discussing their sexual behaviour with health professionals, not least due to the historical medicalisation of gay men's sexuality (Scarce, 2000). While it is understandable that some gay and bisexual men may want to limit unwanted medical surveillance of their sexual behaviour, it is important that they have access to health services that allow for the discussion of such problems⁵⁴. Ben's statement that if diabetes had a significant impact on his sex life *as a gay man* he would exchange his care to someone who advertised as 'gay friendly', suggests a degree of trepidation about discussing sex with his current doctor. There is no suggestion by Ben that he has any experience of discrimination from his endocrinologist. However, as highlighted by the questionnaire responses in Chapter 3, non-heterosexuals may be reluctant to disclose their sexual identity to health professionals for fear of potential repercussions in the quality of care they receive (see also Stein and Bonuck, 2001). Riggs (2009) suggests that heterosexism

⁵⁴ It is also critically important that gay and bisexual men in general feel able to discuss erectile problems with health professionals as this may be the first symptom of diabetes or among those already diagnosed with diabetes, it may be the first sign of complications such as heart disease.

operates subtly in this way. The mere possibility that discrimination may occur has the power to influence gay and bisexual men's decisions not to be 'out' in certain environments and keep non-heterosexual people in marginalised positions. The compartmentalisation of Ben's health care between the 'gay health clinic' that is aware of his sexual identity and his endocrinologist who is not, could be viewed as problematic in terms of continuity of care. Indeed the separation of his diabetes care and his sexual health creates a situation in which Ben may feel unable to discuss sexual difficulties related to diabetes with either of these health professionals. Ben reports feeling that such problems do not fall within the remit of the gay health clinic's services, and appears to express a degree of trepidation about discussing them with his diabetes specialist.

A more common problem reported by the men with insulin dependent diabetes was experiencing hypoglycaemia ('having a hypo') during, or resulting from, sex. Symptoms of hypos can vary widely and include shakiness, sweating, nausea, difficulty speaking and behaviour sometimes likened to 'drunkenness'. Having a hypo was commonly described as interrupting sexual activity and requiring explanation. Enzo spoke of how symptoms of a hypo might 'scare' partners:

Extract 7

It affects your sex life radically. Erm, there are times when if it all gets too energetic at the end of it I get the shakes or I'm half way to collapsing and the other guy who may have come to meet me for the first time, it's gonna scare the shit out of em, because they're wondering what the hell they've walked into, y'know what I mean? So what I do now is, I deliberately overload my body. I eat an entire packet of biscuits if I know somebody is coming, to counter balance y'know what I mean. (Enzo)

We see here how Enzo deliberately maintains a high blood glucose level before sex in order to avert such a situation occurring. Having hypos during or after sex was also common for Gordon who had experienced them with all of his previous partners. In contrast however, Gordon explained how he prepared for this

eventuality by warning partners, keeping energy drinks containing glucose nearby and explaining to partners what to do:

Extract 8

I've had bad hypos in the middle of the night with them [his boyfriends] in fact one, two, three, I've had hypos with all of them at different times and of course they know about the diabetes and I've warned them about it... I generally put a lucozade by the bed and say 'listen if I get into trouble there's the lucozade alright'...it's difficult for boyfriends, it's so unexpected and they've never seen it before. (Gordon)

Again, here Gordon emphasises the impact of hypos on his partners. While Enzo and Gordon's strategies for managing the possibility of hypos differed, note the different relational contexts of these two accounts. Enzo describes a situation in which someone is potentially meeting him for the first time. Gordon, by comparison, refers to 'boyfriends' and states that 'of course they know about the diabetes'. Thus the different strategies described by these two men may be indicative of the relational context and level of communication with their sexual partners. Indeed, communication about diabetes with new or casual partners was a common theme among the men's talk; one that I consider a 'difficulty' in itself and one to which I now turn.

Disclosing diabetes to sexual partners

Many of the men spoke about whether or when they would tell new sexual partners that they had diabetes. This was described as a particular dilemma for those using an insulin pump which may render an otherwise invisible illness visible:

Extract 9

I'm single and when I meet up with guys, I'm the proverbial queer and like my sex. But being on an insulin pump, I usually end up telling them what the infusion site is all about 'cause it does look odd especially when it's an odd spot like my inner thigh or near a nipple on my chest. (Justin)

Whilst explaining an insulin pump or its infusion site to a new sexual partner is not a unique experience to a single gay man, Justin nevertheless begins by making reference to himself as *the proverbial queer* who likes sex. As Riggs (2009: 523) suggests, self-referencing in this way draws our attention to the fact that gay male communities 'make available to gay men a range of intelligible subject positions and relational expectations'. In this instance, Justin positions himself as falling within the stereotyped 'norm' of a single gay man who enjoys recreational sex and, as such, must negotiate discussing his infusion site on a regular basis. Decision making regarding whether or not to explain an insulin infusion site was described as being based on its location on the body, the relational context of the sexual counter and also from previous experience of negative reactions from partners noticing the site. In particular the concern was expressed by two participants that this sign of illness may be mistaken as signs of a positive HIV status:

Extract 10

I just don't like guys wondering about it when they inevitably see it. I'm usually unhooked from pump, so it's just the site. I tell them that I'm a diabetic and on an insulin pump and that is where I hook up to it at. Sometimes it's before, sometimes after. But unless it's just a quickie thing, I tell them 'cause I usually don't like to be unhooked from pump for too long. Anonymous stuff, I don't bother unless they ask...from guys seeing [the] site before I tell them it's like "oh man, what's that?!?!?" or "what's wrong with you, you aren't sick or something are ya?" which I take to mean HIV status and then explain. (Justin)

Extract 11

Again, because it's different, they either don't ask but are looking at it (the insulin pump operates through a small tube that goes into the abdomen) or query what it is. A second device, a continuous glucose monitor is a second device that[s] attached to the body...The result is that when you first get intimate with someone, it's usually a shock to that person...Usually it's not a big deal since almost everyone has heard of diabetes. I always wonder whether people are worried about whether it's some sort of intravenous HIV treatment. (John)

This may be indicative of the significance of HIV within the psyches of gay and bisexual men. Lipton (2004) has argued that within gay communities notions of illness readily evoke HIV as those with other chronic illnesses are relatively 'invisible' within these communities.

Dilemmas about whether, or when, to tell sexual partners about diabetes were not, however limited to those using insulin pumps. A number of the men felt that telling new partners about their diabetes was a hurdle at the beginning of any new relationship and disclosing this information early on was described as increasing their risk of rejection. For example, Graham stated that when he was single he would avoid staying the night at others' homes to avoid having to inject:

Extract 12

I've probably avoided y'know even staying over and stuff. I probably would have avoided injecting in front of them or- I'd have it with me but I wouldn't because obviously you can't really, because then you've got to open up the whole thing so... again you just wouldn't because it's kind of like a one night stand so therefore you're never gonna- I mean that would just be really strange if you sort of started talking about stuff like that. (Graham)

This extract demonstrates how a discussion of one's health with a casual sex partner is understood as violating norms that govern casual sex (Davis, 2001). Here Graham characterises such an idea as 'really strange'. While communication with partners is often emphasised within the self help literature (e.g. Roszler and Rice 2007), these accounts suggest that this may be particularly challenging in certain situations and, in particular, casual sex may not be conducive to a discussion about one's health or sexual problems.

The absence of women's accounts

Thus far my focus has been on men's sexual problems. In some ways, this mirrors the literature on sex and diabetes in which women's sexual problems have been marginalized. Only in recent decades has sexual 'dysfunction' in women with

diabetes been acknowledged. For example twenty five years ago, Kerson and Kerson (1985: 121) stated that ‘sexual response in women is not generally affected’ by diabetes. What research was conducted into sexual complications of diabetes among women simply compared them to the male norm, asserting that women were significantly less likely to report sexual problems than men (Jensen, 1981). However it has been recognised that diabetes can affect women’s sexual response in terms of desire, arousal and orgasm. Women particularly report experiencing a decrease in genital sensation, vaginal dryness and recurrent thrush, which can interfere with women’s sexual enjoyment (Muniyappa et al., 2005). Over the last decade a growing body of literature has emerged which explores the impact of diabetes on women’s sex lives (Erol et al., 2002; Enzlin, Mathieu and Demytteeaere, 2003; Rockliffe-Fidler and Kiemle, 2003; Muniyappa et al., 2005). Only one of the women I interviewed spoke of experiencing diabetes-related sexual difficulty. There are a number of possible reasons for this. It may be that the women did not feel comfortable discussing such issues with a male researcher, or it may have been that the women I interviewed did not experience such problems. In the remainder of this chapter, I will consider Becky’s experience. The following was in response to a question asking if diabetes affected Becky’s relationship with her partner Jo:

Extract 13

Becky: It can do because it can give you, oh what’s the word?

Jo: Thrush

Becky: Oh I wasn’t even thinking of thrush. Lack of sexual desire. You just don’t feel like it [...] but yeah as a lesbian thrush is a good one, well done love. You are prone to get thrush [I: yeah] well that’s a sex killer straight off isn’t it

[8 lines omitted]

Jo: Doesn’t bother us does it?

Becky: Nah

Jo: If we were together because of sex then-

Becky: It’s not the be all and end all is it?

Jo: No it’s not

Becky: It's a benefit. That's how we see it, it's a benefit. It doesn't affect us does it?

Jo: Nah

[14 lines omitted]

Becky: I think that it wouldn't make a difference to a woman anyway because sex is mental in a woman, whereas it's physical for man isn't it y'know. I mean men can't really go without sex but a woman can. It's seen completely differently, it's more emotional for a woman. So as long as we have that cutch [cuddle] it's the same as sex for us because it's that physical contact. With a man he needs the physical release doesn't he ((interviewer laughs)) basically in basic words

Jo: And our relationship isn't based on sex anyway

Here lack of libido and thrush are identified as sexual difficulties associated with diabetes. What is perhaps most striking about Becky and Jo's joint account is the way in which these issues are described as having a minimal effect on their relationship. Jo states that 'it doesn't bother us' and Becky concurs, commenting 'it doesn't affect us'. Furthermore, both Becky and Jo construct their relationship as one which is not 'based on sex'. Becky also contrasts male and female sexuality, suggesting that for women, sex is primarily an emotional activity. Feminist scholars have suggested that androcentric and heteronormative definitions of 'sex' which focus on genital activity, and in particular penetration, may not capture physical intimacy present in lesbian relationships (Peplau and Garnets, 2000; Peplau, Fingerhut and Beals, 2004). This can be seen above in Becky's comment that a cuddle is 'the same as sex' as a form of physical contact and emotional expression. Similarly, research has found that some women include hugging, kissing and touching in their definition of sex (Conway-Turner, 1992) and that many lesbians have fulfilling relationships without genital sex (Rothblum and Brehony, 1993; Rothblum, 1994). Winterich (2003) found that although most of the menopausal women she interviewed experienced vaginal, libido and orgasm changes, many suggested that they continued to enjoy an active sex life by communicating with their partners and changing the way they had sex. Winterich also suggests that her lesbian participants had broader definitions of sex which led to such changes being

less problematic within their relationships. Although no definite conclusions can be drawn from this one account, it may provide some insight as to how lesbian women's sexuality may shape how they experience sexual complications associated with diabetes and may provide a clue as to why the women in this study did not discuss sexual 'problems' in relation to their condition.

Summary

In this chapter I have examined the perceived impact of diabetes on the sex lives of gay and bisexual men. In line with the high prevalence of erectile dysfunction among (assumed-to-be-heterosexual) men with diabetes, problems getting or maintaining erections were the most commonly reported sexual problem described by this sample. Much of the literature regarding sex and diabetes takes its cue from the medical model of sexuality and sexual 'dysfunction'. As Potts et al. (2004: 498) argue, this medical model homogenizes the diversity of sexual experiences, reduces sexual problems to those of desire, arousal and orgasm, as well as positions (vaginal) penetrative intercourse as central to sexual relationships. The gay and bisexual men and the lesbian women's accounts here challenge such notions of sexuality and sexual dysfunction. Moreover, while 'erectile dysfunction' is often the only sexual problem addressed among men with diabetes, these men spoke of a range of problems including candidiasis, experiencing hypos as a result of sexual activity and negotiating the disclosure of diabetes with sexual partners. Accounts of these sexual problems highlighted how such difficulties are shaped both by sexual identity and the relational context in which they occur.

In my final chapter, I will summarise the findings across the thesis and outline how it has contributed to the areas of critical health psychology and LGBTQ psychology, before considering the limitations of this research, and the potential for future research in this area.

Chapter 7: Discussion and conclusions

In this final chapter, I consider the thesis as a whole. I begin by summarising my findings. I then discuss the contributions my research has made to both critical health psychology and LGBTQ psychology before considering some implications for practice. I then identify a number of limitations of my research. Finally, I end by identifying avenues for future research following from my findings, both in terms of gaps in the literature and the use of different approaches.

Summary of the findings

In Chapter 3 my aims were to explicate some of the ways in which (non-hetero)sexual identities may shape experiences of chronic illness and to ‘give voice’ to LGB(TQ) people who have rarely been represented in health research. By using an online qualitative questionnaire, I captured the perspectives of people living with a wide range of illnesses. While respondents differed in terms of age, gender, ethnicity, nationality, how they identified their (non-hetero)sexuality and health conditions; what ran through many of the responses were experiences of oppression, invisibility and isolation. Many respondents suggested that they faced prejudice from within LGBT communities and felt a sense of isolation from those communities. Furthermore, the ‘support’ infrastructure available for those with their illness often did not represent them, rendering LGB(TQ) people invisible and at times they experienced (or feared) prejudice from within health care services. In this way, the respondents could be said to experience multiple forms of marginalisation. Not only were these respondents marginalised by heterocentric and heterosexist societies, but many also felt marginalised within their own LGBT communities because they do not fit the health-related norms of society (Lipton, 2004). Green (1997) suggests that LGB people from ethnic minority backgrounds similarly encounter such ‘double’ discrimination, experiencing heterosexism within their ethnic cultures and racism within LGBT communities. While in this thesis I have focused specifically on the intersection of sexuality and physical health, multiple forms of oppression (or privilege) may be experienced simultaneously.

In Chapter 4 I turned my attention to the internet. A number of survey respondents reported seeking support online and using the internet to connect with other non-heterosexuals living with illness. Such groups may be used to alleviate social marginalisation and isolation, as well as to discuss issues such as relationship problems and sexual difficulties in an environment safe from heterosexism. In this chapter I used discourse analysis to examine one person's attempt seek support and to connect with another 'gay diabetic' within a diabetes newsgroup. This case study 'naturalistic' data for interrogating heteronormativity in understandings of health and illness and evidence of the heterosexism which may occur in online support groups. By examining the way in which posters contested the relevance of sexuality to a diabetes newsgroup, I was able to demonstrate how sexuality and diabetes were socially constructed. When framed within a biomedical discourse, diabetes was constructed in terms of metabolism, blood glucose levels and illness management activities such as carbohydrate counting and blood testing. Reductionist discourses were also deployed that constructed 'gayness' solely in terms of sexual behaviour and associated gay sex with HIV. By contrast, others attempted to bring these two subject positions ('gay' and 'diabetic') together drawing on a 'social model' of sexuality and diabetes which considers issues such as stigma, isolation, discrimination, relationships and social support.

In Chapter 5 I continued to take a discursive approach and focused on LGB people's talk about social support within relationships. Here I drew on interview data with LGB people living with diabetes and examined how interviewees constructed 'support'. Talk about their diabetes self management and their relationships displayed negotiation of wider discourses of gender and sexuality as well as discourses of interdependence and individual responsibility. Participants drew on a number of interpretative repertoires in order to position their partners and relationships favourably. Traditional notions of gender were at times drawn upon, constructing women as more caring or positively portraying men as stoical and rational. At other times, participants drew on the notion that they were different to heterosexuals, for example constructing gay men as possessing the 'feminine' qualities needed to care for a chronically ill partner. Therefore in their search for language to describe their relationships, they often drew on dominant discourses of

gender and heteronormative discourses of gender inversion. Same sex relationships were also constructed as more equal than different sex relationships.

In Chapter 6 I explored how diabetes intersects with gay and bisexual men's sex lives. In line with the high prevalence of erectile dysfunction among (assumed-to-be-heterosexual) men with diabetes, problems getting or maintaining erections were the most commonly reported sexual problem described by this sample. Much of the literature regarding sex and diabetes takes its cue from the medical model of sexuality and sexual 'dysfunction'. As Potts et al. (2004: 498) argue, this medical model homogenizes the diversity of sexual experiences, reduces sexual problems to those of desire, arousal and orgasm, as well as positions (vaginal) penetrative intercourse as central to sexual relationships. In line with Potts et al.'s findings from their analysis of men and women's 'viagra stories', the accounts of these gay and bisexual men demonstrated a range of significances attached to erections, and the problem was spoken of in relation to sexual activities other than intercourse. Such accounts do not map onto the 'typical' definitions of 'erectile dysfunction'. The gay and bisexual men and the lesbian women's accounts here challenge such notions of sexuality and sexual dysfunction. Moreover, while 'erectile dysfunction' is often the only sexual problem addressed among men with diabetes, these men spoke of a range of problems including candidiasis, experiencing hypos as a result of sexual activity and negotiating the disclosure of diabetes with sexual partners.

Accounts of these sexual problems highlighted how such difficulties are shaped both by sexual identity and the relational context in which they occur. Throughout, the men's accounts were contextualised by the sociocultural milieu of their relationships and their identities as gay or bisexual men. This involved experiencing sexual difficulties within a highly sexualised gay culture in which notions of health are entwined with HIV and seeking help from potentially heterosexist medical professionals. I highlighted the need for a contextually sensitive approach that explores sexual difficulties within their cultural and interpersonal contexts in order to provide support which is appropriate for men of diverse sexualities in various forms of relationships.

The key contribution this thesis makes to the psychological literature is its nuanced exploration of the support that LGB people living with chronic illness seek and receive. It challenges dominant narratives that LGB people disengage from families of origin to more ‘supportive’ families of choice within LGBT communities. In contrast, the research presented here suggests that non-heterosexuals may feel they can no longer live up to cultural norms and expectations of LGBT communities and may experience isolation from those communities. ‘Supportive’ networks such as face-to-face or online support groups may also not be experienced as such. Indeed the nature of ‘support’, what counts as supportive within a relationship and whether LGB people require specific forms of support have all been shown to be contestable matters.

Contributions to a critical health psychology

Throughout this thesis, I have drawn attention to the heterosexual bias within much of health psychology. The health of non-heterosexual people beyond the confines of sexual and mental health is clearly a neglected topic within the discipline and as such our knowledge base with regards to chronic illness is heteronormative. When topics such as partner support, the management of chronic illness within relationships or sexual dysfunction related to chronic health conditions are studied, the focus is either explicitly on heterosexuals, or the sexual identities of participants are not collected or documented. There is a tendency within health psychology to fit a broad range of experiences into one, invariably heterosexual-based model (Riggs, 2007a).

I have argued that critical health psychologists should critique the normative status of heterosexuality within the discipline and illustrated some ways in which psychologists might incorporate non-heterosexual experience as a more central concern within critical health psychology. As Brown (1989: 448) argued more than twenty years ago, the ‘tendency to perceive lesbian and gay issues...as tangential “special topics” robs psychology of much of its ability to understand human behaviour’. Yet LGB people remain at the margins of health psychology beyond sexual health. As Fish (2006: 143) notes, ‘particular health problems, such as those relating to sexual behaviour or mental health, are considered more relevant to one’s

sexual identity than others'. Consequently, sexual identity is often not considered 'relevant' to the study of illnesses such as diabetes. This is perhaps not surprising given that health and illness are predominately understood within a biomedical model (Wellard, 1998). Accordingly, ill health is typically understood as affecting individuals on a biological level irrespective of their social identities. Even health psychology which claims to adopt a biopsychosocial model often uncritically relies on biomedical concepts and notions of relevance. Heterosexuality, meanwhile is routinely deemed relevant to illness in the form of discussions about support from (heterosexual) partners, (hetero)sexual dysfunction and so on. In this thesis I have challenged concepts of relevance that are based on individualistic and biomedical frameworks.

I have also contributed to critical health psychology by giving voice to a marginalised group often rendered invisible. In doing so, this thesis might be viewed as part of a larger project to write sexual identity into health (Wilton, 2000), 'proliferate the possible identities of illness' and allow 'space for queer identities' (Jain, 2008: 506) within the health literature. Epstein (2003: 156) has suggested that it is unlikely that 'academic health researchers will be prone to value the kinds of experiential, community-based knowledge about health, illness and sexuality that are cultivated in grassroots activists circles'. By drawing on the social activist approach of critical health psychologists, who define themselves as 'scholar-activists' (Murray and Poland, 2006) and on the qualitative paradigm of critical health psychology, it is precisely this kind of experiential and community based knowledge I have captured. Throughout the thesis, I have positioned the individual as embedded within macro-social contexts (e.g. within a culture which marginalises or renders them invisible) and within meso-social contexts (e.g. their relationships with their partners, families and health professionals) (Flowers, 2009).

An overarching thread that runs throughout this thesis is the nature of 'support' which chronically ill LGB people either seek or receive, both virtual and in 'real life' contexts. As a source of both information and support, health psychologists have tended to display an optimistic view about the internet, believing it to 'empower' those living with illness (e.g. White and Dorman, 2001; Coulson, 2008). The internet is a vast repository of medical information which, providing one has

access to it, can be found quickly and conveniently, twenty four hours a day. In addition, one can make contact with and join online support groups which otherwise might not be available due to geographic or other limitations. Such groups provide access to experiential knowledge of living with chronic health conditions and provide opportunities for emotionally supportive interaction. I do not wish to downplay the benefits of the internet, indeed I have pointed to further benefits for chronically ill LGBTQ people who wish to create their own supportive communities. In addition to 'support' Charmaz and Rosenfeld, (2010: 322) also note that the internet 'has created possibilities for participating in the collectivization and politicization of illness' (see also Cartwright, 1998). However, although the potential benefits of online support should not be dismissed, possibilities for 'empowerment' have perhaps been romanticised (Pitts, 2004).

I have argued for a more critical examination of online 'support'. When health psychologists have expressed concerns about online health information and support groups, these have tended to be related to the accuracy of medical information (e.g. Morahan-Martin and Anderson, 2000). Critical health psychology should also consider how power relations manifest themselves in these online environments. Coulson, Buchanan and Aubeeluck (2007: 173) suggest that 'online support groups may bring together a more varied range of individuals offering diverse perspectives, experiences, opinions, and sources of information than might otherwise be the case'. I would argue that more critical attention should be paid to the 'diversity' within such groups, examining exclusionary practices and norms around participation and what can be said in such groups. More specifically, I contend that heteronormativity and heterosexism extend to these health-related online contexts.

I have also contributed to discursive approaches to health psychology which, as Willig (2000) notes is interested in how people 'make sense of their experiences of health and illness within the context of social norms and culturally available commonsense knowledges' (p552). I have built upon work which applies discourse analysis to health-related computer-mediated communication (Lamerichs and te Molder, 2003) and added to work which has investigated the negotiation of gender identities in relation to health concerns (Seymour-Smith et al., 2002; Peel et al., 2005). I have extended this body of literature by focusing specifically on non-

heterosexuals and examining how sexual identities are negotiated within health talk. In doing so, I have highlighted the discursive economy within which LGB people live, specifically in the context of chronic illness and diabetes in particular. As Willig (2000) suggests, this discursive economy is likely to have implications for how individuals subjectively experience their illness and how they experience the support that their partners and others provide. I did not seek to answer the question of whether diabetes is managed *differently* within same sex relationships. This would require engaging with a comparative paradigm of research which I have actively avoided here. Rather, I adopted discourse analysis which views talk as constructing rather than reflecting reality (Potter, 1996), in order to consider the multiple ways in which participants discussed the management of their condition in the context of their relationships.

Contributions to LGBTQ psychology

This thesis contributes to LGBTQ psychology by responding to calls for more qualitative research on LGBTQ health, beyond the almost exclusive focus on sexual health (Wilkinson, 2002; Adams et al., 2004). It also contributes to the academic wing of an LGBT health movement that seeks to highlight the barriers faced by LGBT people (Rofes, 2007). The success of this movement has resulted in Government recognition of health inequalities for this population (Fish, 2007), however the requirement of providing statistical evidence of health disparities has led to a research agenda which relies predominantly on quantitative methods and takes a comparative approach.

In this thesis I have actively avoided a comparative model of research which seeks to determine how LGB people differ from heterosexuals. This paradigm is currently dominant within the field, with an over-reliance on ‘community’ surveys that seek to provide quantitative data about how prevalent certain health behaviours are within LGBT communities. What such research does not tell us is how health is experienced by non-heterosexuals and how sexual identity colours people’s experiences of illness. Furthermore, such research is based on a heteronormative foundation which takes non-heterosexuals’ health and experience of illness as only worthy of study when compared to the heterosexual norm. LGB people are framed

in relation to how they differ to heterosexuals, while studies of heterosexual people's experiences of health and illness are simply taken to be studies about health and illness. Moreover, comparative approaches focus overwhelmingly on how LGB people's health is poorer than that of heterosexuals (or the 'general' population). The ways in which LGB people's health may be better than their heterosexual counterparts is rarely emphasised and therefore this literature risks pathologising non-heterosexuals (Flowers, 2009; Ussher, 2009). This is not to denigrate comparative health research within this field. The relationship between sexual identity and health remains poorly recognised, and highlighting health inequalities between heterosexuals and non-heterosexuals is vital for pushing sexual identity firmly onto public health agendas and speaks well to policy makers. Indeed it has been argued that, in many ways, mainstream approaches that use quantitative and comparative methods can be more effective in producing social change than qualitative and critical approaches (Kitzinger, 1997; Clarke and Braun, 2009). However, in choosing to adopt qualitative methodologies and critical approaches we should interrogate the implications of mainstream research and counter them.

I have argued that LGBTQ psychologists could usefully draw on critical health psychology and qualitative methods to explore why certain health conditions are constructed as 'lesbian', 'gay' or 'bisexual' health issues (and therefore worthy of study), while sexual identity is considered irrelevant to other health concerns. For instance in Chapter 4, an online newsgroup provided a virtual environment where arguments about the (ir)relevance of sexuality were played out and available for analysis. By examining a single thread I was able to illustrate how, and in what ways sexuality was constructed as a relevant issue to their experience of diabetes and how it was constructed as irrelevant by others. By adopting a discursive approach I was also able to examine which arguments were more successful than others and why.

LGBTQ psychologists researching the role of the internet in LGBTQ health have tended to focus on gay men's use of the internet to find sexual partners and the implications of this for sexual health promotion (e.g. Bull, McFarlane and Rietmeijer, 2001; Tikkanen and Ross, 2003; Bolding et al., 2007). To my knowledge, my research is unique in examining online health-related support

groups specifically for LGBTQ people. The broader literature on the internet and sexuality, as with the health literature, has taken an optimistic view of the medium couched within a discourse of empowerment (Pitts, 2004). Wilding (1998: 9) suggests that this literature has tended to portray a 'net utopianism' where 'you can be anything you want to be' (see also Ebo, 1998). Within this utopian vision, the internet is viewed as the great equalizer. Others, by contrast, have argued that the internet is not an inherently empowering medium; conventional power relations are evident within online interactions and social norms are often reproduced (Herring et al., 1995; Pitts, 2004). I have added to this literature by demonstrating how heteronormativity and heterosexism operate to regulate and police sexuality within an online health-related support group. This raises wider questions about what online groups for LGBTQ people represent. It could be argued that they represent the empowering possibilities of the internet, enabling a more diverse range of illness experiences to be represented. However, they could also represent 'cyberghettos' (Ebo, 1998), or necessary 'safe spaces' within a heteronormative and heterosexist world (both on and off-line). The internet provides a wealth of opportunities for (critical) LGBTQ psychologists to explore the ways in which gender and sexuality are socially constructed through language. Indeed social theories about the internet emphasise the textually represented nature of 'identity' within a disembodied cyberspace, and view online interaction and participation as projects of defining the self (Turkle, 1995). It also provides many opportunities to study heterosexist interactions that have been archived for public viewing (and scrutiny). My research builds on work which explores heterosexist talk in interaction (e.g. Speers and Potter, 2000) by examining it specifically in the context of online discussion boards.

Although one of the aims of this thesis has been to push the LGBTQ health agenda beyond an almost exclusive focus on sexual health, I have also contributed to LGBTQ psychology by diversifying the literature in this field. Much of the literature on gay and bisexual men's sexual health has focused specifically on sexually transmitted infections, rather than sexual dysfunction. When sexual dysfunction among gay and bisexual men has been addressed, such research has tended to focus on HIV-related sexual dysfunction or been concerned with preventing HIV transmission by those experiencing sexual dysfunction (Sandfort and de Keizer, 2001). I have added to work on sexual dysfunction, by focusing

specifically on diabetes. To my knowledge my study is the first to examine gay and bisexual men's experiences of sex and diabetes. I examined the cultural and relational context in which sexual complications of diabetes are experienced, which is often missing within the clinical literature about diabetes and sexual 'dysfunction'. By employing an experiential approach my study illustrates the psychosocial and cultural milieu in which these experiences were situated. As noted in Chapter 2, some scholars have commented that it is naïve to suggest that qualitative researchers can simply 'give voice' to their participants (e.g. Fine, 2002; Braun and Clarke, 2006). As researchers, at the very least, we inevitably select certain stories over others and tell these through a particular theoretical lens in the process of academic writing (Fine, 2002). Moreover, we may wish to take a critical stance regarding the discourses that our participants draw upon in order to tell their stories. For instance, in Chapter 6 gay culture was routinely constructed as highly sexualised. This view of gay male culture is commonplace, as is the idea that this is in some way problematic (Braun et al. 2009)⁵⁵. For example, it was suggested by some participants that a highly sexualised gay culture exacerbated their negative experiences of sexual difficulties associated with diabetes. I was initially somewhat wary of these constructions as they often suggest a singular gay culture and a singular straight culture, which is clearly an oversimplification (Flowers and Langdrige 2007). Furthermore, such accounts could be taken up and reinterpreted in ways which may further stigmatise gay male communities. At the same time, neither do I wish to discount my participants' experiences or insist upon a liberal acceptance of sexualised cultures which give rise to personal anxiety and pathologise sexual difficulty. By adopting a critical realist approach I argue that we can give voice to participants, while at the same time interrogating such discourses, holding them up for scrutiny and assessing their positives and pitfalls.

As Peel and Thomson (2009), note in their special issue on LGBTQ health psychology, to date this field of study remains underdeveloped and would greatly benefit from a research agenda which goes beyond sex and pathology. In sum, this thesis builds on the work of critical LGBTQ health psychologists (e.g. Adams et al., 2004; MacBride-Stewart, 2004; Riggs, 2005a; Adams et al., 2007; MacBride-

⁵⁵ As Braun et al. (2009) note this appears to be the case regarding gay cultures in different Western countries including, the US, the UK and in their own study in New Zealand.

Stewart, 2007; Braun et al., 2009) and contributes specifically by focusing on the neglected area of chronic illness.

Implications for practice

Much of my research may not seem to be of immediate relevance to the practice of health care. Lawton et al. (2005: 1424) ask more broadly of qualitative health research; ‘in our enthusiasm to understand and situate patients’ disease perceptions, experiences and understandings in the settings of their everyday lives, have we pushed the medical context too far to the sidelines?’ This relates to the question of how qualitative health researchers situate their work in relation to medicine, which has long been debated within medical sociology (e.g. Straus, 1957), but is only recently being considered within (critical) health psychology (Flick, 2006). Do we wish to serve medicine, answering questions set by medical agendas or do we wish to examine the nature and experience of health and illness which may include, but also go beyond, medical contexts? This thesis can be firmly located in the latter camp. However, this is not to suggest that my research has no implications for the practice of health care. On the contrary, I argue that issues such as heterosexism and social marginalisation should not be viewed as tangential concerns within health psychology or within health care itself (see also Wilton, 2000).

The participants who have contributed to the research reported in this thesis came from a number of countries with different health care systems, which may have implications for patients’ experiences. In terms of diabetes, the form of treatment is similar in both the UK and the US (where all interviewees resided). The key difference between these two countries’ health care systems is access; universal access to care is provided in the UK by the NHS while a market-based system operates in the US (Mainous, 2006). The significant shift in social attitudes towards LGBTQ people in both these countries over recent decades will likely have had a significant impact on health care services. People in same sex relationships, on both sides of the Atlantic have in the past feared that should they be admitted to hospital, health professionals may not acknowledge their partners or even deny them hospital visits. It is commonly believed that, in the UK, the introduction of the Civil Partnership Act (2004) solved this problem by giving registered partners next-of-kin

status. Guidelines by the Royal College of Nursing and Unison (2004), however point out that the term 'next-of-kin' has never had much legal meaning in UK health care and the wishes of clients' should always have been respected. Civil partnerships did bring such issues to widespread attention and gave rise to an unprecedented amount of positive media recognition of same sex relationships (Jowett and Peel, 2010), but it was the subsequent Equality Act (2006) which outlawed discrimination against LGB people in the provision of goods and services (including health services). Meanwhile in 2010, President Barack Obama directed the US Department of Health and Human Services to prohibit discrimination in hospital visitation on the basis of sexual orientation (Shear, 2010).

Despite this, I believe legal prohibition of discrimination alone is unlikely to eradicate heterosexism altogether due to underreporting of homophobic incidents (Peel, 1999) as well as the insidious and mundane nature of some forms of heterosexism (Peel, 2001; see also Harding and Peel, 2007b for a discussion of the limits of anti-discrimination law). In fact, such legislation may risk creating the illusion of equality while heteronormative assumptions and practices continue to pervade health care (Fish, 2006). We should not assume that because discrimination is illegal that mainstream services will adequately cater for the needs of LGB people. Based on my findings, I would argue that top-down structural change should not be seen as eradicating the need for grassroots initiatives within LGBT communities. It is clear from my research that non-heterosexuals living with a chronic condition may require additional support and welcome the opportunity to interact with other LGB people with the same illness. As illustrated in Chapters 3 and 4, in the absence of support groups for non-heterosexuals, LGB people are increasingly turning to the internet to form their own supportive networks. However, such groups are often not as active as members would like.

Perhaps one practical way that both LGBT communities and health organizations can be of assistance is to help such groups be more active by coordinating these supportive networks. An exemplary example of this is the Alzheimer's Society's LGBT support group⁵⁶. Other health organisations such as Diabetes UK could

⁵⁶ See http://alzheimers.org.uk/Gay_Carers/

follow this example, by providing online support for LGBT people that is moderated to prevent heterosexist interaction. They could then advertise this support through their publications and by having stalls at Pride festivals alongside HIV organisations. Such actions would also raise awareness of chronic health conditions among LGBT communities and send the wider signal that they are recognised and welcome. In addition to specific support for non-heterosexuals, which may be preferable for some, all health services should be inclusive of LGB people and should seek to make this clearly evident (Fish and Bewley, 2010). Health organisations could, for instance, ensure that their support materials do not assume heterosexuality and include images of same-sex couples in their leaflets and on their websites⁵⁷.

Health professionals may benefit from specific education regarding LGBT health. Currently, such information is rarely taught within medical degree curriculums beyond information regarding HIV/AIDS (McNair, 2003). Diversity training and education about the cultural stereotypes that are in circulation about LGB communities may also enhance their understanding about how heterosexist assumptions may be experienced by LGB service users (Peel, 2002). Training about how to discuss sexuality with non-heterosexual patients should also be incorporated into communication skills training within medicine (e.g. Lloyd and Bor, 2009). The Gay and Lesbian Medical Association (GLMA, 2006) have published guidelines advising health care providers on how to create a welcoming environment for LGBT service users. These include some very simple steps such as using visual cues of acceptance. This can include medical leaflets that address LGBT health and LGBT magazines within waiting rooms. They also suggest incorporating sexual identity in routine intake/registration forms and consultation techniques, such as using gender-neutral language and avoiding assumptions of heterosexuality. Furthermore, they contend that it is important that all staff undergo such training, and that administration staff such as GP receptionists are not excluded. Findings from research such as my own may be usefully used to train health practitioners and encourage them to consider sexuality beyond the realm of sexual health.

⁵⁷ A brief glance at their website show that Diabetes UK do a good job of representing people from a wide range of ethnic origins.

Comments made by participants in Chapter 6 highlight the importance of a sensitive approach to sexual difficulties by those involved in diabetes care. As Bokhour et al. (2005: 655) comment in relation to their research about prostate cancer and erectile dysfunction ‘physicians may need to probe beyond the mechanics of erectile function, and ask questions about men’s feelings about their sexual lives and relationships’. It is useful for doctors and nurses to be aware of and appreciate the range of ways in which sexual difficulties may be experienced and their emotional impact⁵⁸. Clinicians should be well trained in how to talk to patients about erectile dysfunction in ways that do not assume that the problem is an inability to perform intercourse. My findings may also be useful for counsellors and psychotherapists working with gay and bisexual clients experiencing sexual problems. Physicians and therapists may wish to discuss with clients, not only treatment options but also the nature of their concerns. For example, are erectile problems preventing them from engaging in their preferred sexual activities or are they more concerned about what partners may think, or with the progression of their health condition. Clinicians may also wish to discuss new ways of being sexual and open up opportunities to discuss other sexual difficulties or concerns, not usually considered sexual ‘dysfunction’ (e.g. blood glucose levels during/after sex).

Previous research has shown that despite being out in most other contexts (e.g. to family and at work), many people do not disclose their sexual identity to their health care professionals (Eliaison and Schope, 2001). Many of those who were not out to their health professionals in my research commented that they did not deem their sexuality to be relevant to the treatment of their condition (see also Fish, 2006). While it may not be necessary for health professionals to know the details of each patient’s personal relationships, it is important that LGB people feel comfortable enough to share personal information freely and discuss their sex lives and relationships should it become relevant. The way in which one participant compartmentalized his ‘gay health’ at a specialist genitourinary medicine (GUM) clinic, from his general health and diabetes care raises possible concerns about continuity of care. While specialist sexual health clinics may provide an important

⁵⁸ After presenting my research from Chapter 6 at the 2009 LGBT health Summit, which was sponsored and accredited by the Royal College of Nursing, a number of trainee nurses commented on how useful such research can be.

service which guarantees that a gay identity will be accepted and treated confidentially, if non-heterosexuals fear disclosing their sexuality to other health professionals they may not receive adequate care. Although this came from a US participant, this may also occur in the UK which has similar specialist sexual health clinics for gay men that keep their records separately from those held by one's main primary health care provider. Sexual health clinics that work regularly with gay and bisexual clients may wish to consider the possibility of raising other health concerns beyond STI screening, in the event that these men have avoided raising such issues with their general health professionals.

Limitations

There are a number of limitations worth noting about the research presented within this thesis. Neither my online survey of chronic illness experiences nor the interview data presented here can claim to be representative of the non-heterosexual population in the UK or elsewhere. The aim of qualitative research is not to generalise one's findings to the population as a whole but rather to consider the range of subjectivities and subject positions within the specific accounts being examined. Nevertheless, a reflexive approach requires some consideration of the constitution of our research samples. It is generally recognised that it is near-impossible to obtain a representative sample of non-heterosexual people as this population is not clearly defined (Harding, 2011). For this reason it is difficult to know what a representative sample of LGB people would even look like (Fish, 2006). Online data collection methods, however are widely used by sexualities researchers and are viewed as an effective way of recruiting a more diverse sample (Harding and Peel, 2007a; Fish and Bewley, 2010).

My sample was diverse in terms of age, geographical location and the illnesses respondents lived with, however few came from ethnic minority backgrounds. The nature of online survey research also means that all respondents are literate, computer literate and have access to the internet. Despite more people than ever having access to the internet, there continues to be a 'digital divide' based on socioeconomic status. Recent figures published by the UK's Office for National Statistics (ONS) show that internet access is significantly dependent on household

income. The 10 per cent of highest earners in the UK (of whom 96% have a household connection) are over three and a half times more likely to have internet access at home than the lowest 10 per cent of earners (of whom 26% have a household internet connection) (ONS, 2010). Furthermore, socioeconomic status may also be related to the kinds of activities people use the internet for and their willingness or interest to take part in academic research. Participants taking part in my research may have had a particular interest in the topic due to experiencing heterosexism or heteronormativity in health care and research has suggested that LGB people taking part in online surveys are more likely to be 'out' about their sexual identity (Riggle, Rostosky and Reedy, 2005).

My survey looked specifically at the intersection of sexuality and chronic illness and variations based on other aspects of identity such as age and race were difficult to tease apart. In-depth interviews are perhaps a better method when looking at several dimensions of intersectionality simultaneously. Nevertheless, I believe there are a number of benefits to using this method. It allowed me to collect a large number of respondents' perspectives, in their own words and in a short time period and thus provides an insight into a diverse range of views and experiences within LGB communities. There is also a case to be made for using this methodology for exploratory and preliminary research which can be followed up with more in-depth forms of data collection such as interviews. For instance, by allowing respondents to indicate their willingness to take part in a follow up interview, researchers can use participants' responses in order to obtain a purposive or theoretical sample for their interview study and ensure that a range of experiences are included.

The use of pre-existing online material as data also has its limitations. Seale et al. (2010) note that a perceived limitation of using online forums as data is that such material may not be viewed as adequately providing answers to the social scientist's research question. I would argue that the selection of online material for analysis is guided by initial research question(s), but also that the research questions are 'evolving' in qualitative research and are refined based on the material collected, whether this be interview transcripts or pre-existing online material. As Seale et al. (2010: 605) contend:

The conventional image of quantitative research is that research questions derive from a literature review, then are formulated as hypotheses that drive research design and data collection. Qualitative research, though, is often said to be more exploratory, with initial research questions being discarded in favor of better ones as an inquiry proceeds.

By selecting a single discussion thread which has been inactive for a number of years, I cannot claim that the heterosexism displayed or the ways in which diabetes and sexuality were written about are widespread within online support networks or beyond. Nor can I claim that large numbers of diabetic LGB people seek or want support specifically for LGB people⁵⁹. There is also no way of knowing if the original poster was genuinely seeking support from another ‘gay diabetic’, or if s/he was seeking to provoke the debate that ensued. In some respects this is immaterial to the analysis, as a discursive approach to computer-mediated communication should be interested in the way in which posts are oriented to as ‘trolls’ or ‘flames’ rather than determining their ‘true’ nature (cf. Herring et al., 2002).

As with my online survey, I cannot claim that my interview data are representative of non-heterosexual people with diabetes. As the majority of my participants were recruited through a Diabetes UK magazine, my sample may reflect the readership of this publication. Those who subscribe to and read this magazine are perhaps more likely to have higher levels of knowledge about the condition and take an active interest in the management of their diabetes. During my discussions before and after interviews, several participants suggested that the magazine projected a middle-class, middle aged and family focused representation of diabetes. My sample was also predominately middle aged and middle class. The absence of non-white voices is salient given that many ethnic minority groups are more likely to develop type 2 diabetes. This in some ways mirrors LGBTQ psychology generally which has tended to focus on the experiences of white lesbians and gay men (Greene, 1997). Just as heteronormativity pervades the discipline, racial norms also operate within psychology (Riggs, 2007b). I recognise the absence of non-white people and

⁵⁹ In fact it was clear from other self-identified ‘gay diabetics’ within the forum, that they saw no reason for this kind of support. Many of my interviewees similarly felt it unnecessary to have specific support for LGB people, although several stated that it would be nice if such groups did exist and would like to meet other non-heterosexuals with diabetes.

acknowledge that my research does not provide a complete picture of non-heterosexual lives (Greene, 1997). Non-white people are often considered a 'hard to reach' group for LGBTQ researchers, alongside those who are not 'out', those from rural areas and older people (Meezan and Martin, 2003). I would add to this list those living with chronic illness and would argue that difficulties in access and recruitment become even more difficult when trying to recruit from several of these 'hard to reach' groups simultaneously. My sample however was not derived entirely from the 'usual suspects' in LGBTQ research who tend to be younger, white, middle-class able-bodied lesbians and gay men (Clarke et al., 2010). My survey and interview samples were comprised of a wide age range and all were living with chronic illnesses and in some cases disability also. On a broader level, I also recognise that any attempt at representation is likely to marginalise others (Riggs, 2005) and this is in some respects an unavoidable problem within an experiential paradigm. Even if our samples were to be as diverse as the population, we would still fail to represent the myriad ways in which such identities intersect to shape individual lives.

As an exploratory study, my research also sought to cover a range of topics related to their diabetes rather than focus on one particular topic. As such, not all my participants were in long term same sex relationships or had experienced sexual difficulties. Specific studies which focus on these issues in particular and recruit participants on this basis would allow for more in-depth discussions of these issues in the future. My research however has sketched out some new avenues and highlighted how critical approaches may be adopted within LGBTQ health psychology.

Future directions

Throughout this thesis I have highlighted many areas where non-heterosexuals or same sex relationships have been overlooked in the health psychology literature, which could be fruitful areas for future research. I noted early on in the thesis that there is currently little epidemiological data about the prevalence of many chronic illnesses among LGB people. Although I have taken a critical perspective on comparative health research and the framing of particular conditions as 'lesbian',

‘gay’ or ‘bisexual’ health issues, statistical evidence of health disparities between social groups has proved a rhetorically powerful political strategy for influencing public health bureaucracies and funders of research. The lack of research in this area is surprising given that there is a body of literature which suggests that LGB people have higher rates of the most common risk factors of chronic illness such as smoking, excessive alcohol use and obesity (GLMA, 2001). This is possibly because these behaviours have tended to be framed more in terms of ‘mental’ health issues such as alcoholism, substance abuse and eating disorders rather than in terms of risk factors for physical ill health. Future epidemiological research therefore could significantly contribute to the LGBT health movement and provide a basis for future LGBTQ health psychology research.

In terms of further qualitative research, future investigations could examine how the onset of chronic illness may be experienced alongside other forms of ‘biographical disruption’ (Bury, 1982), for example, forming an LGB identity or coming out to family and friends (Wilkerson, 2003). Narrative approaches would be better suited for such a study, allowing for a detailed examination of how sexual identity and chronic illness are interwoven into a person’s life story. Such research could also examine trans people’s experiences of illness. While there may be a number of similarities between the illness experiences of non-heterosexual and trans people, there will likely also be important differences. For instance, in addition to medical interactions relating to chronic illness, trans identities continue to be medicalized and trans people may also seek ‘sex reassignment’ surgery and hormone therapy. Future research could examine critical junctures in chronically ill trans people’s experiences of medicine and the narrative construction of their identities.

There is also a lack of research on how illness is managed within same sex relationships from either a social constructionist or positivist perspective. By examining the illness narratives of same sex couples, the ‘identity spaces’ that such narratives create for themselves and their partners could be investigated. Much research has been conducted which considers how the gender dynamics of heterosexual relationships play out when either heterosexual men or women live with a chronic illness (e.g. Peel et al., 2005; Wong et al., 2005; Seymour-Smith and Wetherell, 2006), yet we know little about the management of chronic illness within

same sex couples. Further discourse analytic work could build on my research by interviewing same sex couples together in order to examine their co-constructed accounts of living with illness. Although in Chapter 1 I argue for LGBTQ health psychology to look beyond sexual health, more qualitative research could be done that explores the nature of sexual dysfunction among LGB people and how it is experienced (Bancroft et al., 2005). In addition there is a lack of qualitative research that examines experience of sex and diabetes, especially women's experiences.

In addition to new areas of research, critical LGBTQ psychologists could also consider new approaches. Flowers (2009) argues that the focus of LGBTQ health psychology has tended to be on the negative aspects of LGBTQ health. Future research could consider adopting a positive psychological approach to LGBTQ health which considers the strengths and resilience of LGB people. For instance such research could consider the ways in which same sex couples adapt to sexual difficulties and continue to enjoy fulfilling relationships. In addition, psychologists could focus on positive experiences of health care and good relationships between LGB people and health professionals in order to identify and share good practice.

From here to queer?

In Chapter 1 I noted that in recent years scholars have begun to explore how insights from queer theory might be applied to psychology (e.g. Minton, 1997; Warner, 2004; Hegarty and Massey, 2006; MacBride-Stewart, 2007; Riggs, 2007a; Hegarty, 2008, 2009). Clarke and Braun (2009), for instance, point out that even mainstream psychological research that appears to be 'in the interests' of lesbians and gay men may reinforce problematic assumptions and perpetuates binary thinking about gender, sexuality and the sex/gender system. On the other hand, the deconstructive work of queer theorists is often viewed as far removed from the world of health care practice and policy making (Wilton, 2002).

There is a tension between queer and lesbian and gay approaches to action (Vance, 1998). The queer impulse is to dismantle the sexual categories and assumptions that give rise to heteronormative practices, while lesbian and gay movements are based on an identity politics that act to 'defend the interests of "lesbian and gay people"' (Vance, 1998: 169). Likewise, there would be an irresolvable tension between an

LGBT health psychology and a queer health psychology. An LGBT health psychology would fit in well with an LGBT health movement that is very much grounded in the politics of identity, inclusion and recognition (Epstein, 2003). Queer theory's separation of identities and behaviour, however appears antithetical to the agenda of a movement which has sought to establish LGBT people as groups who are disadvantaged by health inequalities and need specific health interventions. How exactly queer theory might inform a critical *LGBTQ health psychology* specifically (beyond HIV and sexual health research; cf. Macbride-Stewart, 2007) has yet to be fully explored. A queer health psychology would argue that sexual identity categories are not natural or inevitable and would question how the constitution of sexual 'identity' contributes to the ways in which LGB people are constructed as 'healthy', 'ill' or 'at risk' (MacBride-Stewart, 2007). It would also ask how health psychology theory and practice contribute to heteronormativity? Health psychologists may contribute to heteronormativity not only by excluding non-heterosexuals from their studies, but also when attempting to 'write sexual orientation into health' (Wilton, 2000). A queer health psychology would question the way in which LGB people are 'added in' (Hicks and Watson, 2003) by portraying them as having distinct health risks for instance, and proliferating discourses which re-inscribe pathology. It would also critique the regulatory role health psychology plays in policing normative frameworks of gender, sexuality and health.

As with my approach to methodology, I advocate a pragmatic outlook towards identity politics versus queer approaches. I believe that both identity politics and queer theory have their part to play in a critical LGBTQ health psychology. As Clarke and Peel (2007) suggest, there are advantages to both shoring up and deconstructing sexual identity categories and either can be used strategically to resist heteronormativity and heterosexism. For instance, in this thesis I have selectively drawn on queer insights and arguments when attempting to deconstruct the idea that only certain conditions are 'lesbian', 'gay' or 'bisexual' health issues, which has led other illnesses not to be studied in non-heterosexual contexts. At other times, I have drawn on identity politics as a corrective to a health psychology whose heteronormative practices have denied LGB people with chronic illness an opportunity to be heard (Sampson, 1993). As Parker (2007:7) suggests, it is

necessary within critical psychology to ‘work with the potential of each new approach, but then to reflect on the limits that such an approach may put in place as it becomes popular in the discipline’.

Queer theory has been taken up more readily within other health-related disciplines such as disability studies. *Disability studies* is an interdisciplinary field that incorporates disciplines such as sociology, history, cultural studies, politics, law and literature. Unlike much mainstream health psychology, which has often had a medical and rehabilitative focus in relation to physical disability, disability studies is explicitly grounded in a social model that examines the way in which social, cultural, economic and political factors disable those with non-normative bodies and how society fails to take into account individual differences (Olkin and Pledger, 2003). Robert McRuer (2003; 2006) proposes how queer theory might inform disability studies, in order to produce what he refers to as *Crip Theory*. McRuer draws on Judith Butler’s (1993) idea of performativity and Adrienne Rich’s (1980) concept of ‘compulsory heterosexuality’ and applies them to (dis)ability. In line with the social model of disability, McRuer argues that (dis)ability is performatively constituted rather than biologically given and that like heterosexuality, ‘compulsory able-bodiedness’ is an institution which masquerades as the ‘natural order of things’ (p.1). More importantly, he theorises that compulsory heterosexuality and compulsory able-bodiedness are interlocking (see also Kafer, 2003). Within ableist discourse disabled people are commonly constructed as asexual or when sexual activity is considered, they are presumed to be heterosexual (see White, 2003). Meanwhile within heterosexist discourse, disability is used as a metaphor for non-heterosexuality (see Peel 2001). Moreover, chronic health conditions are increasingly being viewed as within the domain of disability studies (McRuer, 2006). Critical LGBTQ health psychologists could usefully draw upon this discipline more in the future.

Queer theory may also provide a useful framework within which LGBTQ psychologists can reflexively consider their own research. By specifying that participants should identify as lesbian, gay or bisexual I have engaged in practices which regulate sexuality. There was however some resistance to this form of regulation. For example, six per cent of respondents in my online survey selected

‘other’ and described themselves in their own terms. Some specifically described themselves as ‘queer’ or ‘gender queer’, others described themselves as ‘pan/polysexual’. One respondent simply stated ‘no label’ while another wrote that he was ‘romantically attracted to women but sexually attracted to men’. We can only speculate as to why such people would self select to participate in an online survey that specifically stated that it was for lesbians, gay men and bisexuals. This would be an interesting area for future research in itself. It may be that these respondents assumed that my interest was in those who identify in ways other than heterosexually and took the opportunity to identify themselves in their own terms. They certainly would not have been wrong in their assumption, hence why their responses were not excluded from the final analysis. Had the survey not included the option to select ‘other’ and self-identify, however it may be that some respondents would have chosen to select one of the available options, therefore engaging in practices of self-regulation. Several interview participants also hesitated when completing the pre-interview demographic questionnaire when answering the question about sexual identity. One even discussed with their partner how they should answer this question. This highlights that while we may incorporate commonly used sexual identity categories such as lesbian, gay, bisexual and heterosexual in our research these are by no means unproblematic, and people’s sexual identification, attraction and/or behaviour may not easily fit on to these labels.

Some final reflections

In this final section, I end with some personal reflections on the process of conducting this research. As well as being intellectually stimulating, it has also been personally enlightening and challenging. Researching chronic illness for three years has challenged my thinking and taken-for-granted assumptions about health and illness. Before embarking on this thesis, my health was something I tended not to give much thought to unless I felt unwell or someone close to me was affected by illness. The fact that people living with chronic conditions often choose not (or feel unable) to talk about their illness publicly (Charmaz, 2002) allows people like myself to avoid having to confront issues of illness. A number of my interviewees commented that taking part in my research had given them license to talk to

someone at length about an important aspect of their lives which they usually feel unable to share with others. Likewise it was an opportunity for me to hear stories about a subject I have perhaps avoided thinking about in the past.

One thing that surprised me during this process was how difficult I found talking about my research to others both outside of and within academia. While many of my non-heterosexual interviewees were delighted by my academic interest in their experiences of diabetes, I also received a letter from a self identified heterosexual woman with diabetes, objecting to my research on the basis that sexual identity was of no relevance to diabetes. It has also been clear from discussions at academic conferences that some psychologists (including health and qualitative psychologists) have been bemused as to the ‘relevance’ of sexual identity when studying chronic illness. When discussing my research with other postgraduate students from more positivist backgrounds, the ‘validity’ of qualitative methods has been also questioned⁶⁰. These experiences are perhaps indicative of the continued marginalised status of LGBTQ and qualitative psychology respectively. In other contexts I have been wary of being open about the fact that my research focuses on LGB people. While I am ‘out’ in most areas of life, I would be selective about what I told certain people. For example, when talking to strangers, friends’ parents or even my own Grandparents, I have spoken about researching chronic illness and omitted its focus on sexual identity. Some may say that in not being completely open about my research in these contexts I have ‘colluded’ with heterosexism or failed to challenge heteronormativity. I would argue that such experiences are yet further evidence of the influence of heterosexism on LGB people, as testified by participants in my research.

For me, the most personally rewarding part of this research project has been meeting my interviewees and having the privilege of listening to their stories. While questionnaires, online interviews and extant texts are all good means of gathering data, there can be no substitute for sitting down and talking with the

⁶⁰ One distinctive feature about the institutional context of my research is that, as a small institution, Aston University has a relatively small number of postgraduate research students. As such, I was one of only a handful of research students whose research used qualitative methods and many of the other postgraduates within the School of Life and Health Sciences were from biomedical science disciplines.

people whose lives we wish to study. It was the face-to-face interviewees with whom I felt an emotional connection. Of course, the rapport formed varied from participant to participant. Some interviews provided more rich data than others and some were more 'eventful' than others. For instance, one interview was affected by a participant's low blood sugar while another was cut short due to the participant's emotional state. At the time, incidents such as these appeared to interfere with the collection of interview data. However, on reflection I view these as important experiences which brought me closer to the reality of living with a chronic condition. Interviewing face-to-face also allowed me a glimpse into the lives of my participants through being in their home or workplace and from informal discussion before and after the interview. At the end of each interview I would ask participants why they had decided to take part. Their responses were varied and insightful. In many ways they mirrored the altruistic responses Peel et al. (2006) found when examining why people take part in qualitative health research generally. For example, one participant (Colin) said that he had told his story of erectile difficulties in the hope that it might help other gay men in his situation. However participants also took part out of curiosity. For instance, one participant stated; 'I thought it was interesting because nobody ever asked me about diabetes and gayness before'. Others suggested that they felt that my research represented a form of 'recognition' or 'acknowledgment' of their dual identities that they had not previously experienced. However, perhaps the most profound response came from one participant who simply stated that; 'your research, and others like it, can help me define my own reality as a lesbian'.

LGBTQ psychologists would do well to take this statement seriously. As I have argued throughout this thesis, by focusing exclusively on health concerns and illnesses currently constructed as 'lesbian' or 'gay' health issues, we may inadvertently bolster biomedical constructions of relevance and marginalise non-heterosexuals living with many of the most common chronic health conditions. However I am optimistic about the future of the field having recently attended an international LGBT psychology summer institute where many of the delegates' research had a health focus. Although much of their work concentrated on the usual topics (sexual and mental health), as the field grows I am confident that it will continue to diversify. I was also pleased recently to see a section devoted to type 1

diabetes in the April 2011 edition of the gay lifestyle magazine *Attitude* (Jessen, 2011a), followed by a focus on type 2 diabetes in the subsequent May edition (Jessen, 2011b). The serendipitous appearance of these articles as I come to the end of this process provides a refreshing contrast to my initial observations of gay media, as outlined at the beginning of this thesis. It also fills me with hope for a future that recognises LGBTQ people living with illness in all its forms.

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Appendices

Appendix 1: Full list of illnesses reported within the survey sample

Illness	<i>n</i>	Illness	<i>n</i>
Arthritis	38	Chemical sensitivity	1
Hypertension	38	Congenital lipodystrophy	1
Diabetes	29	Diverticulosis	1
Asthma (moderate/severe)	27	Electrical sensitivity	1
Mental illnesses	19	Gastro-oesophageal reflux	
Chronic fatigue syndrome	15	disease	1
Multiple sclerosis	14	Hepatitis B	1
Cancer	12	Hirschprung's disease	1
HIV/AIDS	12	Hypotension	1
Osteoporosis	10	Myoclonic dystonia	1
Coronary heart disease	9	Polycythemia	1
Fibromyalgia	8	Pulmonary embolism	1
Epilepsy	7	Sensory hypersensitivity	1
Hypothyroidism	7	Shingles	1
Chronic pain	6	Spinal stenosis	1
Irritable bowel syndrome	6	Trigeminal neuralgia	1
Liver disease	6		
Cardiovascular disease	5		
Polycystic ovary syndrome	5		
Autoimmune diseases	4		
Colitis	4		
Severe allergies	3		
Chron's disease	3		
Degenerative disk disease	3		
Endometriosis	3		
Kidney disease	3		
Skin conditions (e.g. psoriasis)	3		
Sleep apnea	3		
Genital herpes	2		
Hepatitis C	2		
Lupus	2		
Angioedema	1		
Arnold chiari malformation	1		
Hughes syndrome	1		
Barretts syndrome	1		
Enlargement of the prostate	1		

Appendix 2: The qualitative questionnaire

Information about the Study

Researcher: Adam Jowett, a gay male research student based at the School of Life and Health Sciences, Aston University, Birmingham, UK.

WHAT IS THE PROJECT ABOUT?

The purpose of this study is to explore LGB people's experiences related to chronic illness.

IF I TAKE PART WHAT WILL IT INVOLVE?

The questionnaire consists of a mixture of multiple choice and open-ended questions. The questionnaire will take about 15-20 minutes to complete, however this will depend on how much you wish to say.

You will be asked to choose your own identification code. Please make a note of this code. If you wish to withdraw any data you have submitted, you may do so within two weeks of submitting your completed questionnaire, by emailing me with your identification code. No explanation for your withdrawal is required.

CONFIDENTIALITY

Only my supervisor and I will read the questionnaires in their entirety. You will remain anonymous; you will be given a pseudonym (false name) which your responses will be recorded against. Any information you provide will be destroyed at the completion of the study. Information you provide will be held on Survey Monkey's server, however Survey Monkey guarantee that the data will be kept private and confidential (see Survey Monkey's privacy statement for more details). Any comments made may be quoted in future publications but you will remain anonymous.

If you would like to ask any questions regarding the study, please contact me by email: jowettaj@aston.ac.uk. If you would like to take part, please move on to the next page.

Consent

Before continuing, please confirm that you agree with the following statements:

1. I have read and understood the information given to me. I have had the opportunity to contact the researcher and ask any questions I may have.

- ☐ Agree
- ☐ Disagree

2. I understand that I am free to withdraw from the study, without providing a reason, within two weeks of submitting my completed questionnaire by emailing the researcher with my identification code.

- ☐ Agree
- ☐ Disagree

3. I agree to take part in the following study.

- ☐ Agree
- ☐ Disagree

Part 1. About you

1. Please choose your own personal identification code. The code should be at least six characters long and made up of numbers or letters. Try to make the code as unique as possible, for example by combining the last letters of your name with the last numbers of your phone number (e.g. dam818). Make a note of this code as you will need it if you wish to withdraw from the study after completing the questionnaire.

2. What is your age?

- ☐ 18 - 24
- ☐ 25 - 30
- ☐ 31 – 40
- ☐ 41 – 50
- ☐ 51 – 60
- ☐ 61 – 70
- ☐ 71 – 80
- ☐ 81+

3. How would you describe your gender?

- ☐ Male
- ☐ Female
- ☐ Trans Male (FTM)
- ☐ Trans Female (MTF)
- ☐ Other (please specify)

4. How would you describe your sexual identity?

- ☐ Lesbian
- ☐ Gay
- ☐ Bisexual
- ☐ Other (please specify)

5. Which country do you live in?

6. What is your current occupation?

- ☐ Administration/Clerical
- ☐ Manual
- ☐ Professional

- ☐ Student
- ☐ Unemployed
- ☐ Retired
- ☐ Prefer not to respond
- ☐ Other (please specify)

7. What is your current relationship status?

- ☐ In a same sex relationship
- ☐ In a civil partnership (domestic partnership/civil union/ same-sex marriage)
- ☐ In an opposite-sex relationship
- ☐ In an opposite-sex marriage
- ☐ Single
- ☐ Prefer not to respond
- ☐ Other (please specify)

8. How would you describe your ethnicity?

- ☐ Black African
- ☐ Black Caribbean
- ☐ Black Other
- ☐ Indian

- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Asian Other
- ☐ White European
- ☐ White Other
- ☐ Prefer not to respond
- ☐ Other (please specify)

Part 2. About your general health

1. How would you describe your physical health at the current time?

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Prefer not to respond
- ☐ Other (please specify)

2. How would you describe your weight?

- ☐ Overweight

- ☐ Underweight
- ☐ A healthy weight
- ☐ Not sure
- ☐ Prefer not to respond
- ☐ Other (please specify)

3. How often do you drink alcohol?

- ☐ Never
- ☐ Only on special occasions
- ☐ Less than once a month
- ☐ About once a week
- ☐ 1-2 days a week
- ☐ 3-4 days a week
- ☐ Everyday or almost everyday
- ☐ Prefer not to respond
- ☐ Other (please specify)

4. Do you smoke tobacco/ cigarettes?

- ☐ Regularly
- ☐ Occasionally

- ☐ Socially (only when others are smoking)
- ☐ Never
- ☐ Prefer not to respond
- ☐ Other (please specify)

5. Are you a carer for someone with a chronic illness?

☐ Yes

☐ No

If yes (please specify your relationship e.g. partner, parent, child)

6. Do you know an LGB person with a chronic illness?

☐ Yes

☐ No

☐ Don't know

7. To the best of your knowledge what, if any, chronic illnesses do you have in your family history:

- ☐ None
- ☐ Alzheimer's disease (or other form of dementia)
- ☐ Arthritis
- ☐ Asthma (moderate/severe)
- ☐ Cancer

- ☐ Cardiovascular disease
- ☐ Cerebrovascular disease (strokes)
- ☐ Chronic fatigue syndrome (ME)
- ☐ Coronary heart disease
- ☐ Diabetes
- ☐ Epilepsy
- ☐ HIV/AIDS
- ☐ Hypertension
- ☐ Kidney disease
- ☐ Liver disease
- ☐ Multiple Sclerosis
- ☐ Osteoporosis
- ☐ Parkinson's disease
- ☐ Prefer not to respond
- ☐ Other (please specify)

Part 3. Experience of Chronic illness

Please write as much as you like in the comment boxes. There are some additional questions listed under the main questions for you to also consider when writing your response. Reflect on how your sexual identity may be relevant to any of the questions and feel free to add anything you consider is relevant to the topic that doesn't answer the specific question.

1. What chronic illness(es) have you been diagnosed with?

- ☐ Alzheimer's disease (or other form of dementia)
- ☐ Arthritis
- ☐ Asthma (moderate/severe)
- ☐ Cancer
- ☐ Cardiovascular disease
- ☐ Cerebrovascular disease (strokes)
- ☐ Chronic fatigue syndrome (ME)
- ☐ Coronary heart disease
- ☐ Diabetes
- ☐ Epilepsy
- ☐ HIV/AIDS
- ☐ Hypertension
- ☐ Kidney disease
- ☐ Liver disease
- ☐ Multiple Sclerosis
- ☐ Osteoporosis
- ☐ Parkinson's disease
- ☐ Other (please specify)

2. Please provide any more specific details about your illness (e.g. breast cancer, diabetes type 2)

3. When were you first diagnosed?

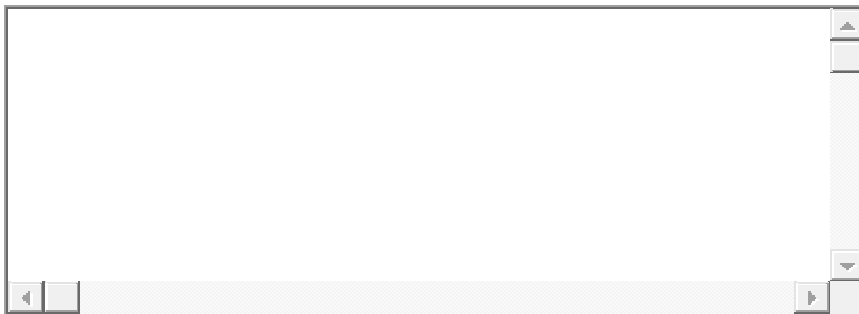
- ☐ When were you first diagnosed? Within the last year
- ☐ Within the last 2-3 years
- ☐ Within the last 4-6 years
- ☐ Within the last 7-10 years
- ☐ Within the last 11-20 years
- ☐ Longer than 20 years ago

4. What, if any, lifestyle changes have you made since your diagnosis?
- For example changes to lifestyle

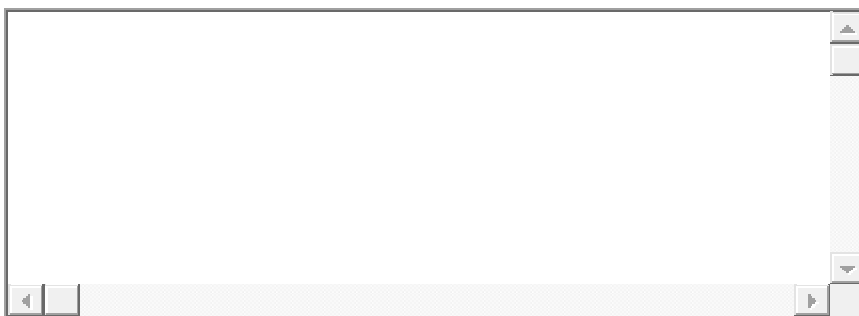
5. *In what ways, if any, has your chronic illness affected your personal life?*

- For example relationships, dating, family life, social life

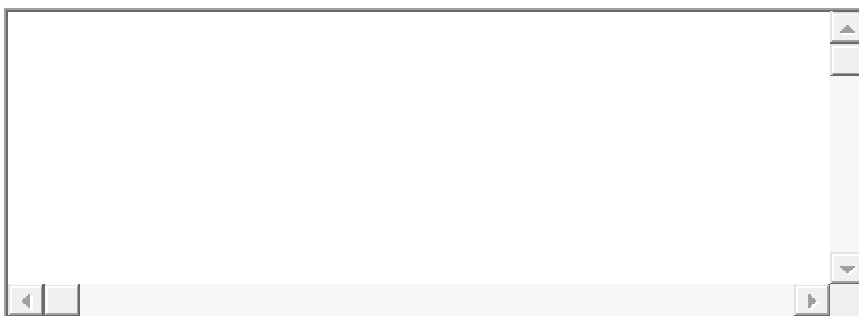
6. What roles have significant others (e.g. partners, families of origin, friends etc) played in the management of your chronic illness?
- What kinds of help/support have they provided?



7. What, if any, support have you received from LGBT communities?
- Do you feel that you have been supported by LGBT communities or individual LGBT friends?
- Do you feel that LGBT communities are aware and/or inclusive of your condition?



8. In what ways could LGBT communities or organisations be more supportive of people with your condition?



9. What are your experiences of other sources of support and information about your illness(es) (e.g. books, the internet, support groups, religious/cultural communities)?
- Have these been inclusive of your sexual identity?

A large, empty rectangular text box with a thin gray border. It features a vertical scrollbar on the right side and a horizontal scrollbar at the bottom, both with standard arrow and track controls.

Part 3 Experience of chronic illness

1. What, if anything, do you think is unique about being lesbian, gay or bisexual and having your particular chronic illness(es)?

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2. Please describe any particularly positive experiences with health care professionals?

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3. Have you had any particularly negative experiences with health care professionals?

A large, empty rectangular text box with a thin gray border. It features a vertical scrollbar on the right side and a horizontal scrollbar at the bottom, both with standard arrow and track controls.

4. Do the health care professionals you come into contact with the most know your sexual identity?

- If so how/why was your sexual identity disclosed? If not, why not?



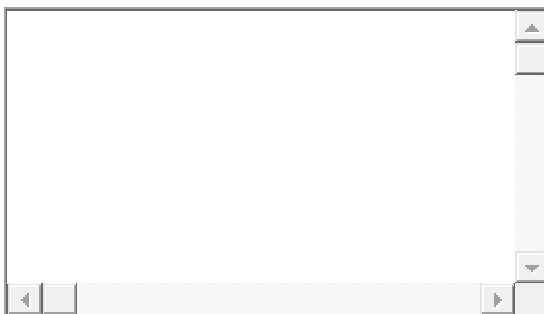
5. I would like to invite you to further take part in this research in the form of a research interview in order to discuss your experiences of your chronic illness in more depth. If you live in the UK this would take the form of a face-to-face interview or a phone interview. If you are elsewhere in the world the interview would be via instant messaging (e.g. MSN messenger). Would you be willing to participate further in the form of an interview?

☐ Yes (please leave your email address on the following page or email me directly)

☐ No

Further comments and contact details

1. Is there anything else that you would like to comment on either regarding chronic illness and sexual identity or about this questionnaire?



2. Contact details: If you would like to participate further in the form of an interview, please leave your email address or email Adam Jowett at jowettaj@aston.ac.uk. Please note that if you choose to provide your email address, this will not be passed on to any third parties.

Email Address:

THANK YOU

THANK YOU for taking part in this study.

I would like to remind you that any information you have provided will be kept strictly confidential. Any comments made, may be quoted in future publications but you will remain anonymous. Please ensure that you have made a note of your identification code. If you change your mind and wish to withdraw your data from the study after submitting it please email me with your identification code within two weeks and your responses will be deleted.

If you know of anyone who would like a paper-version of this questionnaire please email me with a postal address and I will send a copy with a stamped addressed envelope (UK only).

Please continue to the next page and click 'Done' to submit your completed questionnaire. Here you will find a list of websites which provide more information on physical health, chronic illnesses and LGBT health.

Further Information (Mainly UK based websites)

GENERAL HEALTH

NHS Direct (National Health Service, UK) provide information on a wide range of health issues from information about specific illnesses to how to improve your diet and make changes to your levels of physical activity:

www.nhsdirect.nhs.uk

LGBT HEALTH

Health with Pride provides health information for LGBT people.

www.healthwithpride.com

Out With Cancer is a US based social networking site for LGBT people who are diagnosed with cancer in association with the US non-profit organisation MaleCare:

www.outwithcancer.com

CHRONIC ILLNESS

The Long-term Medical Conditions Alliance provide information about long-term

conditions:

www.lmca.org.uk

The following can provide information and resources on specific chronic conditions:

Alzheimer's Society

www.alzheimers.org.uk

Epilepsy Action

www.epilepsy.org.uk

Arthritis Care

www.arthritiscare.org.uk

Macmillan cancer support

www.macmillan.org.uk

British Heart Foundation

www.bhf.org.uk/

Multiple Sclerosis Society

www.mssociety.org.uk

British Hypertension Society

www.bhsoc.org

National Osteoporosis Society

www.nos.org.uk

British Liver Trust

www.britishlivertrust.org.uk

Parkinson's Disease Society

www.parkinsons.org.uk

Diabetes UK

www.diabetes.org.uk

Terrence Higgins Trust (HIV/AIDS)

www.tht.org.uk

UK National Kidney Federation

www.kidney.org.uk

Appendix 3: Interview schedule

Diagnosis

- 1) To start, could you please tell me a little bit about how you came to be diagnosed with diabetes?
- 2) How did you feel when you were told about the diagnosis?

Management

- 3) What, if any, lifestyle changes have you made since being diagnosed?
- 4) In what ways does managing your health condition affect your life?
- 5) In what ways has your health condition affected your relationships?

Health care professionals (HCPs)

- 6) What kind of HCPs do you see and how often?
- 7) Could you talk a little bit about your relationship with these HCPs?
- 8) Are your HCPs aware of your sexual identity?
- 9) Does your partner (if applicable) ever accompany you to medical consultations?
- 10) Are there any topics you find difficult discussing with HCPs?

Social support

- 11) Who would you say are your main sources of support?
- 12) How does your partner help support you in the management of your condition?
- 13) Have you had discussions with other LGBT people about your health condition?
- 14) Have you received any support from within the LGBT community?
- 15) Do you think you experience your health condition differently from heterosexuals with your health condition?

Concluding questions

- 16) Can I ask why you decided to take part in this study?
- 17) Is there anything else you'd like to discuss that we've not already touched upon?

Appendix 4: Pre-interview demographic questionnaire

What is your age?

How would you describe your gender?

How would you describe your sexual identity?

How would you describe your ethnicity?

What is your current or most recent occupation?

What social class do you consider yourself to belong to?

Please describe your relationship status (i.e. whether you have a partner, the gender of that partner, whether you cohabit and if the relationship is legally recognised)

What type of diabetes do you have?

When were you diagnosed?

What are the main ways you manage your diabetes (e.g. diet and exercise, insulin, oral medication)?

Appendix 5: Transcription notation (face-to-face interviews only)

[Word]	Transcribers' comments are placed in squared parentheses
((Words))	Transcribed action (e.g. laughter)
Wor::d	Colons mark elongation of words
Wor-	Marks the abrupt termination of word or sound
(.)	Dot in brackets is an untimed pause
>Word<	Marks speech faster than the surrounding speech
<Word>	Marks speech slower than the surrounding speech
WORD speech	Capitalisation marks speech louder than the surrounding speech
°Word°	Marks speech which is quieter than the surrounding speech
<u>Word</u>	Emphasised speech
“Word”	Reported speech
Word=word	Where one word runs into another

Appendix 6: Sample consent form

A qualitative study of non-heterosexual people's experiences of diabetes

What is the project about?

Traditionally when LGBT health has been researched there has been an emphasis on sexual and mental health rather than physical health more generally. LGBT people's experiences of chronic illnesses other than HIV have largely remained unexplored. The purpose of this study is to explore lesbian, gay and bisexual experiences of living with diabetes.

If I take part, what will it involve?

During the interview I will ask you a number of broad questions about your experience of living with diabetes and how it fits into your life more generally. There are no right or wrong answers and you can respond in any way you like. The interview will be tape recorded and should last approximately an hour; however this will depend on how much you wish to say. The interview will be transcribed (typed up) and parts of the interview may appear in publications or presentations, however your identity will remain anonymous.

What if there is something I do not wish to discuss?

You are free to refuse to answer any questions or end the interview at any time. Given the nature of the topic, some questions may be of a sensitive nature. If a question is asked which you do not wish to answer, please make this clear and I will move on to another question.

What if I wish to withdraw myself from the study?

You may end the interview at any time if you are not happy about the interview, you may withdraw your interview from the study up to two weeks after the interview has taken place. In order to do this you may email myself or, if you prefer, my supervisor. You will not be required to provide a reason for your withdrawal.

How will any information I provide be kept confidential?

The confidentiality of personal information and anonymity of all volunteers involved will be preserved in the following way:

All transcripts will be stored on a password protected computer and any hard copies will be stored in a locked filing cabinet with no identifiable

information attached. Any identifiable information such as names will be excluded from the transcripts and any reports or publications. You will be given a pseudonym (false name) which any other information such as your age will be recorded against. Only my supervisors and I will read the transcripts in their entirety.

Research workers, school and subject areas responsible

Researcher: Adam Jowett, postgraduate research student

Contact details: School of Life & Health Sciences,
Aston University,
Birmingham,
B4 7ET
Email: jowettaj@aston.ac.uk
Tel: +44(0)121 204 3895

Supervisor: Dr Elizabeth Peel, senior lecturer in psychology

Contact details: School of Life & Health Sciences,
Aston University,
Birmingham,
B4 7ET
Email: e.a.peel@aston.ac.uk
Tel: +44(0)121 204 4074

Volunteers statement

Please sign below to indicate that you agree with the following statements.

I have read and understood the above explanation. I have had the opportunity to discuss it with the researcher and ask any questions.

I agree to take part in the above project and have been informed that I am free to withdraw at any time during and up to two weeks after the interview has taken place.

Name:.....

Signed:.....

Date:.....