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YOUNG PEOPLE LIVING WITH LIVER DISEASE: A QUALITATIVE STUDY OF EXPERIENCES OF TRANSITIONS

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Doctor of Philosophy

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Aston University

Title: Young People Living with Liver Disease: A qualitative study of experiences of transitions

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Degree: Doctor of Philosophy

Date: January 2017

Thesis Summary

Childhood liver disease is a rare chronic illness which up until a few decades ago had no known survivors. However, thanks to advances in medicine young people diagnosed with liver disease are now surviving into adulthood. To date, there has been very little research done in the United Kingdom exploring the impact of liver disease on young people's lives and this thesis aimed to explore the impact of liver disease across different life transitions. In chapter 1, I provide an introduction to childhood liver disease. In chapter 2, I introduce liver disease within a historical context as having a stigmatising reputation due to the negative connotations associated with alcoholism. I explain Goffman's (1963) Stigma theory and Bury's (1982) concept of biographical disruption as useful tools for understanding experiences of health and illness. In chapter 3, I address the methodology used; a social-constructionist perspective, semi-structured interviews with twenty 14-17 year olds, twenty-one 18 – 26 year olds and twenty-one parents about their lives living with liver disease and the use of thematic analysis to analyse the data. In light of the transition from paediatric to adult services, Chapter 4 contributes towards the literature on health communication and stigma by demonstrating how young people can make the transition into a stigmatised space. Chapter 5 demonstrates the complex ways in which alcohol can be stigmatising for young people living with liver disease due to ambivalent societal attitudes and how experiences of some South Asian participants can differ. Chapter 6 contributes to the childhood literature on biographical disruption by demonstrating how liver disease disrupts various transitions young people make and how parents can experience vicarious biographical disruption. In the final chapter I reflect on the contributions my thesis has made to the literature on childhood liver disease.

Keywords: Health, adolescents, chronic illness, biographical disruption, stigma

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The sky is not the limit; that is why we have planes.

Dedication

This thesis is dedicated to my parents for bringing me into this world

List of Abbreviations

AIDS - Acquired immune deficiency syndrome

BME – Black and Minority Ethnic

CLDF – The Children’s Liver Disease Foundation

HIV - Human immunodeficiency virus

NAFLD - Non-alcoholic fatty liver disease

NASH – Non-alcoholic steatohepatitis

NHS – National Health Service

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1 Introduction to childhood liver disease

1.1 Chapter Aims

This chapter aims to provide a basic introduction to childhood liver disease in the United Kingdom, highlighting the rarity of the condition and the health implications for those diagnosed. First, I will present a short, medical overview of childhood liver disease which will focus on the prevalence of liver disease in the United Kingdom. I will then present a synopsis of selected types of liver disease in order to demonstrate the differences for those diagnosed. Further, I will present information on the treatment of liver disease to demonstrate the variety of treatment options, including the liver transplant. Finally, I will end this chapter with a brief description of paediatric liver disease services and the coordination of hospital care for childhood liver disease in the United Kingdom.

1.2 Childhood Liver Disease in the United Kingdom

Liver disease in childhood is rare; figures suggest that ‘just over 1000 children per year’ are diagnosed with liver disease in the United Kingdom (Dhawan, Samyn, & Joshi, 2016). Recently, there has been recognition from health professionals within hepatology that young people undergo many transitions “physically, academically and socially” which may be difficult for young people with a chronic illness, notably, health professionals were concerned about “risk-taking behaviour” such as “excessive alcohol consumption”, “smoking”, and the “use of illicit drugs” (Dhawan et al., 2016, pp. 1-2). That said, there is currently very little research exploring the lives of children with liver disease in the United Kingdom. This is because forty years ago, a child diagnosed with hepatoblastoma or biliary atresia would have had a less than 20% chance of surviving, whereas now thanks to medical advancements and liver transplants, that figure is around 90% (Dhawan et al., 2016). Therefore, young people with childhood liver disease today represent a unique cohort to reach adulthood and this thesis aims to add to the literature on their experiences. I will now turn my attention to the medical constituents of liver disease.

Some of the functions of the liver include “regulating energy metabolism, normal growth and development, immunological function and drug metabolism” (Kelly, 2008, p. 10). Physical signs of liver disease include jaundice and abdominal distension (protruding stomach) as well as symptoms experienced by the person with liver disease including vomiting, nausea, diarrhoea, weight loss, lethargy and pain (Kelly, 2008). Chronic liver disease, categorised as liver disease which has persisted over six months, can affect all of the body’s organs (Amathieu & Al-Khafaji, 2015; Kelly, 2008). This is important as there is convincing evidence that the liver is an organ that lay people (people who are not clinicians or healthcare practitioners in the field) may not always understand in terms

of functionality or the implications of the liver compared to other organs such as the heart for example (Kelly, 2008; Kimbell, Boyd, Kendall, Iredale, & Murray, 2015; Lipworth, Davey, Carter, Hooker, & Hu, 2010).

1.2.1 Types of liver disease and their implications

There are over 100 different types of liver disease which differ in aetiology. More broadly, the causes of liver disease can be grouped in three ways; liver disease can be congenital, that is some people are born with the condition or it can be transmitted genetically from parent to child; it can arise due to behavioural factors such as lifestyle (alcohol, drugs, diet); and finally, liver disease can suddenly arise for an unknown reason.

Congenital biliary atresia can be defined as “an inability to excrete bile associated with malformations of the extrahepatic biliary tree” (Stowens, 1963, p. 337). Described as a “rare birth defect” (Sanchez-Valle et al., 2017, p. 285), the cause of biliary atresia is unknown (McKeirnan, Baker, & Kelly, 2000). Biliary atresia has a prevalence rate of 1 in 15-20,000 across mainland Europe (Lakshminarayanan & Davenport, 2016). The outcome of biliary atresia has changed in the past four decades; once deemed to be fatal, the development in surgical interventions, such as the Kasai portoenterostomy, has resulted in better outcomes for those diagnosed (Hartley, Davenport, & Kelly, 2009). According to Hartley et al. (2009, p. 1704) 80% of children whose surgical interventions are successful “will reach adolescence with a good quality of life without undergoing liver transplantation”. However, Lakshminarayanan and Davenport (2016) warned against categorising biliary atresia as predictable, highlighting the complex etiology which can affect disease outcomes. For example, research emphasized despite the promising 20 year survival rates for those who have undergone the Kasai procedure, nearly half of those in one study ended up with liver cirrhosis or associated problems (Shinkai et al., 2009).

Wilson’s disease is an example of a cause of liver disease stemming from a genetic origin. It is an autosomal recessive condition, categorised by an accumulation of excess copper in the body, which has a prevalence rate of between 1 in 30,000 to 1 in 40,000 globally (Brewer, 2012; de Andrade Sócio et al., 2010; Sternlieb, 1990). Children inherit one defective gene from each of their carrier parents (Brewer, 2012). Siblings of an affected person, who have a one in four chance of having the same condition, can often present as asymptomatic (Brewer, 2012). The symptoms of Wilson’s disease can have a sudden onset; often presenting in teenagers or those in their early twenties, who may have until that point, appeared healthy (Brewer, 2012). Young people affected by

Wilson's disease can face a sudden decline in their performance at school, experiencing difficulties with their speech and handwriting, in addition to drooling, confusion, tremors, difficulties walking and behavioural issues (Brewer, 2012). Although Wilson's disease can be fatal, if diagnosed in time, it can be treated easily and some of effects of the disease can almost be reversed.

Although not often diagnosed in childhood, non-alcoholic fatty liver disease (NAFLD) is an example of a spectrum of liver diseases which could be regarded as having a behavioural cause as it is strongly associated with obesity - its commonality is believed to be due to sedentary lifestyles in the western world (Dyson, Anstee, & McPherson, 2014). NAFLD reportedly affects a third of the population in developing countries, and as the name suggests, occurs exclusive of excessive alcohol consumption (Anstee, McPherson, & Day, 2011; Dyson et al., 2014). Most NAFLD patients are overweight and NAFLD has been reported to be present in those with metabolic syndrome or type 2 diabetes (Grander, Grabherr, Moschen, & Tilg, 2016). Unlike Wilson's disease, for example, NAFLD can remain asymptomatic until a blood test is taken. Currently, there are no drugs licenced to specifically treat aggressive forms of NAFLD such as non-alcoholic steatohepatitis (NASH) and in light of the low numbers of children who go onto develop it, it has been suggested some people could be more genetically susceptible to NASH (Anstee et al., 2011; Suchy, Sokol, & Balistreri, 2007). Healthcare professionals have been reported to underestimate the prevalence of NAFLD in their own patients; one study which was conducted in Brisbane, reported 71% of healthcare professionals surveyed made no referrals to hepatology for suspected NAFLD (Bergqvist et al., 2013).

Autoimmune hepatitis is a disease of the liver with an unknown aetiology which can have a sudden onset (Suchy et al., 2007). The actual prevalence of autoimmune hepatitis in the United Kingdom is not known due to the scarcity of epidemiological data. However, research estimates a prevalence in Europe of 10 to 17 per 100,000, with females up to four times more likely than men to be affected (Gleeson & Heneghan, 2011; Liberal, Grant, Mieli-Vergani, & Vergani, 2013). It was reported in one specialised liver centre in England, approximately 10% of 400 new paediatric referrals a year were related to autoimmune hepatitis (Liberal et al., 2013). Age of onset is commonly between ten to thirty years, although very rarely, some children are diagnosed before age two (Ferri, Ferreira, Miranda, & Simões E Silva, 2012). Clinical features of autoimmune hepatitis include fatigue, "itching, skin rashes, joint pain and abdominal discomfort" (Cassell & Rose, 2014, p. 106). Autoimmune hepatitis is regarded as very responsive to treatment compared to other liver diseases, however, the treatment can have unfavourable side effects (Hirschfield & Heathcote, 2011).

The treatment for liver disease varies depending upon the type of liver disease. Autoimmune hepatitis is treated with steroids which have been linked to visible side effects such as cushingoid facies, “obesity, acne and cosmetic changes” which can lead to those affected discontinuing with their prescribed treatment (Hirschfield & Heathcote, 2011, p. 10). Biliary atresia, a congenital liver disease, is commonly treated with the ‘Kasai’ procedure, an operation also known as a portoenterostomy which is usually carried out within the first three months of life (Howard, 1995). It is followed up with low dose oral antibiotics and nutritional support (Kelly & Wilson, 2006). Other types of liver disease have different management strategies. In the case of chronic liver disease the management includes nutritional therapy such as vitamin A and E supplementation and ursodeoxycholic acid (20 mg/kg/day) (Kelly & Wilson, 2006). However, not all liver diseases are solely treated with medication, for example non-alcoholic fatty liver disease treatment often includes diet and exercise (Kelly & Wilson, 2006, p. 54).

Regardless of the initial treatment strategy, if a person’s liver disease is unresponsive to treatment or they develop cirrhosis (the end-stage of many different liver disorders, such as alcoholism and chronic hepatitis) they will usually require a liver transplant (Duan et al., 2014; Sargent, 2009). In 1968, Roy Calne performed the first liver transplant in the United Kingdom at Addenbrookes Hospital, Cambridge (Calne, 2008). There are two classifications for liver transplants. Liver transplants can be classed as being *elective*, where the expectation of a liver transplant was routine, or *super-urgent*, as the name suggests, required in emergency/urgent circumstances. There is a shortage of liver transplant donations in the United Kingdom (Neuberger, 2016). Currently, there is no known cure for liver disease and despite transplantation, some recipients, for example, those with primary liver diseases such as autoimmune hepatitis or primary sclerosing cholangitis, can face relapse (Tannuri & Tannuri, 2014). Transplant recipients are usually prescribed lifetime immunosuppressants to decrease the risk of their bodies rejecting their liver transplant, however, being immunosuppressed can leave recipients vulnerable to infectious diseases (Tannuri & Tannuri, 2014). Neuberger (2016) noted that adolescents in particular find it challenging to adhere to the lifelong immunosuppression treatment. This is due to the numerous side effects of immunosuppression and the impact of medicine-taking on their lives (Dobbels, Damme-Lombaert, Vanhaecke, & Geest, 2005).

Between April 2005 and March 2015, 937 paediatric liver transplants took place across the United Kingdom, this figure included re-transplantation (Statistics and Clinical Studies, 2015). On average, a first time recipient of a paediatric liver transplant has

between a 75-90% survival rate five years post-transplant (Statistics and Clinical Studies, 2015). Interestingly, within the Statistics and Clinical Studies (2015) report there were differences in what constituted a paediatric or an adult statistic; figures for post-transplant survival rates for paediatrics were calculated at less than 17 years and adults at age 17 years and above, however, survival rates for adults from the point of being listed for a transplant were calculated as equal to or over 18 years. This is a pertinent example which highlights how the classification of adulthood within hepatology is variable; what constitutes adulthood in one situation may not constitute adulthood in another.

1.2.2 Hospital care for paediatric liver disease

In the United Kingdom, there are three specialised centres for children with liver disease in the following locations; Birmingham, London and Leeds (Dhawan et al., 2016; Statistics and Clinical Studies, 2015). I will now briefly describe how care for children with liver disease is arranged at one of the specialised centres for treating childhood liver disease, using the example of Birmingham Children's Hospital. Children with suspected liver disease are referred in to the centre where initial tests and assessments are conducted to facilitate a diagnosis (National Health Service, 2017). There can be further tests carried out if necessary. The multidisciplinary team involved in the child's care include liver surgeons, paediatricians, metabolic disease specialists, liaison nurses, dieticians, physiotherapists and psychologists (National Health Service, 2017; Suchy et al., 2007). Patients attend regular follow up appointments, usually until they transition to adult services between the ages of sixteen to eighteen years.

According to the United Kingdom Department of Health directive for England and Wales (DOH 199/0268 30.4.99), "all infants with suspected biliary atresia should be referred" to one of the specialised centres, and research has reported "the centralisation of surgery reduced the need for liver transplantation and improved the outcome for children with biliary atresia" (Kelly & Davenport, 2007, p. 1134). However, the management of liver disease for adults (not including transplantation) is not as centralised, and as explained by Dhawan et al. (2016, p. 1), "non-transplant hepatology care for adults is provided in several regional and district general hospitals".

1.3 Chapter summary

In this chapter I have provided a basic introduction to childhood liver disease for those who may not be familiar with the condition. I have drawn attention to the rarity of childhood liver disease as well as the breadth of the types of childhood liver disease and

their implications. The purpose of this was to highlight the complexity of childhood liver disease, as well as the unique status of young adults diagnosed with childhood liver disease; they are the first to survive to adulthood. Currently, we know very little about this group and how they experience or manage the many symptoms and side effects associated with liver disease. Through the way statistics for transplants are reported and the way paediatric and adult services are designed, age maybe an important factor for this cohort; the boundaries separating the classification of an adult or a child are context-dependant. Questions remain to be answered; what are the experiences of children and young people who are suddenly diagnosed with liver disease; what is it like to grow up with liver disease; what impact does liver disease have on children's lives and their family's lives; how do young people manage the transition to adult services? To highlight the issues associated with these questions, I will now turn my attention to situating this thesis within the chronic illness literature, drawing on issues which may affect children diagnosed with liver disease and their parents. In order to understand what it is like to live as child with a chronic illness, it is also important to understand the context surrounding what it means to be a child in today's society without a chronic illness. I will also present the past research on childhood liver disease.

2 Chronic illness in childhood

In the previous chapter I presented a medical overview of childhood liver disease and explained how paediatric liver services in the United Kingdom are organised. There are many physical symptoms associated with liver disease and its treatment which can be visible, such as a protruding stomach, or invisible, for example, pain or fatigue. I will now turn my attention to the literature on chronic illness and disability to provide a backdrop to this thesis. I will focus on research which addresses the experiences of childhood chronic illness, the hospital environment, understandings of adolescence as a period of transition, stigma in relation to liver disease, the impact of chronic illness on identity as biographical disruption and finally, I will focus on the sociology of childhood literature to explain how children's position in society affects our understanding of children's experiences of chronic illness.

2.1 Defining chronic illness and disability

A chronic illness is defined as an illness that lasts over six months and "young people with chronic conditions often face more difficulties negotiating the tasks of adolescence than their healthy peers" (Yeo & Sawyer, 2005, p. 721). The definition of disability has been debated by scholars in the past and the way disability is defined can have an impact on research outcomes (Grönvik, 2009) and changes to definitions within legislation can affect prevalence rates (Blackburn, Spencer, & Read, 2010). According to the Equality Act 2010, disability is defined as someone having a "physical or mental impairment", which "has a substantial and long-term adverse effect on the person's ability to carry out normal day-to-day activities" (Legislation.gov.uk, 2010). Blackburn et al. (2010, p. 10) reported children with a disability in the United Kingdom "experience higher levels of poverty and personal and social disadvantage than other children". Other features noted by the authors included living in lone-parent households and being more likely to live with a parent with a disability (Blackburn et al., 2010). This suggests, alongside managing the chronic illness or disability which can affect their day-to-day life, children can be further affected by contextual factors in their family life, including their access to financial resources.

2.2 The impact of a chronic illness in childhood

Previous research has identified a chronic illness can affect the following areas of young people's lives; physical health; emotional and psychological health; social, educational and vocational achievement; and the transition to adult services (Yeo & Sawyer, 2005). Physically, young people with visible markers of their illness may stand out amongst their peers. Young people may face issues with their body image and a reduction in their self-esteem, issues Yeo and Sawyer (2005) reported could persevere into adulthood. Young

people can find navigating the healthcare system and managing their chronic illness frustrating, leaving them feeling isolated from their peers; psychological distress may manifest as reduced school performance and behavioural difficulties. Due to ill health or hospitalisation, young people may be frequently absent from school, which can negatively affect their school performance and result in young people becoming socially isolated as they are unable to participate in recreational activities or sports. Furthermore, experiencing educational disadvantages can mean young people face difficulties in finding employment as they get older (Yeo & Sawyer, 2005). This demonstrates that chronic illnesses can affect multiple areas of young people's lives whilst growing up and issues can persist into their adult life.

Raising a child with a chronic illness or disability can also affect multiple aspects of parents' lives. As Waldboth, Patch, Mahrer-Imhof, and Metcalfe (2016, p. 45) reported, "chronic childhood diseases are associated with a substantial economic burden including direct, indirect and informal costs". Related to this, one such area which is impacted in parents' lives is employment, for example, their participation in work and career progression can face negative consequences; this can affect mothers in particular who are usually the primary person who looks after the child with a chronic illness (Crettenden, Wright, & Skinner, 2014; Parish, 2006).

Parents own social lives can also be affected; parents can feel isolated, or excluded by friends and families as they are not invited to events or one of them has to stay at home while the other attends (Alaee, Shahboulaghi, Khankeh, & Kermanshahi, 2015). Parents can feel overwhelmed by their child's illness; one study exploring experiences of caring for a child with juvenile idiopathic arthritis found parents felt the condition consumed their own and their family's lives, particularly as partners and other children were affected (Yuwen, Lewis, Walker, & Ward, 2017). For example, parents reported their intimate lives had been disrupted due to sleeping arrangements to accommodate their child, some mothers felt resentful their partner did not wake up at night to help, siblings found it difficult witnessing their brother's or sister's pain, and some parents reported their other children felt unhappy about the attention their sibling got, the different parenting rules and the reduction in family time (Yuwen et al., 2017)

In addition, parents can experience psychological distress whilst managing their child's condition, especially if their child faces functional limitations such as visual or auditory impairments, communication restrictions or their condition restricts their daily activities (Silver, Westbrook, & Stein, 1998). Sociodemographic factors which can influence parental psychological distress include the age of the child, parental financial status and

ethnic background (Silver et al., 1998). Furthermore, another study found associations between the high levels of psychological distress experienced by mothers of children with autistic spectrum disorders and the lower levels of family support they received or if they were a lone parent (Bromley, Hare, Davison, & Emerson, 2004). These are all examples of the types of factors which can affect the lives of parents of children with a chronic illness.

2.3 Healthcare and childhood chronic illness

Usually, illnesses are diagnosed within hospitals and children with chronic illnesses often have to attend hospital either as part of their routine health care, or during emergencies. Lambert, Coad, Hicks, and Glacken (2014, p. 195) stated hospitals were “strange, anonymous and authoritarian” places for children, where they experienced many different feelings including worry and sadness. Children can be extremely fearful or even extremely bored in hospital, and hospital décor is carefully constructed, for example, through smaller entrances to reflect children’s perspectives, or the use of colour and patterns, to reduce tension and provide visual appeal (Dalke et al., 2006). Research has highlighted the importance of hospitals as a social space with the provision of “age/developmentally appropriate and gender inclusive activities” for children (Lambert et al., 2014, p. 199). Another change which has improved historically is the provision of overnight parental stays as the importance of parental presence for hospitalised children was recognised; previous research has reported even in the 1980s in England, parents were still deemed to be ‘visitors’ in nearly 50% of acute children’s awards (Gross & Kinnison, 2013). Furthermore, with the provision of familiar items, such as toys, efforts are made to make the hospital appear more homely for children (Aldiss, Horstman, O’Leary, Richardson, & Gibson, 2009; Avila-Aguero, German, Paris, Herrera, & The Safe Toys Study, 2004).

Research has demonstrated it is important to take into account children’s previous experiences with medical procedures as some children can behave in a more distressed manner if they have had negative experiences in the past (Dahlquist et al., 1986; Faust, Olson, & Rodriguez, 1991; McCann & Kain, 2001). An example of adjustments to make hospital care more child-friendly includes the use of distraction techniques during procedures, such as; the provision of electronic toys, music, television or guided imagery (Koller & Goldman, 2012), and nurse clowns to reduce preoperative anxiety in children and parents (Dionigi, Sangiorgi, & Flangini, 2014; Vagnoli, Caprilli, Robiglio, & Messeri, 2005; Weaver, Prudhoe, Batrick, & Glasper, 2007; Yun, Kim, & Jung, 2015). However,

children eventually have to transition to adult services where there may not be special provisions.

It is not be underestimated the powerful role health professionals have or the meanings children can associate with hospitals. For example, one study of parents of children with complex needs reported the child's siblings developed a fear of doctors due to the levels of exposure to doctors within the home (Diehl, Moffitt, & Wade, 1991). Other studies have found children as young as four years of age have expressed fears about hospitals, including the exercise of power by staff, and the social and symbolic environment of hospitals, e.g. fears of being separated from their family (Salmela, Salanterä, & Aronen, 2009).

2.3.1 Communication

One particular area which is important in light of children's experiences of hospital care is their experiences of communication with healthcare professionals. Communication is viewed as important aspect of managing one's own healthcare for adolescents who will soon go on to become young adults (Knopf, Hornung, Slap, DeVellis, & Britto, 2008). In their qualitative study examining the views of young people with a variety of different chronic illnesses, Beresford and Sloper (2003) reported children, particularly those that fell into the 10-12 year old category were impacted by issues around status. They stated;

“Participants ascribed their doctors with very high status that was reflected in a sense of their own inferiority. For some, this acted as a powerful inhibitor to communication” (Beresford & Sloper, 2003, p. 175).

Children in their sample reported feeling nervous or shy when it came to asking questions and this has been documented in other studies (Beresford & Sloper, 2003; Coyne & Gallagher, 2011). Given the differences in perceived status between children and doctors, this may explain why children are hesitant to ask questions and reinforces the power of the medical profession. Coyne and Gallagher (2011, p. 2334) found children “wanted to participate in ‘small’ everyday decisions about their care and treatment but were constrained mainly by adults’ actions”. This is an example of how power struggles can take place in the context of the hospital consultation where parents may dominate the consultations and young people may not feel like they are given a chance to communicate with the doctors, or the language used by healthcare professionals is beyond the understanding of children and young people, inhibiting their involvement (Coyne & Gallagher, 2011).

There have been recommendations that the power between medical professionals and patients should be rebalanced towards the patients, however, as Canter (2001) highlights, medical power is not a currency which can simply be transferred from a doctor to a patient. This also suggests in light of unbalanced power relationships between adults and children more broadly, medical power cannot be simply transferred from adult healthcare professionals to children and young people. This is important as adolescents may already be struggling to establish power within other relationships with adults in their lives.

2.3.2 Differences between paediatric and adult healthcare services

There are clear differences between paediatric services and adult healthcare services (Stewart, 2009); research has highlighted one of the key issues surrounding the transition from paediatric services to adult healthcare services for adolescents includes the imbalance between the ethos of the two service points (Viner, 1999). Paediatric care has been labelled as “family centred and developmentally focused” which can ignore an adolescent’s emerging independence and shift towards adult behaviour, while adult medical services are appreciative of “patient autonomy, reproduction and employment issues” but overlook “growth, development and family concerns” (Viner, 1999, p. 271).

A systematic review on transitions reported that age was not an adequate indicator of when it was time for a young person to make the transition to adult services, instead, suggesting the “developing maturity” of a young person was more important (Yassaee, Hale, Armitage, & Viner, 2016, p. A187). Yassaee and colleagues (2016, p. A186) summarised the barriers to transition as “fragmented healthcare systems, lack of age-appropriate services, and poor continuity” and facilitators to successful transitions as “adequate planning... teaching patients healthcare skills; and specialist training for healthcare staff”. The review concluded by suggesting there are benefits to those transitioning by postponing transition until later on and that this may result in “increased patient satisfaction” (2016, p. A186). Later on in this thesis, I will explain how given that adolescence in current society can be protracted into the late 20s, the existence of a fixed age period for the physical transition to adult services does not sit comfortably in relation to the other transitions young people may be making in their lives (Arnett, 1999).

The transition period is also important for young people with liver disease. Annunziato et al. (2007) analysed the medical notes of paediatric liver transplant recipients and noted after the transition to adult services, patients were less likely to continue taking

their medication (tacrolimus, an immunosuppressant prescribed to people after a transplant) as per medical recommendations. This suggests the hospital transition period is indeed a “vulnerable” period in the lives of young liver transplant recipients, especially given the risk of mortality as a result of health complications (Annunziato et al., 2007, p. 612). Young people are sometimes abruptly transferred to adult services “once they leave school, during crises such as pregnancy or a suicide attempt, and refusing to continue attending paediatric clinics” (Viner, 1999, p. 272).

More specifically, there has been recent research published on the transfer of young liver transplant patients from children’s to adult services (Wright, Elwell, McDonagh, Kelly, & Wray, 2016). Using Interpretative Phenomenological Analysis to analyse the data, the authors carried out seventeen interviews of transplant recipients and reported the following two main themes; “relationships with health professionals” and “continuity of care” (Wright et al., 2016, p. 3). The findings revealed that young people were anxious about being unknown at adult services, feeling sad about leaving their children’s hospital, and feeling frustrated at having to repeat their medical history during appointments due to being seen by multiple clinicians (Wright et al., 2016). This suggests young people may experience emotional reactions in addition to bureaucratic barriers when transitioning (being seen by multiple doctors may be indicative of funding issues as assigning one doctor to a young person may not be financially feasible). The research drew attention to many noteworthy findings including how the differences between the paediatric model of care (having a “substantial relationship with one clinician”) and the adult model (seeing multiple clinicians) may “obstruct the formation of future working relationships” (Wright et al., 2016, p. 7). However, the purpose of that research was to solely examine the transition from paediatric to adult services and thus concentrated on a narrow understanding of transition.

2.4 Adolescence as a period of transition

According to Harris (2015, p. 64);

Adolescence in itself is a period of transition, both physically and mentally. It is characterised by development of an identity, greater social autonomy, biological and sexual maturity, and increased competency.

Adolescence can be understood as the period between puberty and early 20s which connects childhood with adulthood (Arnett, 1992).

Youniss and Ruth (2002, p. 264) stated that within society there is a “reflexive association of “adolescence” with “problems,” and “youth” with “troubled””. One such notion supporting this is the idea of the reckless teenager. Arnett (1992, p. 339) wrote;

Adolescence bears a heightened potential for recklessness compared to other developmental periods in every culture and in every time. The forms that this proclivity takes, and even whether it is allowed expression at all, depend on the characteristics of the particular culture and the particular time.

Indeed, historically the adolescent period has been categorised as difficult, for example, Hall (1904, p. 73) referred to the “storm and stress period”. The storm and stress period consists of three components; ‘conflict with parents’, ‘mood disruptions’ and ‘risk behaviour’ (Arnett, 1999, p. 319). An important point to note is part of the conflict with parents is down to parents making attempts to control and regulate their child’s activities such as drinking, drug use and sexual encounters; risk behaviour is only categorised as risky depending on the social norms which define it as such, for example, drinking and driving (Arnett, 1999). Furthermore, experiencing storm and stress is not ingrained in the human life course and there are cultural differences in how much each of the components are experienced, notably adolescents from Western cultures are more likely to experience them (Arnett, 1999; Arnett, 2003).

It is important to recognise that there is a changing landscape in how and when this transition period is experienced, including changes to the order in which young people reach adulthood; boundaries can be blurred as young people may simultaneously fall into both categories of adolescence and adulthood (Mortimer & Larson, 2002; Youniss & Ruth, 2002). Traditional markers of the transition to adulthood such as securing fulltime work, getting married or becoming a parent, have been ‘postponed’ along with prolonged schooling for young people (Mortimer & Larson, 2002). The period of transition into adulthood can be difficult for young people without a chronic condition as they navigate potentially ‘turbulent’ terrain during the transition from school to work, a transition for which they can be ill-prepared for due to the potential mismatch in the skills they acquire at school and those needed for their careers (Mortimer & Larson, 2002, p. 10). In addition, the inequalities faced by some adolescents cannot be ignored, for example, differences in social class and the lack of resources some young people from ethnic minority backgrounds may have access to (Youniss & Ruth, 2002). There are some chronic conditions, such as human immunodeficiency virus (HIV), which have both social and sexual implications which can amplify the issues experienced by young people

during adolescence (Harris, 2015). Stewart (2009, p. 169) highlighted that given the importance of “the transition from adolescence to adulthood” as a “developmental stage for all young people”, it was important to recognise that there are particular challenges associated with this transition period for all parties involved including young people themselves, their families and healthcare teams.

2.5 Stigma: definition and history

The term stigma originated from the Greek language, and referred to specific signs which were marked (either through cutting or burning) on a person to identify them as morally flawed or possessing an unfavourable trait, such as being a ‘traitor – a blemished person, ritually polluted’ (Goffman, 1963, p. 1). Whilst in the past a person possessing these outwardly signs would be avoided in public, according to Goffman (1963, p. 2), the term stigma now serves the function to highlight the ‘disgrace itself’ as opposed to the ‘bodily evidence of it’. Stigma refers to an attribute that is ‘deeply discrediting’ (Goffman, 1963, p. 3). However, it is important to first understand the preliminary conceptions about stigma in the context of societal expectations. Goffman (1963, p. 2) drew attention to how categorisations exist in society, for example when one meets a stranger, based on that stranger’s appearance a number of assumptions or unconscious demands may be made about them; in effect, one may assign a ‘virtual social identity’ to that stranger based on our presumption of which category they belong to and the attributes associated with that category. It is only when those assumptions do not become fulfilled do they come to our attention and the person’s ‘actual social identity’ comes to light (Goffman, 1963, p. 2). Furthermore, society agrees on what constitutes to be ‘normal’ and if the stranger’s actual attributes are undesirable, or mark them as different in comparison to everyone else, then that stranger may no longer be viewed as a ‘whole and usual person’ but a ‘tainted, discounted one’ (Goffman, 1963, p. 3). One of the important points raised by Goffman (1963) highlighted that the problem lies with the *discrepancy* between the expected attributes of a person and their actual attributes, rather than the undesirable attribute itself. This is because an attribute may mean different things depending on who it is associated with and consequently may not necessarily be a negative attribute for some groups of people. However, for other people, despite not having the stigmatised attribute themselves, they can face stigma by merely being associated with someone with a stigmatised attribute; this is known as courtesy stigma, something I will address in more detail later on in the chapter.

2.5.1 Stigma in relation to liver disease

Much of the literature on young people’s experiences of liver disease has focused on children who have received a liver transplant, one UK based study focused on the

concept of “health-related quality of life (HRQL) that incorporates physical, psychological and social function” (Taylor, Franck, Gibson, Donaldson, & Dhawan, 2009, p. 1179). Taylor et al. (2009) reported HRQL was significantly reduced in adolescents following liver transplantation. Their findings suggested young people may find the symptoms which follow a transplant distressing such as “weight gain, difficulty sleeping, painful joints and headaches” (Taylor et al., 2009, p. 1185). Interestingly, the symptoms which occurred most frequently, such as bruising easily, were not perceived to be the most distressing and the authors concluded further work was needed in this area to help explain the findings from their study. Young people’s HRQL was also negatively affected by the development of other illnesses following their immunosuppression (medicines used to prevent the body from rejecting the new liver) and the authors reported 75% of the participants developed other chronic medical conditions following their transplant (Taylor et al., 2009). The study also highlighted that young people may face repeat hospital admissions following their transplant; this is important as being in hospital may affect young people’s wider lives e.g. school, friendships, hobbies (Taylor et al., 2009). Whilst all of this quantitative information is valuable in recognising the impact of liver disease on young people’s lives, as the authors suggest, more work is needed to uncover the reasons why and how these factors affect young people’s lives and this can be achieved through qualitative work.

Another qualitative study explored the views of nine young people post-liver transplant and reported they were aware of their visible differences compared to their peers; an important finding was that the participants were often more concerned about how they appeared to others than themselves (Wise, 2002). This highlights how important it is for children to fit in with their peers. There were reports of feeling angry at other people’s comments about their physical appearance and feeling like an ‘outsider’ due to their limited social circles and reduced health (Wise, 2002). Wise (2002, p. 81) reported “regardless of their age, all the children sought a “best” friend to normalize their experiences at school and with friends”. This involved an element of secret-sharing and friends were reported to be sources of support and encouragement and it was younger children in this study who were less likely to conceal their transplant from others (Wise, 2002). Another theme from Wise’s (2002) research reported on children’s experiences of hospital changing the taken for granted aspects of everyday life; children reported incorporating medicines into their lives, the difficulties of the hospital environment and the identification of others as sick in hospital, not themselves. The major theme was that children strived to live normal lives, similar to those without health conditions (Wise,

2002). One way of understanding young people's strive to be "normal" is through the concept of stigma which I will now explain further.

2.5.2 Conceptualising stigma in relation to chronic illness

The concept of stigma is regarded as multidisciplinary, spanning many disciplines including sociology and psychology; the two disciplines which reflect my own research interests and academic background. Link and Phelan (2001) highlighted how the broad applications of stigma in different disciplines had led to differing conceptualisations of stigma by individual researchers. Their paper highlighted two particular challenges associated with the stigma concept; the first challenge comprises of scientific researchers who do not belong to the stigmatised group yet study stigma, Link and Phelan (2001, p. 366) reported those researchers "do so from the vantage point of theories that are uninformed by the lived experience of the people they study". The problem of able-bodied researchers studying the experiences of those with disabilities was raised by Schneider (1988, p. 64) who noted they often "give priority to their scientific theories and research techniques rather than to the words and perceptions of the people they study". Schneider (1988) drew attention to how social scientists have enforced their own theories and concepts to the study of disability and illness rather than focusing on their participants' definitions.

The second challenge lies within the 'individualistic focus' of stigma; academic attention tends to focus on an individual's perceptions and the events which precede those perceptions, as opposed to exploring the role societal structures have in shaping stigma (Link & Phelan, 2001, p. 366). More importantly, the role of other people in the production of stigma is absent; "the stigma or mark is seen as something in the person rather than a designation or tag that others affix to the person" (Link & Phelan, 2001, p. 366). This is problematic because it assigns the accountability of the stigma to the individual experiencing it. Abbey et al. (2011, p. 2) summarised the 'multi-layered process' through which stigma develops; 1) a person is labelled or categorised; 2) stereotyping occurs, this is where connections are made between the label or category and undesirable traits; 3) separation, where "the us and them effect" takes place and the stereotyped person is held to be different from 'humanity'; 4) an emotional reaction occurs alongside stereotyping and separation; 5) discrimination takes place, this is when the stigmatization is 'acted upon' and the stigmatised person is 'rejected, excluded or devalued' either on a 'personal level' or stigma is 'enacted through societal and structural inequalities'; and finally; 6) power differential occurs between the stigmatised person and those responsible for the stigmatising.

This leads us to an important question; why do people stigmatise others? According to Link and Phelan (2014, p. 24) stigma is a resource some people 'who have an interest in keeping other people down' employ to achieve their purpose, something they called 'stigma power'. This power can be used to 'keep people down, in and away' according to Link and Phelan (2014, p. 25). When stigmatizers employ stigma power they are able to exploit, manage, control and exclude others (Link & Phelan, 2014). By using stigma power, those who stigmatise can attain 'wealth, power, and high social status' (Link & Phelan, 2014, p. 25). An important part of the work of Link and Phelan identified the function of keeping people away. In this thesis I will demonstrate how and why stigma may be utilised to stigmatise those with liver disease.

2.5.3 Courtesy Stigma

Through courtesy stigma, stigma can be spread "from the stigmatised individual to his close connections" which can lead to others terminating or avoiding these relationships (Goffman, 1963, p. 30). Previous research across different cultures has demonstrated siblings or parents of children with a disability or illness can face courtesy stigma whereby other people, such as friends and family, do not want to spend time with them or exclude them from activities (Gray, 2002; Kinnear, Link, Ballan, & Fischbach, 2016; Uba & Nwoga, 2016). For parents in particular, courtesy stigma extends across multiple social contexts, including when they are not in the presence of their child and can work to produce a biography of them which is 'situationally sensitive' (Gray, 2002, p. 737). In this case, the courtesy stigma stems from parents' 'larger biographical relationship with their child' and their identity as parents of children with a disability (Gray, 2002, p. 737).

Courtesy stigma has been reported in many cultures. One study exploring South Asian people's views on disfigurement revealed some participants felt family members of those with disfigurements would be ashamed of the person with a disfigurement (although these attitudes were changing), and that the person would struggle to find somebody for marriage (Hughes et al., 2009). Alongside this, there also existed superstitious beliefs about the cause of disfigurements including viewing their condition as a punishment from God and seeking to avoid the person; interestingly, participants also reported feeling sorry for those with disfigurements and wanting to help them as their condition was seen as God's will (Hughes et al., 2009).

Parents can worry about the diagnosis of one child affecting the marriage prospects of other children; for example, in Gray (1993) a participant reported she was worried potential spouses would think there was something wrong with the 'genetic structure' of their family because they had an autistic child. Courtesy stigma with regards to marriage

is also present in other cultures, for example, one study from Pakistan revealed the presence of a disability or chronic illness can affect the marriage prospects of other children (Bryant, Ahmed, Ahmed, Jafri, & Raashid, 2011). Marriage can be viewed as an important part of South Asian culture, particularly for women where it has been reported to be a cultural script and there can be a lifelong focus on marriageability whilst they grow up and emphasis on avoiding activities which could damage that or the expected order of marriage within the family e.g. eldest daughter gets married first (Mehrotra, 2016). Another study reported none of the participants of Pakistani descent living in the United Kingdom would consider marriage to a person with a mental illness (Tabassum, Macaskill, & Ahmad, 2000). This suggests for people with an illness or stigmatised condition, courtesy stigma can become particularly problematic with regards to future relationships.

2.5.4 Liver transplants and stigmatising reputations

Liver disease has been described as having a 'stigmatising reputation' due to its associations with alcohol misuse (Kimbell et al., 2015, p. 7). I will now explore the historical context in relation to liver disease and its connections with the development of liver related stigma in the United Kingdom. This is important in order to illuminate the nuances in the development of stigma. The first liver transplant days were described by the initial surgeon as 'exciting, demanding, subject to terrible disappointments and sadness' (Calne, 2008, p. 1775). Like other organs, there was, and still is a shortfall in donor livers in comparison to the 'perceived need' and the 'rationing' of donor livers has been argued as necessary (Calne, 2008, p. 1777; Neuberger et al., 2008, p. 252). The allocation of donor livers is morally and ethically complex in light of competing needs and decisions regarding who would benefit the most from a liver transplant based on their age, quality of life, and projected life expectancy (Neuberger et al., 2008).

Amongst the criteria for donor liver allocation, there are further recommendations reserved for those with substance misuse issues or alcoholic liver disease who require liver transplantation, dictating that they should abstain from alcohol, adhere to medical advice, and continue with follow-up care (Arulraj & Neuberger, 2011; Bathgate, 2006). Transplant procedures which take place for alcoholic liver disease account for approximately 25% of all liver transplantations in the UK and it has been reported alcoholic liver disease remains 'the most controversial indication in terms of the attitude of the general public', thus calling for standardised national approaches for this group (Bathgate, 2006, p. 2045). The morally charged status of liver donation and transplantation is of concern as young people born with liver disease may be exposed to these attitudes despite the aetiology of their liver disease being unrelated to the

‘deviant’ behaviours of alcohol and drug misuse. Furthermore, this highlights there are a number of sources of stigmatisation including societal attitudes and the additional pressure from the medical profession to ‘earn’ liver transplants with compliant behaviour. In this thesis, I will later explore how all of these components may interact with young people’s experiences of growing up with liver disease.

A survey reported the public rated those requiring a liver transplant due to alcoholic liver disease or drug misuse as less deserving, which does not necessarily reflect the ethics of medical care which advocate patients should be treated based on their medical needs rather than behaviours (Arulraj & Neuberger, 2011; Neuberger, Adams, MacMaster, Maidment, & Speed, 1998). Public attitudes towards alcohol were influenced by the temperance movement in the nineteenth century, which drew on the Christian values of ‘modesty and restraint’ (Macfarlane & Tuffin, 2010, p. 46). Macfarlane and Tuffin (2010, p. 46) reported alcohol consumption was viewed as a “personal choice, drunkenness framed as a weakness of moral character and alcoholics deemed as responsible for their condition due to character flaws”. This may explain where negative public attitudes towards those with alcoholic liver disease stem from and why liver disease can be seen as a stigmatising condition. Ostracising those with liver disease can be seen as the utilisation of stigma, which can allow for the elevation of those who do not have liver disease into positions of higher social status (Link & Phelan, 2014).

2.5.5 Stigma and the responsibility for one’s own health

There is an additional nuance which is of interest in exploring the relationship between liver disease and stigma; the shift towards individual responsibility for one’s health. As explained by Harris, Wathen, Wyatt, and Palgrave (2010, p. 1), with respect to the continuing rising costs of health care, ‘public health policy in advanced industrialised countries increasingly emphasises the importance of citizens’ personal responsibility for their own health’. In their book, Harris et al. (2010, p. 1), identified a number of discourses which emerged alongside newer models of service delivery, such as ‘patient-centred care, shared decision making, consumer health information and patient autonomy and empowerment’. They described the labelling of the lay public as ‘consumers’, and the deliverance of messages to consumers to adopt healthier lifestyles and avoid ‘risky’ behaviours which can compromise their health. Arguably, drinking excessive alcohol can also be regarded as a risky behaviour which could compromise a consumer’s health.

Marketing health as an individual’s own responsibility as opposed to a ‘collective responsibility’ has implications in relation to being a ‘good citizen’ (Harris et al., 2010, pp. 13, 22). Part of being a good citizen involves carrying out one’s responsibilities to

‘seek and act on health information to facilitate an efficient health care system’ (Harris et al., 2010). In light of this information, those who fall outside of the parameters of the good citizen may have their moral character questioned, as they are also violating the supposed relationship between following health information and cost-effectiveness; they are viewed as a financial burden. Although, the paper by Teghtsoonian (2009) was written on the subject of mental health, the principle remains the same and can be applied to a liver disease setting with regards to ‘at risk’ populations. Teghtsoonian (2009, p. 31) reported those who are at risk of a condition are expected to ‘actively’ manage their risk as good citizens, and ‘not burden the health care system with inappropriate requests for costly and unnecessary services’. If this was applied to liver disease, those who were seen as responsible for their liver disease through risky behaviours such as excessive drinking would no longer qualify for being regarded as good citizens. Hence, the ‘good citizens’ could use stigma power to enhance their own social status and ostracise those with liver disease. However, I would like to emphasise, the causes of liver disease are not only due to excessive alcohol consumption and neither is the status of excessive alcohol consumption in United Kingdom (UK) society as straightforward as being unquestionably a deviant behaviour from that of a ‘good citizen’.

Attitudes towards alcohol in the United Kingdom are ambivalent; despite the negative attitudes towards those with alcoholic liver disease, alcohol is also regarded as ‘an integral part of social life in the UK’ and an indicator of social cohesion (Heath, 1995, p. 297; Valentine, Holloway, & Jayne, 2010). Young people who do not consume alcohol at all, or infrequently, are perceived as being outside of the norm, with discourses presenting them as ‘socially isolated and dull’ (Herring, Bayley, & Hurcombe, 2014, p. 101). The ambivalent attitudes towards alcohol in the UK are why I would consider it to be a double-edged sword for young people growing up in the UK with liver disease. They may encounter both stigmatisation for not drinking alcohol, and stigmatisation by others in relation to beliefs that their liver disease was caused by alcohol misuse. One possible explanation for why people may hold incorrect beliefs about the cause of childhood liver disease is a lack of knowledge that the condition can affect children; after all, childhood liver disease is a rarity (Kelly, 2002). Young people with liver disease are often advised to be cautious of their alcohol consumption, especially if they have had a transplant, as excessive alcohol consumption can lead to a reduction in their survival (Lurie et al., 2000). However, not consuming alcohol can become stigmatising due to the negative attributes associated with non-drinkers such as being boring (Herring et al., 2014). What

this demonstrates is the complexity of the relationship between stigma and liver disease in the United Kingdom.

Liver disease is not only seen as a stigmatising condition in the UK, but viewed as such more globally. Previous literature with adults living with types of liver disease, such as hepatitis, has reported participants experienced stigma; this was found in many Western countries (Harris, 2009a; Treloar & Rhodes, 2009) and amongst those from non-Western countries, e.g. Iran (HassanpourDehkordi, Mohammadi, & NikbakhatNasrabadi, 2016), Pakistan (Rafique et al., 2014), Malaysia (Mohamed et al., 2012), and Chinese culture (Cotler et al., 2012). Some of the reported experiences of those with the condition include fears of social rejection and of transmitting the disease to others (Mohamed et al., 2012). Whilst literature exploring adult experiences of liver disease related stigma has been useful, it is important to consider young people's experiences within their own right as there are a number of contextual factors which can differentiate between their experiences and those of adults with liver disease (Brady, Lowe, & Lauritzen, 2015).

2.5.6 Visible stigma in liver disease

Although I have predominantly focused on the historical underpinnings of liver-related stigma and how looking at wider societal structures may help contextualise the manifestations of stigma, it is equally as important to focus on visible stigma. Referring back to the origins of the term stigma in the Greek language, the focus around visible marks becomes important in the context of liver disease (Goffman, 1963). This is because childhood liver disease may be accompanied by a number of different visible manifestations; for example, those who have had liver transplants will have scarring (Wise, 2002), certain medications such as steroids can lead to cushingoid facies (Kelly & Mayer, 2009), or young people may have jaundice (Roberts, 2009). Physical appearance is of significance given findings from previous social psychology research with children and adolescents, which highlighted the role of attractiveness in peer acceptance; possessing a 'desirable attribute' such as being "good looking" may give children 'an advantage when it comes to being liked by their peers' (Vannatta, Gartstein, Zeller, & Noll, 2009, p. 303). This then leads to the question of whether those who are not deemed to be attractive are then rejected by their peers.

Andrade (2007, p. 1020) drew on controversial examples where views have been held in the public domain that feeling repulsed by physical deformities was a 'natural' and 'instinctive' reaction; the rejection of those with deformities was something he reported as observable in daily life. Indeed, a plethora of research exists reporting experiences of bullying or rejection of children who grew up looking different to the norm or having a

'deviant appearance' e.g. cleft lip and palate (Havstam et al., 2011, p. 22), microtia (Spielmann & Neeff, 2013), and scoliosis (Rullander, Lundström, Lindkvist, Hägglöf, & Lindh, 2016). These previous studies support the idea that young people can experience stigma, given the stages of stigma as described earlier which included rejection (Abbey et al., 2011). I would argue in present society that exploring young people's views around transplant scars or looking different is of importance given societal pressures to look 'good'. According to Clark and Tiggemann (2006), girls as young as nine years of age can experience body dissatisfaction and are affected by what they described as an 'appearance culture' which stems from media and peer influences to prescribe to ideas about how they should look. This is linked to wider sociocultural beauty standards which can influence how young people feel about themselves (Mieziene, Jankauskiene, & Mickuniene, 2014). More specifically, adolescent girls may be influenced by digitally enhanced images of models as they grow up and learn about 'societal ideals regarding appearance' (Clay, Vignoles, & Dittmar, 2005, p. 471). Although, I am not implying here that this phenomenon only affects females; males are also influenced by societal ideals regarding appearance, for example, experiencing the pressure to have a muscular physique (Atkinson & Kehler, 2012; Martin, Kliber, Kulinna, & Fahlman, 2006).

Wise (2002, p. 87) described the 'obvious scar' from a liver transplant as a 'barrier to normalcy' for young people in her study and reported young people looked for other people with similar experiences. Another recent study, reinforced liver transplant scars 'triggered feelings of difference' (Wright, Elwell, McDonagh, Kelly, & Wray, 2015b). Wright et al. (2015b, p. 1135) reported liver transplant recipients looked for ways to avoid telling people about their transplant and created narratives, including one about a shark story 'to shock and also reprimand people for intruding into their privacy by asking about their scar'. Experiences of stigma can be further broken down into two types; felt and enacted stigma. Felt stigma refers to the 'fear of discrimination' and enacted stigma refers to 'actual discrimination' (Scambler, 2007, p. 704). According to Scambler (2007) 'felt stigma can predispose people to conceal their condition if they can, this being the strategy of choice for many', Scambler further argued that 'felt stigma causes more distress than enacted stigma'. It would be useful to explore in the context of the current study whether young people experienced felt or enacted stigma in relation to their liver disease, in particular their scars, which constitute a visible difference.

According to Green (2009, p. 3) 'stigma is often portrayed as an inevitable companion of long-term conditions'. The common narrative with regards to chronic illnesses depicts a process whereby 'society has stigmatizing attitudes towards the chronically ill and they in turn internalize social attitudes towards them, leading to low self-esteem' (Green,

2009, p. 3). However, Green (2009) was critical of this and argued in light of changing social attitudes, it may be possible to be chronically ill without automatically facing stigma. A unique component of chronic illnesses is that they can affect people from different social backgrounds, including those who are 'resource-rich and powerful'; something Green (2009, p. 114) identified as offering protection from experiencing stigma and the assumed 'social exclusion' and 'disempowerment'. This highlights the relationship between an illness (or an undesirable attribute) and experiencing stigma may not be as straightforward as previously assumed. Furthermore, there are opportunities in present society for those with chronic illness to 'retain their social position' and challenge the stigmatising beliefs which may exist regarding their condition (Green, 2009, p. 114). Examples of doing this include turning to mass media to achieve the status of a 'hero' or through campaigns which challenge stereotypes. However, this can be problematic as 'many people with long-term illnesses do not want to identify themselves as 'disabled'', thus, leading to issues 'about how to build solidarity while at the same time championing diversity' (Green, 2009, p. 119). Additionally, not all illnesses receive the same scope to allow those with them to draw on 'hero' discourses (which can be beneficial to the person), for example, those with HIV/AIDS may not receive the same recognition for how they cope with their condition in comparison to those with cancer (Fife & Wright, 2000). We do not yet know if and how liver disease intersects with 'hero' discourses with regards to young people with liver disease, thus, warranting further exploration. However, these discourses may be relevant in relation to the liver transplant scar; previous research reported the transplant scar can reinforce feelings of differences from their peers for young people, although, it also can symbolise a lifesaving procedure (Wright et al., 2015b). I will not explore the hero discourse literature in detail in this thesis, however, I will be exploring the impact of liver disease on young people's identity which may be influenced by labels and opportunities to reframe managing a condition.

2.6 What is biographical disruption?

In light of the literature on stigma and the potential for liver disease to be experienced as a stigmatising condition, and the previous research describing the disruption to the lives of young people, we know very little about how young people's identities may be affected by these factors. One way of understanding and contextualising the changes young people may go through following their condition is through the lens of biographical disruption. The term biographical disruption was coined by Bury (1982), who conceptualised chronic illness as a disruptive event. Bury (1982, p. 169) identified three important stages in biographical disruption. The first stage consists of 'the disruption of taken-for-granted assumptions and behaviours; the breaching of commonsense

boundaries' (Bury, 1982, p. 169). Here, a person's attention is directed to 'bodily states not usually brought into consciousness, and decisions about seeking help' (Williams, 2000, p. 43). The second stage of biographical disruption is where 'there are more profound disruptions in explanatory systems normally used by people, such that a fundamental rethinking of the person's biography and self-concept is involved' (Bury, 1982, p. 169). In the third stage of biographical disruption, 'there is the response to disruption involving the mobilization of resources in facing an altered situation' (Bury, 1982, p. 169). A chronic illness can result in different consequences depending on who is affected and how they respond to the illness, as summarised by Faircloth, Boylstein, Rittman, Young, and Gubrium (2004, pp. 258-259), "treating all survivor experiences as universal may gloss over some important aspects of the survival experience, resulting in poorly designed interventions, and in turn, poor outcomes for particular people". I first want to unpack the meaning of 'biography' and 'disruption' and in order to do so it is important I also briefly explore the meaning of 'identity' as often these basic definitions are overlooked.

Literature which discusses the impact a chronic illness can have on a person's life frequently talks about a "perceived loss of identity or sense of self" (Asbring, 2001; Golub, Gamarel, & Rendina, 2014, p. 577). The work of Erik Erikson (1980; 1994; 1995) is a useful starting point for understanding what is meant by identity. Erikson developed theories of identity (which I will only briefly refer to as they are outside the remit of this thesis) and I would like to draw on relevant ideas from his explanations of the *sense of the ego identity*. Erikson (1980, p. 94) argued "the sense of the ego identity, then, is the accrued confidence in one's ability to maintain inner sameness and continuity (one's ego in the psychological sense) is matched by the sameness of continuity of one's meaning for others". This is further explained by Fearon (1999, p. 4), who cited the work of Erik Erikson and stated identity is a complicated social construct; Fearon claimed identities can be both "social" and "personal". Social identity refers to a person belonging to a social category "a set of persons marked by a label and distinguished by rules deciding membership and (alleged) characteristic features or attributes" and personal identities refer to "some distinguishing characteristic (or characteristics) that a person takes a special pride in or views as socially consequential but more-or-less unchangeable" (Fearon, 1999, p. 4). The key elements from both the work of Erikson and Fearon would suggest identities are distinguished as being relatively stable and recognisable by others. I will now explain how identity is related to biography.

Definitions of what is meant by a person's biography vary; one definition was presented by Kaufman (1988) in her paper where she explored the relationship between biography

and illness. Kaufman (1988, p. 217) referred to “biography as knowledge of the self and as an expression of part of the self - a part that, following a massive illness, needs as much attention as the body”. Other definitions of biography have alluded to biography referring to a person’s life story or the expected course of their lives (Alexias, Savvakis, & Stratopoulou, 2016; Hubbard & Forbat, 2012). In his book *The Sociological Imagination*, Mills (2000, p. 104) described an individual’s biography as a record of the way they moved between different roles in their lives for example; a child, a workman, a student etc. Mills (2000, p. 104) claimed “much of human life consists of playing such roles within specific institutions” and in order to understand people’s biographies it was important to “understand the significance and meaning of the roles” people had played. Thus, I would argue that identity and biography are connected as the roles a person plays will have characteristics which define them.

This leads me onto *disruption*; something Alexias et al. (2016, p. 586) described as a “rupture in the continuity of one’s biography”. Examples of disruption include being unable to perform one’s duties at work, being unable to maintain social activities – both of which can lead an “identity-loss in relation to work and social life” (Asbring, 2001, p. 315). Disruptions, for example due to conditions such as endometriosis, can also affect personal relationships; Hudson et al. (2016) reported participants faced changes to their expected life courses in relation to family planning, sex lives and roles within marriage. There was the additional element of culturally derived differences which affected how some people experienced the condition and viewed themselves; the authors concluded “the disruptions caused by chronic illness are experienced in conjunction with relational identities and gendered cultural expectations” (Hudson et al., 2016, p. 732). This is particularly important because we know very little about how liver disease may affect young people’s expected life courses and their relational identities. Furthermore, there may be cultural and gendered influences on the impact of liver disease on young people’s lives which may manifest as a perceived loss of identity as seen in the adult chronic illness literature (Asbring, 2001). According to Bury (1982, p. 169), chronic illness “involves a recognition of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others”. Drawing on this quote it would suggest that chronic illness is a significant event in the life of the individual diagnosed; although some researchers have highlighted how biographical disruption may not be appropriate to describe the experiences of everyone diagnosed with a chronic illness, especially if the chronic illness does not present itself as symptomatic or if the individual already experiences many difficulties.

2.6.1 Biographical Congruence, Biographical Continuity and Biographical Flow

Some researchers have argued against accepting biographical disruption as “an inevitable consequence of chronic illness” (Bell, Tyrrell, & Phoenix, 2016, p. 178). Despite the wide use of biographical disruption in social science, there have been criticisms of the theoretical concept in light of the evolving literature base. The three main challenges biographical disruption faces have been identified by Llewellyn et al. (2014, p. 50) as the age and stage in the life-course of the affected individual, their exposure to prior illness, and finally, any general hardships they may have encountered prior to the onset of the illness. Some researchers have argued that older people may not experience a disruption to their lives following the onset of a chronic illness as the illness may be a “continuation” of the “significant health and social problems” already present in their lives; this is known as biographical continuity (Sinding & Wiernikowski, 2008, p. 389). Another concept which has evolved as a result of work with older stroke survivors is “biographical flow”; Faircloth et al. (2004, p. 256) described this as a better way to “understand the process of illness as a part of an on-going life”. Their research suggested that illnesses can be integrated into people’s lives to formulate a biography which flows across “time and space” (Faircloth et al., 2004, p. 256).

Another example, Harris (2009b, p. 1037), whose work looked at those diagnosed with hepatitis C, noted people may already be familiar with “pain, suffering and the possibility of death” long before they are diagnosed with a chronic illness; here she was referring to people who had experienced ‘hardship’ in their lives. As noted by Williams (2000, p. 50) “the biographically disruptive nature of illness is perhaps most keenly felt among the privileged rather than disadvantaged segments of society”. Harris suggested the term “biographically congruent” was more appropriate to explain the experiences of the participants in her research, who had “normalised” their diagnosis of hepatitis C. Although hepatitis C is a type of liver disease, the population in Harris’s work were adults who had injected drugs and thus the findings from the study may not be appropriate to the experiences of young people with liver disease who are likely to have been born with liver disease or acquired it for unknown reasons. However, there may be elements of “hardship” in the lives of young people with liver disease by which they may experience liver disease as biographically congruent; this would be something to explore within the research interviews.

2.6.2 Biographical Work

“Biographical work is a distinctive kind of reality-constructing activity that deals specifically with the interpretation and representation of lives in relation to the passage of time” (Gubrium & Holstein, 1995, p. 209). Using the example of an “emotionally disturbed child” who was being treated at a residential facility, Gubrium and Holstein (1995, p. 2010) explained how different staff members formulated different explanations or “histories” of the child in order to create ways of explaining the child’s behaviour. More broadly, what this highlighted was that the interpretations or “histories” others offered depended on what they were trying to achieve, for example, justify a shortcoming. This idea was further explained by Alasuutari (1997, p. 2) who stated as it was observable that “life stories can be seen as a means of personality or identity construction”, it was important to examine in which situations “the “personality” or “disposition” of an individual is invoked”. Alasuutari (1997, p. 2) noted it was important to question “the social function of personality in interaction” which is similar to Gubrium and Holstein’s (1995) point about understanding the purpose behind presenting “histories” in a certain way. So far, I have only referred to third party’s conducting biographical work whilst examining someone else’s life, however, I would now like to move onto the type of biographical work people complete in relation to their own lives.

Felde (2011, p. 102) sought to expand the concept of biographical disruption with a preference for the metaphor “biographical work” stating it had more “experiential cogency”. Focusing on what she described as a “symptomless chronic condition” (p.101), her work on elevated levels of cholesterol, led her to highlight the limitations of biographical disruption as being “too substantive, too constant, and indicates a linear, consistent and categorically coherent course of experience” in this particular context (Felde, 2011, pp. 102-103). Felde (2011, p. 103) explained biographical work as representing the continual work on “building situationally-appropriate identities” from situation to situation that a person undertakes in relation to “the shifting contexts of being sick or not sick”, in addition biographical work is both ‘reflexive’ and ‘interpretative’. Similarly, Kaufman (1988, p. 217) explicated this idea of biographical work stating; “following a catastrophic illness, the individual needs to “repair” and “heal” the self by revising and re-creating the biography so that it makes sense in light of the current changed circumstances of the individual’s existence”. The common thread between all of the depictions of biographical work are the adaptations made to a person’s biography in order to achieve a plausible outcome.

One way of repairing or healing following a chronic illness is by ‘normalising’ the condition by psychologically “bracketing off” the illness to minimise the impact of the

condition on the person's identity (Bury, 1991, p. 460). Some people may normalise a condition by maintaining activities associated with their pre-illness life to maintain an identity and others will find ways of redesigning their identity to incorporate their illness (Bury, 1991; Hubbard & Forbat, 2012). Moving away from chronic illness to consider biographical repair in terminal illness, Locock, Ziebland, and Dumelow (2009, p. 1051) reported denial of death acted as a 'defence mechanism' to facilitate coping with the prospect of death and this could be seen as a 'reconstructive activity' (Salander, Bergenheim, & Henriksson, 1996, p. 993). I would argue by denying a consequence of an illness, people are able to maintain their former identity. The work of Radley and Green (1987, p. 183) is often cited with regards to the idea of "active-denial" which refers to the attempt to "fight against the illness" through the maintenance of former activities (Bury, 1991; Williams, 2000).

2.6.2.1 *Parents and Biographical Work*

There is some research to suggest parents can also undergo a form of biographical disruption as they attempt to construct new self-identities following their child's illness and can take on new 'nursing' roles (Young, Dixon-Woods, Findlay, & Heney, 2002). Previous research by Young et al. (2002, p. 1837) with mothers of children with cancer, found their accounts bore a 'striking resemblance' to biographical disruption (Bury, 1982). This research highlighted the important transition mothers made from being a mother to a 'healthy child' to the mother 'of a child in crisis' and focused on the biographical work undertaken by mothers, which was also affected by cultural expectations of being a carer and a mother (Young et al., 2002, p. 1837).

There were many factors which affected the mothers' experiences, including the impact of their child's hospitalisation on their wider lives (e.g. work, family) and the need to be in close proximity to their child; although only a few participants were open about their own needs and desire for 'space' during this difficult time, this was constructed in a way to justify the break from the hospital, which suggested mothers were aware of the expectation to be selfless (Young et al., 2002). This piece of research is particularly important as it highlighted the grief mothers had for their former lives and alongside the practical difficulties of managing their child's illness, they experienced significant disruption to their own biographies. Childhood cancer is often characterised by uncertainty with regards to a diagnosis and the absence of a script to explain the cause can be difficult for parents (Young et al., 2002). This is an important area to explore further because liver disease can also arise for an unknown reason and we currently know very little about how this can affect parents of children with liver disease,

particularly, given the impact of a child's chronic illness diagnosis on parents' biographies.

Furthermore, according to Young et al. (2002, p. 1844), motherhood is "defined (at least in part) in relation to social constructions of children and childhood"; this is important as mothers often are expected to protect their children whilst growing up and their future. This suggests parental biographies may be revised and redefined as their children transition through life. I will discuss the social constructions of childhood in more detail later on in this chapter and will now present research relating to children's experiences of biographical disruption.

2.6.3 Children with chronic illness and experiences of biographical disruption

Over the years, the literature on biographical disruption has developed in order to provide an explanatory framework to enhance our understanding of the experiences of those living with many different chronic illnesses including but not limited to; cancer, HIV/AIDS, and even terminal illnesses such as motor neurone disease (Alexias et al., 2016; Hubbard, Kidd, & Kearney, 2010; Locock et al., 2009). There are a number of concepts which have emerged as a result of previous studies exploring biographical disruption in adults with chronic illnesses which include; biographical continuity, biographical flow and biographical work. However, much of the literature on biographical disruption has focused on adults with chronic illness and this has left this area of the literature predominantly neglected with regards to the experiences of children with chronic illnesses. In addition, the relevance of biographical disruption to the experiences of chronically ill children has been questioned by Williams (2000, p. 50) who stated "the (adult-centric) transition from health to illness" remained "a problematic assumption upon which much biographically-orientated research to date has unquestionably rested". The argument made by Williams (2000, p. 50) focused on the lack of transition from health to illness in children born with chronic illnesses; given that a chronic illness can be viewed as an integral aspect of a child's "biographically embodied self", he argued it is debatable whether a chronic illness ever emerges. The key issue here is there may not be a disruption as described by Bury (1982) for children born with congenital illnesses.

However, what the literature on children and young people with chronic illnesses does tell us is that they can be 'exposed constantly to stress of both a physical and psychological kind' (Northam, 1997, p. 370). The physical stresses include unpleasant procedures, ill health and psychological stresses include 'feeling or being different' as well as the battle to 'maintain an appropriate developmental momentum in the face of restricted opportunities' (Northam, 1997, p. 370). Across other childhood chronic

illnesses, we know from quantitative research children with 'chronic fatigue syndrome, fibromyalgia, migraine or tension-type headache, cleft lip and palate, and epilepsy are at highest risk for developing depressive symptoms' (Pinquart & Shen, 2011, p. 383). In relation to children's experiences of chronic illness it must be noted some types of chronic illnesses may only occasionally affect the lives of those diagnosed with them. This is something Monaghan and Gabe (2015, p. 1236) referred to as *biographical contingency* and described as the "now you see it, now you don't" nature of a condition that varies in terms of its symptoms, meanings and consequences". Their study looked at the experiences of young people from the Traveller community of living with asthma and reported young people were keen to present their conditions as being minimally disruptive on their lives, often comparing themselves to those who were worse off (Monaghan & Gabe, 2015). Monaghan and Gabe (2015, p. 1244) found for young people the chronic condition was viewed as 'irrelevant' in comparison to other aspects of their lives; the authors felt their findings resonated to a statement by Atkin and Ahmad (2001, p. 617) stating that "young people's experience of chronic illness cannot be discussed in isolation of the broader context of "growing-up"". The period of growing up can be drawn out and the transition into adulthood is not marked by a single event; Apter (2002) referred to young people transitioning into adulthood as *thresholders* and discussed the various challenges young people face when trying to conquer adult life.

However, amongst the scarce literature, there is research suggesting young people with chronic illnesses do experience biographical disruption. Another study exploring the biographical impact of teenage and adolescent cancer discussed how disrupted biographies and the "transitional nature of the life stage" could bring a "young adult's life trajectory to a standstill" (Grinyer, 2007, p. 266). Chronic illnesses are viewed as making an already difficult transition worse (Grinyer, 2007). One of the themes from Grinyer's (2007) study reported on the disruption of life trajectories; notably young people not achieving the required educational qualifications to continue with getting a good job, feeling their illness status prevented them from being accepted for jobs, and that their peers were moving on ahead of them. Other participants in this particular study discussed their financial difficulties in establishing their independence whilst some struggled with the physical consequences of cancer and having to rely on others to help them wash and go to the toilet at a time when they were becoming aware of their bodies and wanted privacy (Grinyer, 2007). Another dimension which was discussed by Grinyer (2007) was the impact of cancer on physical appearance and the value young people placed on their physical appearance; this is of particular importance because like cancer,

there are physical manifestations of liver disease which can alter the appearance of young people either as a result of the liver disease itself or the treatments involved.

One of the prominent themes from the adult literature focuses on normality, that is whether people diagnosed with chronic illnesses are trying to 'bracket off' their illness or maintain earlier activities, they are trying to attain a sense of normality and their former life. This has further been a finding of the work of Williams, Corlett, Dowell, Coyle, and Mukhopadhyay (2009); their work explored the lives of children with cerebral palsy, a congenital condition, and concluded children experienced a nuanced form of biographical disruption. Williams et al. (2009, p. 1446) reported four types of normality;

"1) Normal to self: A definition of normality based on recognition of an expected illness trajectory and personal life narrative: "To me this is normal."; 2) Normal for self: The principle audience for whom the achievement and/or maintenance of normality is being made is the young person her or himself. Young people attempted to maintain their own personal perceptions of their own normality for their own sake; 3) Normal to others: A definition of normality based on recognition that others might see them as nonnormal, even though to them this might be ill founded; 4) Normal for others: The principal audience for whom the achievement and/or maintenance of normality is being made are surrounding social groups rather than the young person him- or herself. Young people attempted to maintain an appearance of normality in the eyes of others (even if they disagreed with that perception) and for their sake, and thus potentially, indirectly, for themselves".

More recently, Saunders (2017, p. 727) has proposed the concept of 'recurrent biographical disruption' with regards to young people's experiences of irritable bowel disease (IBD), arguing biographical disruption can have a more profound effect during young adulthood in light of 'its unique pressures and expectations'. Saunders took a case study approach to explore the experiences of two individuals in-depth, highlighting how anticipated disruption from a chronic illness can be a current issue which affects young people, rather than solely being located in the future; through this nuanced experience of biographical disruption, young people configure their 'past, present and anticipated future experiences' (Saunders, 2017, p. 727). Building on the work of Larsson and Grassman (2012) on repeated disruptions, the key message is that biographical disruption is not a static, one-off event, but rather for conditions such as IBD which have clear patterns of relapse followed by periods of remission, each repeated

period of illness 'can be equally as devastating as the initial biographical disruption' for young adults as well as adults (Saunders, 2017, p. 735). It is also important to take into account the impact of comorbidities which may develop as a result of the initial chronic illness; young people can be worried about how others will perceive them, suggesting stigma can have a significant impact on their conceptualisations of themselves (Saunders, 2017).

Given the paucity of research exploring biographical disruption and young people's experiences of chronic illness, it would be of great interest to explore whether the accounts of young people with liver disease suggest they experience biographical disruption. In particular, the range of different liver diseases varying in onset age would provide a valuable platform for exploring this concept further as young people can be born with liver disease or develop liver disease later on in life. This means there is an opportunity to understand whether for those born with chronic illnesses, liver disease ever "emerges" causing a disruption to their biographies, and if those diagnosed later in life experience similar patterns of transitioning from health to illness as described in the adult literature.

It is clear that an exploration of the views and experiences of young people with regards to liver disease and stigma is also necessary for a number of reasons. The first and most important reason is to broaden our understanding of how stigma is experienced by young people with liver disease; there is very little research exploring young people's experiences themselves as much of the previous literature on chronic illnesses has tended to focus on adult interpretations. It is important as researchers to allow the voices of young people with chronic illnesses to be heard. The second reason is to take into account the contextual factors associated with growing up with liver disease in the UK, where ambivalent attitudes towards alcohol consumption exist, and young people may be exposed to stereotypes generated from a lack of knowledge about childhood liver disease. The third reason is to explore further felt and enacted stigma, with a focus on the visible markers of liver disease such as transplant scars from young people's perspectives. The sociology of a childhood is one such approach which advocates the participation of children and offers a perspective in understanding children's experiences.

2.7 Sociology of childhood

James and Prout (2004, p. 7) refer to the sociology of childhood as an 'emergent paradigm'. According to James and Prout (2004, p. 7), this approach resonates with the

notion of cultural specificity of knowledge held by social constructionism; as ‘although the immaturity of children is a biological fact, the ways in which this immaturity is understood and made meaningful is a fact of culture’. The sociology of childhood has been reported to dominate the wider field of academic interest labelled childhood studies (Tisdall & Punch, 2012). Tisdall and Punch (2012, p. 251) reported what they described as the ‘mantras’ of the sociology of childhood, particularly in the United Kingdom, which include; viewing childhood as something which is socially constructed; the need to recognise and focus on children and young people’s agency; and valuing ‘children and young people’s voices, experiences, and/or participation’. However, it is important to be mindful that childhood is not universally experienced, it is produced by culture and can “vary across time and place” (Kehily, 2004, p. 7).

The role of children in society has changed. In pre-industrial society, children were viewed as assets to their family (Qvortrup, 2006); they went out to work to help their parents financially and through this were authentically integrated into the community they were living in (Qvortrup, 1987). They further provided reassurances from the ages of six or seven that their parents would have somebody to look after them in their old age (Qvortrup, 1987). However, between late 19th Century to early 20th Century, a shift occurred in the role children had in society; children were ‘sacralised’ or ‘sentimentalised’ and the role of the family in being responsible for ensuring children’s wellbeing and upbringing was reinforced (Qvortrup, 1987, p. 16). Qvortrup (1987) argued the status of children had been declassified, referring to a deprivation of a majority status in society, and issues around simultaneous protection and control became important.

2.7.1 Becoming vs being child vs both

Central to childhood research are the two notions of the ‘being’ and the ‘becoming’ child. The ‘becoming’ child has been described as an ‘adult in the making’ (Uprichard, 2008, p. 303) or an apprentice for adulthood (Kehily, 2004, p. 7). The focus of the ‘becoming’ child is future-orientated and reinforces the idea that children are not fully integrated into society; childhood is depicted as a project to ‘instil values and skills in children’ for their eventual integration into ‘adult’ society (Qvortrup, 1987, p. 5). The focus on an anticipated future adult has been criticised as not recognising children as ‘human beings in their own right’ and being dismissive/not acknowledging the daily realities experienced by children (Uprichard, 2008, p. 304).

In contrast, the ‘being’ child is understood as a social actor who actively constructs their childhood rather than being a passive recipient of the social structures which govern their lives (James & Prout, 2004; Uprichard, 2008). It is important here to state the

differences between children as social actors and social agents as this can be useful in examining children's experiences (Seymour, 2015). Mayall (2002) explicated the differences between children as social actors (they may do something with others) and those who are agents (they negotiate with others and their interactions have an impact or lead to a change). Viewing children as social actors and possessing rights forms part of the approach for the 'new' sociology of childhood, which counters the idea that children are passive and dependent on their family (Tisdall & Punch, 2012).

Tisdall and Punch (2012) drew attention to the premise that children's agency and rights are not universal; the ideas have been argued as engaging in a continuation of colonial imperialism and imposing ideas which are adversative to some cultures and contradictory to their traditions. The cultural-boundedness of childhood more broadly was highlighted by Gittens (2009) who argued childhood itself was class-specific and mirrored middle class, European practices which prescribed to categories differentiating between children and adults. Furthermore, the formulation of children as a distinctive category led to a need for 'cultural products', often referred to as the material culture of childhood (Kehily, 2004), which as Brookshaw (2009) points out, were artefacts imposed by adults rather than produced by children themselves. Examples of artefacts for children include toys and children's books, which are written by adults (Brookshaw, 2009; Hunt, 2004). There is some evidence which suggests children are aware of 'material manifestations of childhood' and have questioned whether one can be a child without these manifestations believed to be intrinsic to childhood (Brookshaw, 2009, p. 367).

Material manifestations of childhood are important in relation to the concept of biographical disruption (Bury, 1982) as in the case of childhood chronic illness, children may be exposed to medical artefacts (such as tablets or syringes) rather than toys/books explicitly associated with childhood. Although efforts have been made to make hospital care more child-friendly through nurse and doctor clowns and distraction techniques, which I would argue to an extent bring back material manifestations of childhood into an "adult" hospital environment, attention needs to be paid to the interactions of medical artefacts or the hospital environment with children's identity. The introduction of medical artefacts could potentially be recognised by children with a chronic illness as disruptive and have an impact on how they identify as a child or an adolescent. This is something worth exploring further within the context of liver disease and growing up, particularly as some children are diagnosed with the condition later in life and may have to assimilate medical artefacts into their current and future lives.

Uprichard (2008, p. 310) argued for children to be viewed as both 'being' and 'becoming' as a means to increase children's agency, stating some children are aware of the changing world around them, their own development and can actively negotiate and imagine "their future lives in a future of the world". With respect to interpretations of the past, present and future influencing how people manoeuvre through their life, Uprichard (2008, p. 310) suggested exploring children's perspectives of their present and future selves could be fruitful in learning about "how issues of empowerment and agency vary throughout the life course".

Brannen and Nilsen (2002) explored the idea of young people's agency during the transition to adulthood, particularly around planning for the future and making choices, arguing how young people perceive and experience time was influential to this process. They cautioned against dichotomising young people's biographies in a simplistic way using the choice/standard biography categories, instead, drawing attention to the multitude of factors which influence the transition to and through adulthood (Brannen & Nilsen, 2002). These factors included the ways opportunities for education and training were structured and the impact this can have on employment patterns; the role of gender identity and the influence of maternal and paternal role models; and race and ethnicity (Brannen & Nilsen, 2002). Children with a chronic illness could be influenced by another factor; their health status, which could disadvantage them with regards to future employment (Yeo & Sawyer, 2005). Brannen and Nilsen (2002, p. 532) also suggested 'youth lifestyle' and 'cultural constructions of what it means to be young' were important factors. Furthermore, given the work of Saunders (2017) on young adults' experiences of recurrent biographical disruption and how anticipated disruption can be an issue which affects young people in their present lives, it is important to consider how the transition to adulthood is affected by the presence of a chronic illness.

2.7.2 Age and competency

Childhood may not be universal, however, the universality of the adult-child dichotomy is more apparent with age separating adults from children (Bass, 2007). The status of one's age marks the power differential in favour of adults over children; usually adults control children's lives (Bass, 2007). According to Walkerdine (2009), adult power underlies the depiction of childhood as an unstable state of being compared to adulthood. Children's age has been an important point of debate, particularly in relation to children's capacity. Some of the questions posed in relation to children's competency include the age in which their accounts can be trusted and they can become "reliable witnesses" to their own lives (Qvortrup, 2006, p. 439).

Developmental psychology was the dominant paradigm for studying children in the early twentieth century (Kehily, 2004). It proposed stages using “age, physical development and cognitive ability” to map children’s evolvement into rational adults; the premise being, with age, they would reach these milestones (Kehily, 2004, p. 7). Consequently, sociologists (see James and Prout, 2004) have been critical of the work of developmental psychologists such as Piaget (1959), arguing it reinforces the notion of the ‘becoming’ child (Kehily, 2004). Despite the criticisms levied, I would argue that Piaget’s research was an important foundation in recognising the observable differences between children and adults and attempting to understand children’s ways of thinking. The sociology of childhood framework also calls for children to be seen as worthy of being studied in their own right (James & Prout, 2004) and early developmental psychology work dedicated academic pursuits to widening our understanding of childhood.

The categories of children and adults are linked by their interdependent associations; according to Alanen (2001) they cannot exist without each other and are constructed by a process which involves both adults and children’s agency. Alanen (2001, p. 21) defined agency as;

“inherently linked to the ‘powers’ (or lack of them), of those positioned as children, to influence, organise, coordinate and control events taking place in their everyday worlds”.

Generally, agency is regarded as a positive thing for children and there are many empirical studies demonstrating children and young people’s agency, highlighting their competence as social actors (Hutchby & Moran-Ellis, 1998; Tisdall & Punch, 2012). Some scholars have been keen to break away from the stereotypical depiction of children as completely powerless by attributing agency to children in different contexts. An example of this would be in the case of child soldiers, where the decision has been highlighted as an important and positive decision (Rosen, 2007) and it has been reported child soldiers can “achieve a strong sense of agency and meaning in life” through their participation (Wessells, 2006, p. 53).

However, Tisdall and Punch (2012) argued for the concept of agency to be scrutinised and to not be unquestionably welcomed as innately positive, urging for the exploration of the potentially negative aspects of children’s agency. Hartas (2011) emphasised how children can face pressure to participate and those who choose not to participate can be marginalised; instead, she called for the interpretation of children’s decisions not to participate to be understood as an exercise of their rights, rather than a failure on their

part. This suggests children have a right to not assert their agency, which is interesting given the emphasis on encouraging children to exercise their agency in different contexts and in light of situations where children may be unaware of how to exercise agency (Hartas, 2011; Tisdall & Punch, 2012). Furthermore, it is important to be mindful of not demonising a child who appears to deviate from responsibility and compliance (Tisdall & Punch, 2012).

As Hartas (2011, p. 84) highlights, the right to childhood is often depicted as a “right to a protected” space, one which affords adults the responsibility of making the decisions and children “free time, to explore and develop, untouched by the evils of the adult world”. This in itself is problematic as although children in some societies receive protection and provision, they are devoid of their right to participate in society; through labels of vulnerability children are marginalised (Hartas, 2011). A further issue is, adults can be selective about in which circumstances to attribute agency to children. Kehily (2004) drew comparisons between two incidences of murder committed by children; the culprits of James Bulger, by English law were deemed to be criminals at age ten, whereas in the Raedergrd case, the six year old culprits were deemed to be victims as in Norway, until a child is fifteen, they are not perceived by the legal system as responsible for a crime. Responsibility is understood on a continuum where by a certain age, a child should know certain things and age was the crucial decider separating whether the children were branded evil or innocent victims (Kehily, 2004).

When children no longer possess their innocence, the foundation for childhood, they are exposed to the same gravities and troubles as adults, and lose their protected status and the sympathy they received; they cease to be children (Kehily, 2004). Although it must be stressed that the polar opposite ideas of children being evil or saintly are not new; Hunt (2004, p. 56) stated;

“Throughout the first half of the nineteenth century, the idea of the child as being inherently evil and needing to be firmly controlled was in tension with the ‘romantic’ idea of the child as pure, free and close to God”.

Similar to notions of evilness and saintliness, in the case of chronic illness, children can be represented as *innocent*, even in otherwise stigmatising circumstances for adults, such as in the case of AIDS. Fassin (2012, p. 179) drew on the controversy around AIDS in South Africa being associated with “sin and deviance” to highlight the advantages afforded by childhood; children were perceived differently for having the same condition, for example, the “sick child” was portrayed as an innocent victim “whose only responsibility for his or her misfortune was to have been born”. Interestingly, children

with AIDS were presented as victims of adults and the blame was also attributed to the “incompetence of the authorities” Fassin (2012, p. 179). Furthermore, the notion of saintliness extends to parents; “parents of disabled children are often perceived as extraordinary and almost saintly” for managing their child’s condition, particularly for encouraging their children to lead a ‘normal’ life (French & Swain, 2008, p. 9).

Notions of responsibility in relation to age are particularly pertinent in light of children with a chronic illness. At some stage in their life, it is decided children should be responsible for their own health, and part of these responsibilities include managing their own medication. Although this is often a gradual change, it is not always easy for children to manage as they may struggle with this responsibility and can be left feeling powerless by their medical condition (Taddeo, Egedy, & Frappier, 2008). Evidence exists within the literature which demonstrates children with chronic illnesses may demonstrate lower rates of actual compliance to therapy compared to what they report (Bender et al., 2000; Milgrom et al., 1996; Moore, Neustein, Jones, Robin, & Muir, 2015). This could mean a number of things; children could be aware that they “should” be taking their medications as prescribed or, they may not be able to accurately predict their consumption. However, it should be noted that parents of children who manage their own medication are not necessarily reliable reporters of their children’s consumption either (Moore et al., 2015). Following medication regimes has been reported to be particularly challenging for adolescents and the consequences of this include medical complications (Taddeo et al., 2008). Furthermore, in light of liver disease research demonstrating the struggles of managing medication during the transition to adult services, age is particularly important as the age of transition may not reflect a young person’s readiness to assume responsibility for their health condition (Annunziato et al., 2007).

Qvortrup (2006, p. 435) warned of the “unalterable reality of adult power” and highlighted that there are limits to what children can actually do, despite the well-intended “rhetoric”. Another aspect of taking responsibility for one’s health includes participation within the clinic setting. According to Tates, Elbers, Meeuwesen, and Bensing (2002, p. 6) “the prototypical supportive triadic medical interaction is a situation in which both the GP and parent encourage the child to take an active role in the medical encounter”. Whilst this refers to an idealistic scenario in the consultation room, it can be difficult for adult patients to maintain involvement in a triadic medical interaction, and this is without taking into account what Kitzinger (1997) described as the ‘odds stacked against children’, referring to a power imbalance between adults and children. Previous research with adults with dementia has already established that in reality this ‘triadic encounter’ is more dyadic in nature between the doctor and companion, with the patient’s attempted success at

actively being involved in the consultation varying (Karnieli-Miller, Werner, Neufeld-Kroszynski, & Eidelman, 2012; Peel, 2015). Bates, Elbers, et al. (2002, p. 8) reported in 72% of their observations of consultations in The Netherlands, both parent and doctor were unsupportive of the child's involvement, stating children were treated as 'passive bystanders' in their own consultation. Other studies have also found children's experiences of involvement in consultations vary and despite the best intentions of parents to involve them, children can feel ignored in the process (Beresford & Sloper, 2003; Coyne, 2006b) or become pushed out of the consultation by their parents (Bates, Meeuwesen, Elbers, & Bensing, 2002).

Brady et al. (2015, p. 2) stated;

“there is no typical child. Children are of different ages, gender, ethnicity, socioeconomic circumstances and capacity. They live in different national and cultural contexts and attend different educational institutions”.

Whilst we already know from previous literature 'children's competence and understanding in dealing with a medical diagnosis is often underestimated' (Brady et al., 2015, p. 6), some young people with chronic conditions may find it daunting assuming the responsibilities involved with managing their own healthcare (Weissberg-Benchell, Wolpert, & Anderson, 2007). This reinforces how a young person's age may not be the best indicator for when they should begin to assume responsibility for their condition and their communication preferences for receiving information provision.

However, the emphasis on encouraging children to participate in their health-related activities raises important questions; what about the children who exercise their agency by choosing not to participate in their health-related activities, or, children who choose not to take their medication as prescribed? This is a potentially controversial issue; Taddeo et al. (2008, p. 19) claimed not adhering to medication regularly “contributes to poorer quality of life and an overuse of the health care system”. There are many factors in current society which may influence the answers to these questions and it could be children who do not follow their prescribed therapy could be demonised in the context of cuts to National Health Service (NHS) funding. For example, other conditions such as Type 2 diabetes have been reported to be a “drain on NHS resources” and discourse exists around reducing the “NHS burden” (Moore, 2000, p. 732). Whilst adults can be demonised for not taking responsibility for their own health, it is not known how children with liver disease experience their condition, particularly given the stigma attached to liver disease. These matters need consideration in the context of understanding children's experiences of liver disease, particularly around the transition to adult

services; generally as children turn into adults, they lose the 'innocence' attributed to them that protected them from the scrutiny adults face (Kehily, 2004). Furthermore, the experiences of parents of children with liver disease is also important; in the context of AIDS (Fassin, 2012), children with the condition were perceived as victims of adult choices and it is not known whether parents of children with liver disease have experienced similar apportionings of blame.

2.8 Conclusions

This literature review has highlighted childhood chronic illness can affect the lives of children and their parents in multiple ways. Adolescence is already a difficult time for young people growing up without a chronic illness as they make numerous transitions to adulthood. Furthermore, liver disease is a stigmatised condition and the rarity of childhood liver disease in the United Kingdom warrants further exploration in light of the minimal existing literature on the experiences of children with liver disease.

2.9 Research Questions

This thesis aims to address the following research questions;

1. What are young people's experiences of growing up with living with liver disease in the United Kingdom?
2. What are the experiences of parents whose children are living with liver disease?
3. What impact does living with liver disease have on young people's identities and how does this relate to experiences of stigma and biographical disruption?
4. How does liver disease affect the medical and social transitions young people make?

3 Methodology

February 2014. My first face to face interview took place with a participant recruited from a hospital and nothing could have prepared me for how intense that afternoon would be. The participant was male, two years older than me, and we met up in a café. He had only provided me with a landline number, something I felt signified a lack of trust given my own personal disposition towards my phone. I was later to be illuminated as to why he did not own his own mobile phone. He was very quiet when he was recruited onto the study so I was not sure if he would open up or even turn up. However, during the interview he opened up about many things and I listened as he narrated his painful memories, trying hard to put into place the various guidelines on interviewing I had read prior to commencing data collection.

He described many incidents of bullying, many he associated with stemming from the disadvantages of his liver disease. However, four points in the interview really stood out for me due to their unexpected nature. The first point was the way he compared our educational attainment, he used my PhD as an example to indicate how I was privileged compared to him because I would easily be able to find a job. The second point was the way he referred to my age being an advantage, commenting how much easier things would be for me because I was younger than him. The third point was he highlighted he did not know about my health problems but assumed as a healthy person I would be preferred by employers. I was not prepared to be the focus of the interview so felt uncomfortable as he drew these comparisons. I felt he had constructed categories between us based on age, health and education. I was placed at the opposite end of the spectrum; his end was laden with restrictions and misery, and my end overflowing with opportunity and privilege.

His comparisons stemmed from what he described as a form of systematic hurdles he encountered due to his various health conditions. In front of me was a young man who had endured repeated disappointments when it came to finding employment and was unable to carry out his role when he did secure employment by what he felt were signs of intrinsic discrimination against people with chronic health conditions. Moreover, he recalled a plethora of incidents whereby he felt discriminated against, ranging from social activities, alcohol consumption, and his relationships with others. The fourth point he raised was not categorising me as different to him but focusing on his desire to be friends with 'healthy' people. He later disclosed he had no friends of a similar age and craved the taken for granted encounters such as meeting up and watching a film.

This revelation forced me to reflect on how the interview may have been perceived. To other customers in the café perhaps we were two friends engaged in a conversation. Perhaps momentarily the interview became an image of the ideal world where friends interacted. Except it was a professional encounter and I was a researcher; this was to be our only encounter. The interview stayed on my mind for many days, I felt many emotions such as shock, sorrow and even guilt. Two people can experience such different worlds concurrently and it is important to be mindful of that as a researcher.

I have started this chapter with a piece of reflection from my field notes which serves the purpose of introducing the multiple factors associated with my journey through the fieldwork. In this chapter, I describe and justify the methodological approach I have used to explore young people's and their parents' experiences of living with liver disease. I will begin by discussing the research paradigm, including the ontological and epistemological framework which steered the selection and use of methods; semi-structured interviews with young people and parents and explain and justify thematic analysis as a method of analysis. I will then discuss the development of the project. I discuss the ethical approval process, methods of data collection, and my own personal journey through the fieldwork.

3.1 The research paradigm

I have adopted a post-positivism research paradigm for this project (Guba & Lincoln, 1994). With respect to the ontology, I have taken a critical realist approach whereby I believe although a reality does exist, it cannot be entirely understood; one can only strive to depict an accurate attempt at making sense of a phenomena (Guba & Lincoln, 1994, p. 110). Ontologically, post-positivist research steps away from the dualisms of positivist research (where everything is seen as black or white), however, there is an emphasis on examining whether findings 'fit' with pre-existing knowledge' (Guba & Lincoln, 1994, p. 110). Guba and Lincoln (1994, p. 110) attribute features of post-positivist methodology to conducting research in 'more natural settings, collecting more situational information, and reintroducing discovery as an element in inquiry'. According to Ryan (2006, p. 18) "The post-positivist stance asserts the value of values, passion and politics in research. Research in this mode requires an ability to see the whole picture, to take a distanced view or an overview". Both post-positivism and critical realist approaches accept that reality cannot be reduced to being only black or white, nor can it be completely understood, hence, both complement social constructionism which affords scope for exploring and contextualising different viewpoints.

3.2 Social Constructionism

The difficulties of assigning a broad definition to social constructionism were highlighted by Potter (1996, p. 1); to try and assign such a 'neutrally and objectively described' definition would be 'anti-constructionist' as it would endorse taking a 'realist account of constructionism'.

According to Gergen (1985, p. 266)

"Social constructionism views discourse about the world not as a reflection or map of the world but as an artifact of communal interchange. Both as an

orientation to knowledge and to the character of psychological constructs, constructionism forms a significant challenge to conventional understandings.”

I would like to clearly state here, I am not aligning this project towards taking the criticised radical constructionism route (Cromby & Nightingale, 1999), described by Mercadal (2014) as claiming ‘human knowledge can never accurately represent reality’.

Social constructionism provides a useful perspective for analysing the data generated from this project. The following quote taken from Shotter and Gergen (1994, p. i) summarises the many uses of social constructionism because it has;

‘...given voice to range of new topics, such as the social construction of personal identities; the role of power in the social making of meanings; rhetoric and narrative in establishing sciences; the centrality of everyday activities; remembering and forgetting as socially constituted activities; reflexivity in method and theorizing. The common thread underlying all these topics is a concern with the processes by which human abilities, experiences, commonsense and scientific knowledge are both produced in, and reproduce, human communities’.

Issues of power are particularly important for this research project due to the age of the younger participants (Grover, 2004). Literature on social constructionism suggests an emphasis on providing children with a voice. One of the difficulties in paediatrics is often children are unable to convey their feelings through traditional methods such as language (Gillis & Loughlan, 2007). Referring to the work of Gergen (1989), Burr (1995) documented the idea that everyone is motivated by a desire to have their own version of events triumph against contending versions. Thus, everyone is competing for ‘voice’; the right to be heard and may consequently present constructions of themselves which are more likely to ‘warrant voice’ (Burr, 1995). The process of ‘warranting voice’ refers to a person using representations that appear to be more valid and legitimate (Burr, 1995, p. 90). Burr (1995) identifies that those in a position of power are equipped with the resources and authority to make lasting version of events, this in turn means their versions ‘warrant voice’ more than others. This is because these versions of events are heard more frequently and consequently are more likely to receive the label of ‘truth’ or ‘common sense’ (Burr, 1995, p. 90).

3.3 Thematic Analysis

When selecting an appropriate tool to analyse the data, I chose thematic analysis as it is theoretically neutral and therefore can be applied to a critical realist/social constructionist study (Mills, 2010). Moreover, this analytical approach (as opposed to, say, biographical analysis) allows for a large amount of data to be synthesised for analysis. Thematic analysis is a “method for identifying, analysing and reporting patterns (themes) within data” and has been widely used in health and wellbeing research (Braun & Clarke, 2006, p. 79; Braun & Clarke, 2014). Braun and Clarke (2006, p. 78) state that “through its theoretical freedom, thematic analysis provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data”. Given the large data set I anticipated collecting, it was appropriate to use a method which could aid in the analysis of that data effectively. Criticisms of thematic analysis have included that the method is poorly defined (Drisko & Maschi, 2015), however, in their paper, Braun and Clarke (2006) outline steps to clarify the process of conducting thematic analysis.

In terms of my own analytic process, the interview transcripts were read several times to understand the participant accounts and I wrote down my initial thoughts related to each interview. Initially, broad codes, such as “hospital” and “school”, were used to organise the data, as these codes referred to the topic areas discussed in the interview. This enabled me to organise the data topically. I then coded each transcript line by line, writing down the initial codes in the margin of the transcript. I had chosen to predominantly take an inductive approach which consists of allowing the data to drive the analysis, rather than trying to map the data against a pre-formed coding frame (Braun & Clarke, 2006, p. 83). However, I also applied deductive codes (such as “periods of illness”) where theoretically appropriate. I will demonstrate how the codes were applied using an extract from an interview below.

Participant: No, I was just I think because I was so poorly I was just like this little ball of yellow, ball just on the bed, you know (laughs), lifeless and energyless and that's-that's not me like I was always fit and active and like I did my gymnastics and you know, I was- I did that like three times a week, three hours each session and it was like a dra-a dramatic change, you know.

The above extract was coded in multiple ways as “periods of illness” (a broad code used when participants were referring to periods of ill health), “health interference” (this code referred to instances where participants reported their health interfered with other

activities), and “social activity” (which was used to capture the activity which was affected by liver disease). These codes were explicit, descriptive codes which resemble the semantic coding described by Braun and Clarke (2006) where the researcher does not look for meanings beyond what the participant says. The extract was also coded as “biographical disruption” at a later stage which was a theory-driven code, this is known as latent coding as it goes beyond a description and involves interpretative work on behalf of the researcher (Braun & Clarke, 2006). This example also highlights how the themes I developed were not mutually exclusive and, often, data was initially coded into multiple themes in order to ensure the most holistic picture about the data was captured. My final themes were produced by reviewing the codes and combining them to form potential themes, these were then reviewed. In this particular illustrative example for instance, this extract eventually became part of a theme titled “morphing into a different person”. We can see here, therefore, how I apply the tools of thematic analysis to my interview data in a way which inductively represented the data and allowed for ‘participants’ voices’ to be well grounded in the analysis whilst also developing a thematic analysis that was theoretically informed by key concepts such as biographical disruption.

3.4 Transcription and Translation

“Transcription is always a time-consuming and demanding task and often this is contracted out to people with the essential skills” (King & Horrocks, 2010, p. 119). I had completed transcription in the past but this was by far the most comprehensive set of transcripts I had produced. As noted by Bird (2005) the process of transcribing data is not straightforward, with the transcriber facing many hurdles even before they commence. After overcoming the psychological barriers of feeling unequipped I developed my transcribing skills through experience and perseverance. It was through transcription the drawbacks of conducting interviews using poor equipment and in public spaces became apparent; many recordings were of poor quality due to electrical interference between my mobile phone and the Dictaphone I was using and others were plagued with background noise which made it difficult to transcribe. I overcame this by using the mobile phone’s in-vitro function to record the conversation. I also realised the importance of conducting face-to-face interviews as some of my participants had speech impediments and I relied heavily on trying to lip read to work out what they were trying to say. Slurred speech has been previously noted in a case study for a young Wilson’s disease patient (Carr & McDonnell, 1986) and although at the time of the interview I could comprehend one participant with Wilson’s disease, I struggled during the transcription to distinguish the individual words.

During the transcription, I also translated all of the non-English interviews myself. Code-switching refers to the use of one or more languages 'in the course of a single communicative episode' (Heller, 1988). Bradby (2002, p. 847) drew attention to the use of borrowed words between languages stating 'Sociologically more interesting reasons identified for code-switching include adding emphasis, a demonstration of intimacy and solidarity with other bilinguals'. This may account for why some bilingual participants, like Naheed, chose to code-switch although the majority of their interview was conducted in English. According to Heller (1988, p. 7), code-switching can be referred to as conventional 'when it indexes a shared frame of reference which represents the neutralization of tension at the boundary of separate domains'. During the transcription, I left incidences of code-switching within the text to try and preserve the natural conversation which occurred and inserted the translated English equivalent in brackets. Here is an example extract from the interview with Naheed;

'He got all the stuff with him 'tehl' (oil) there'

For interviews predominantly conducted in another language, I chose to translate them into English. Previous research has indicated although back-translation can be used, that is having transcripts translated by another person who speaks the same language, it does not always expose all of the potential translation issues (Bradby, 2002; Lowe, Griffiths, & Sidhu, 2007). Furthermore, being a multilingual researcher I was in a position to translate the research without the potential interference of a biased interpreter (Lowe et al., 2007).

3.5 Project Design

This project was funded by CLDF and the design of the study had been formulated in advance through the original funding proposal. As a PhD student, I did my best to carry out the research as indicated in the original project proposal. My PhD was the first Sociology PhD project funded by CLDF and I was keen to reach any milestones. This project emerged during a period where literature on young people's experiences of liver disease and the parental experience of having a child with liver disease was scarce and thus the formation of the project design set out to specifically address this paucity. It was anticipated 60 participants would be recruited; 20 young adults aged 18 – 25 years, 20 young people aged 14 – 17, and 20 parents of young people living with liver disease. Taking into account the difficulty of predicting a robust sample size during the planning stage; these numbers were predetermined based on the premise that sample sizes

should be large enough to encompass the diversity of participants' opinions without becoming excessive (Mason, 2010).¹

The only eligibility requirement was the participant was diagnosed with liver disease before the age of 18; this was to coincide with the move to adult services which usually takes place around 16-18 years. Similarly, the only eligibility requirement for parents was that their child was diagnosed with liver disease before age 18 years. The project did not specify a preference for any particular liver disease diagnosis and the reasoning behind this decision to not exclude certain types of liver disease was to make the project as inclusive as possible for young people living with liver disease. Furthermore, in light of the minimal research which existed at the time of commencement; this project could be viewed as exploratory and therefore to impose exclusions would not be appropriate.

According to Ahmadi (2013, p. 153) "the point of saturation" principle refers to the interview procedure being discontinued once no new themes emerge from the data. This is known as reaching "saturation point" and is seen as a way of determining the sample size (Ahmadi, 2013, p. 153). Many qualitative research reports simply allude to data saturation being reached without contextualizing their claim within their study (Bowen, 2008). The criteria for reaching saturation point has also been widely debated as arguably an experienced researcher in a particular field may have different views in comparison to a novice researcher regarding when data saturation has been reached (Bowen, 2008; Charmaz, 2006; Mason, 2010).

Dey (1999, p. 257) described data saturation as an "unfortunate metaphor"; before all of the coding has been completed there is a reliance on the researcher's own speculation that all of the properties of a category have been fulfilled. As discussed by Charmaz (2006), unless you have done all of the coding you cannot provide evidence that your speculation is accurate. Ahmadi (2013, p. 153) concludes on the matter "that conducting a study on the basis of a qualitative method means, among other things, using the researcher's personal judgment of the point of saturation". I am sceptical of whether true saturation can ever be reached (Parker & Pittsburgh, 2008) and as noted by Mason (2010) the requirement of explicitly stating anticipated sample size to appease funders and institutional requirements prior to commencing the study highlights PhD researchers are often bounded by time and resources. However, eventually I did cease interviewing

¹ Mason (2010) reported the most common sample sizes for PhD research projects were 20 and 30 (followed by 40, 10 and 25). It has been suggested the sample size for a single qualitative study using individual interviews should lie under 50 to prevent hindering the quality of the analysis and data collection (Ritchie & Lewis, 2003, p. 84).

after I felt I had sufficient data and had also reached the predetermined target number of interviews.

3.6 Ethical Approval

This project received ethical consideration from the funding charity whose own panel of lay and expert members scrutinised the project for its feasibility, appropriateness and ethical stature. This project then received ethical approval from The National Research Ethics Service and three Research and Development (R&D) departments involved. The final approval came from the Aston University Ethics Committee. The process of obtaining the required ethical permission took 1 year due to the multisite nature of the study. The process of recruitment began once full ethical clearance had been granted in January 2014 and the final interviews took place in December 2014.

3.7 Ethics of Interviewing Young People

A number of ethical considerations were taken into account during the design and execution of the study. The first consideration was around obtaining written informed consent when interviewing young people under 16 years of age. Williams (2006, p. 19) states 'researchers often refer to 'Gillick competence' in arguing that children can consent to participate in research and that parental consent is therefore unnecessary if the children concerned are deemed to be competent'. Williams (2006, p. 20) highlights how some specialised disciplines, such as youth work, may regard it as patronising to seek parental consent based upon the premise this may override the child's own ability to consent to their participation in research. Researchers may be torn between trying to respect the child's autonomy and the concerns of the ethical review committees to protect the institutions from legal action (Pert & Letts, 2003; Williams, 2006). Thus, it was recommended by Williams (2006, p. 20) that seeking parental/carer permission for those under 16 years of age in addition to the child's permission may be a wiser option for 'more controversial research projects and in cases where the child's capacity to give informed consent is in doubt'.

For the purpose of obtaining ethical approval for the project, this compromise position was implemented where both parental and child consent were sought. I found this difficult as a researcher when I would, using my subjective opinion, deem a young person to be competent enough to give informed consent but still would require their parental consent. It was an interesting paradox to witness where young people within a medicalised context are expected to take responsibility for managing their condition yet

so many of their decisions were dependant on parental consent, such as the opportunity to voice their opinions on their condition through research participation.

3.8 Researcher Safety & Researcher Jeopardy

An issue the ethics committee raised was regarding my own safety as a researcher when interviewing in people's homes and other spaces. Reasonable efforts were made to ensure my own safety, such as letting several people know my whereabouts during fieldwork and having a nominated person who would raise the alarm if they had not heard from me by an agreed time. Previous research has discussed telephone interviews as a safer alternative as opposed to entering a potentially unsafe environment (Sturges & Hanrahan, 2004, p. 109).

3.9 Managing Participants' Emotions and Researching Sensitive Topics

Lee and Renzetti (1990) raised concerns about the problematic nature of the term 'sensitive topic' and reinforced the complexity in defining what a 'sensitive topic' is. Lee and Renzetti (1990, p. 512) state "it is probably possible for any topic, depending on context, to be a sensitive one." For the purpose of this project, I considered talking about experiences of living with a chronic illness as a potentially sensitive topic due to the in-depth exploration of the participants' lives. It had further been noted by Lee and Renzetti (1990, p. 512) research may be considered threatening in a situation 'where research intrudes into the private sphere or delves into some deeply personal experience'. Although, the existence of a private sphere has been contested due to the different situational contexts and cross-cultural differences in what constitutes a private matter (Lee & Renzetti, 1990). I did not anticipate any of the interview topics would result in any harm to the participants and stressed on several occasions throughout the research process that participants are free to cease, terminate or decline to answer at any point during the interview. Previous research has found participants may take part in healthcare research for numerous reasons; some may find it therapeutic to talk about their illness and others may feel the qualitative interview is 'harmless' and 'inherently unproblematic or innocuous' (Peel, Parry, Douglas, & Lawton, 2006, p. 1343).

The ethical review committee raised the point if I was adequately trained to deal with upset/emotional patients and what actions would be taken should patients become distressed. Only one young person cried during a face to face interview and one parent cried during a telephone interview. The young person became teary when recalling the

lack of social support she received; her diagnosis coincided with a move to a new class which had already restricted the social capital available to her. One of her siblings, who was present at the interview, handed her a tissue; the young person continued to talk and quickly composed herself. The first time I met the parent who cried was during a group meeting at the hospital and she cried profusely during this session as she shared her concerns with other parents. She became emotional immediately when talking about her child's liver disease and cried throughout the interview.

Corbin and Morse (2003, p. 352) reflected on managing participants' emotions,

"During the most intensely emotional periods, participants are given the freedom and time to cry, vent, and express anger if necessary. They can stop talking until they've regained composure or stop completely. This again is not to be confused with counseling but is an empathetic and caring response that might occur between any two human beings".

My own approach to managing participants' emotions was very similar to the one cited in Corbin and Morse (2003) whereby I allowed participants to dictate the next step and offered to cease the interview.

Parent: Okay. Um, I find it quite difficult, sorry.

Interviewer: It's okay. You can take a break if you want to.

Parent: No, I am fine. When we had to go to the hospital...

Both participants wanted to continue with the interview. I did ensure the parent participant had sufficient access to support services before terminating the call and although the young person had composed herself by the end of the interview and was looking forward to her plans for the rest of the day, she was accompanied by an older sibling so did not leave alone in a state of 'upset'.

3.10 Data Storage, Confidentiality & Anonymity

The data was stored on Aston University's password protected computers and servers. Participants were assigned a participant code which was kept away from their written consent forms. All written information, such as consent forms, related to the study was kept in a lockable cupboard on Aston University's premises. I was the sole key holder to ensure nobody could access the confidential paperwork and to meet the requirements of the ethical review committee. It was agreed the data would be destroyed 5 years from publication. Keeping in mind all children have different abilities, a customised Participant Information Sheet was produced; this was written clearly in a child friendly tone and

demonstrated clearly how pseudonyms work through the use of visual examples and explained confidentiality in an accessible way.

Walford (2005, p. 85) defined anonymity as “that we do not name the person or research site involved but, in research, it is usually extended to mean that we do not include information about any individual or research site that will enable that individual or research site to be identified by others”. However, given the rarity of childhood liver disease and that only three specialised services exist in the United Kingdom for young people, it would be obvious to anyone with knowledge of liver disease services which sites participants were recruited from. The participants were offered anonymity on the consent forms as far as name changes. Saunders, Kitzinger, and Kitzinger (2014, p. 14) highlighted despite extensive efforts ‘anonymity cannot be completely guaranteed’, especially with the increasing use of social media where participants may even post links to your written work after they have identified themselves. As a researcher, I knew I could assign pseudonyms but would need to be careful to remove identifiable information such as names of doctors and locations as there is always the risk someone with enough insider knowledge could identify the participants.

According to Hiriscou, Stingelin-Giles, Stadler, Schmeck, and Reiter-Theil (2014, p. 411)

“Confidentiality refers to the treatment of information, samples or data that an individual has disclosed in a relationship of trust and with the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure, without permission being given.”

Hiriscou et al. (2014, p. 414) further noted the lack of guidance on the circumstances in which a researcher may have to ‘breach confidentiality by disclosing sensitive information’. All participants were informed that confidentiality may be breached if there was a concern of serious harm to the participants.

3.11 Recruitment

Participants were recruited from two children’s hospitals providing specialised liver services and two adult hospitals.. Other recruitment sources included the CLDF’s newsletters, social media platforms and online forums.

3.11.1 Hospitals

There are three units in the United Kingdom which currently provide specialised paediatric liver services, these are Birmingham Children’s Hospital, King’s College Hospital and Leeds General Infirmary (National Health Service, 2013). Referrals to the units range from newborn babies to 16 year olds. Between the ages of 16-18 years,

service users usually experience the transition to adult specialised care services. The participants for this study were recruited primarily through clinics taking place at four hospital sites (two adult hospitals and two children's services). These varied from adolescent liver clinics which took place specifically to cater for adolescent liver patients aged between 16 to 25, disease-specific clinics such as a clinic for a specific liver disease such as Wilson's disease, and general paediatric liver clinics which usually made the distinction between transplant liver patients and non-transplant liver patients.

One hospital was able to provide me with clinic patterns which enabled me to work out the clinic dates in advance. However, some hospitals did not have a set pattern to determine when they should hold the clinic. This was due to a number of reasons, including the introduction of newly developed services to specifically cater for adolescents. The process of establishing clinic dates meant I had to rely on the information to be conveyed to me by the various hospital departments. This was particularly difficult as I was on numerous occasions not added to the hospital's internal mailing list so was unaware of clinics taking place. Other barriers to accessing the clinic dates included 'informational gatekeepers' being away from the office and the absence of an alternative source of information. This difficulty was also encountered when my primary contact at the hospital was absent and other staff were reluctant to assume their role in introducing me.

The events at the clinics varied depending on the hospital and their individual facilities. The proposed method was a member of the liver team would introduce me to any potential participants. I would then introduce my study and wait for the participant's response. If they seemed interested I would then hand the participant an information pack and invite the participant to open the packet. I would then go through the packet with the participant and run through the participant information sheet. If the participant indicated they were interested in taking part in the study I offered the participants the option to fill out a provisional consent form and leave their contact details. Every patient I met was told to take the packet home and read it carefully before making a decision. Participants then either contacted me or I contacted them by email or telephone to arrange an interview after the duration of at least a week has elapsed since our initial meeting.

An important part of this process which was not previously accounted for during the planning of the study, was the access to space in the hospital. Some hospitals would make sure I was given a room, usually one used for patient consultations. I found this particularly useful as it was a private space to establish rapport, answer questions and I

felt it was a more formal way of legitimising my presence at the hospital as most participants did not know I was going to be there in advance of their visit. However, some hospitals did not have the space to allocate me a room and I would wait in the corridor nearest to the consultation room. The location of the interactions was particularly important as one hospital only had four seats in the immediate waiting area. This meant it was often not practical to have a conversation about my study. I was either standing up and talking 'down' to the participants or in an uncomfortable position. This made me feel like an intruder and I felt it was inappropriate. Previous research has discussed the vulnerability a researcher may feel when approaching participants to complete questionnaires as there is a risk of 'rejection and subsequent embarrassment' (Scott, Hinton-Smith, Härmä, & Broome, 2012, p. 724). In particularly crowded spaces I noticed I was reluctant to ask for a preliminary commitment. I was cautious of asking for contact details if I felt sufficient rapport had not been established and it became more difficult to establish rapport in a crowded space. One of my observations was in the children's hospitals, a staff member told me patient timekeeping was an issue, as many patients and their parents turned up late. This directly impacted my opportunity to convey information about my study and on many occasions due to time constraints I was able to introduce myself and only hand out the information packet rather than go through it with them. I observed that not a single patient who had been given the information packet after a brief corridor conversation actually initiated contact to arrange an interview.

The timing of my introduction to the patients usually happened after their initial consultation with the liver consultant. Some patients then only had a few minutes in between the consultation and being called for their blood test. It was in that space of time I introduced myself. I was sometimes introduced by the nurses as a 'doctor' to the participants and I immediately corrected it once the nurse left. It is important to take into account participants' perceptions about your background as a researcher; Richards and Emslie (2000, p. 74) conducted interviews in the area of healthcare and found if participants thought the researcher was not from a medical background (e.g. GP), they were more likely to talk about 'broader, non-health-related topics'. I was keen not to present myself as a doctor but preferred the role of a researcher as I did not want participants to harbour any false impressions.

The process of being allocated a room in the hospital was not always preferential. On numerous occasions the hospital nurses forgot I was there in that room and did not bring the patients to me after their consultation. This was not resourceful for myself and proved to be particularly frustrating as it meant I had no access to potential participants. On

other occasions patients were deliberately not introduced to me as other staff members working at the liver ward felt the particular patients were not suitable candidates for my study. These staff members consisted of youth workers and nurses. The reasons for the lack of suitability were often quoted as *'he/she just has a bone to pick and you don't want someone who will not have anything positive to say'* or *'he/she is currently going through a really difficult time and I don't think he/she could handle taking part because it's too much'*. The waiting room option here was more beneficial to grant myself access to the patients as it was easier for me to see them being called out for their appointments.

My research was first publicised very shortly after I accepted the PhD and through a feature in the Children's Liver Disease Foundation's (CLDF) newsletter my first participant contacted me wishing to participate in May 2013. This was an example of the many participants recruited through the CLDF's various platforms such as newsletters, website and social media. Another platform for recruitment was the CLDF's page on HealthUnlocked where I posted a message inviting participants to take part. These attempts at recruitment were not directly aimed at any particular person and relied on the participants to volunteer themselves. I would then send the information packet by email to the participant and wait for their response. The participants recruited through these two methods I never personally met until the day of the interview. We arranged the interview over email and if they provided me with a telephone number I preferred to text them. On the morning of the interview I would text the participant what I was wearing so they could easily find me and I usually wore distinctive clothing.

3.12 Interviews: Use and Process

Interviews are used in social science research to provide people with a voice and the opportunity to describe their experiences in their own words (Coyne, 2006a). There is a substantial amount of literature supporting their use as a data collection method (Potter & Hepburn, 2005) and interviews are widely used as a method for collecting data with young people (Jansen, 2015; Järvinen & Ravn, 2011; Reme, Archer, & Chalder, 2013). According to Jansen (2015, p. 37);

The most obvious potential of a qualitative research interview is that it allows us to see the interviewee as a resource, not as a problem. The interview does not necessarily aim to acquire an understanding of how things 'really are' or to describe the participants in simple categorical ways but instead allows the variety and diversity of the interviewee's life to be voiced. This then opens space for telling of complexity, ambiguity, and ambivalence, which in other situations are less welcome because this kind of speaking is viewed as obstructive in finding solutions.

Jansen (2015, p. 37) further suggests that interviews can place young people as competent actors, and open up possibilities for participants to take on subject positions not normally available; 'they become participants whose knowledge is essential for the production of research'. Qualitative interviews have further been successfully used for gathering multiple perspectives from patients and their carers within healthcare research and it is common for people to want to be interviewed together (Kendall et al., 2010).

3.13 Semi-structured Interviews

According to DiCicco-Bloom and Crabtree (2006, p. 315), some of the key features of semi-structured interviews include having 'a set of predetermined open-ended questions, with other questions emerging from the dialogue between interviewer and interviewee'. This allows for what is often described as an 'open response' from the participants as opposed to a dichotomous yes/no type answer (Clifford, French, & Valentine, 2010).

This project was exploratory in nature and the wider aims of the project included exploring what it is like to grow up as a young person with liver disease; what it is like to be a parent of a young person living with liver disease; and how liver disease impacts young people's experiences of growing up. The original funding proposal had provisionally set out the following topics for exploration in order to meet the project aims; illness journey (background of diagnosis and treatment); managing (coping with the condition, adherence to treatment); living with the illness (impact on wider social life); transitions (growing into adulthood); health services (relationships with health professionals, transitions and changes in health services provision) and difficulties (unmet needs). Following on from the literature review, important areas within the broader topics were identified and prompt questions were used to gain more contextual information about topic areas. For example, to find out more about the illness journey (background of diagnosis and treatment), prompt questions such as "can you tell me a bit about the particular type of liver disease you have"; "how old were you when you were diagnosed with liver disease"; "can you tell me about what happened when you were diagnosed" and "how did you feel about being diagnosed with liver disease", were asked. Questions were adapted depending on if a parent was being interviewed or a child, for example, the opening question to the interview was either; *can you tell me how you came to be diagnosed with liver disease* or *can you tell me how your child came to be diagnosed with liver disease?*

Illness journey (background of diagnosis and treatment)

Can you tell me a bit about the particular type of liver disease you have?

How old were you when you were diagnosed with liver disease?

Can you tell me about what happened when you were diagnosed?

How did you feel about being diagnosed with liver disease?

What kind of information were you given about liver disease?

Who did you receive information about liver disease from? (Doctors, nurses, parents)

Was it easy to understand the information?

Do you think information was enough or did you want more information?

Did you receive any support when you were diagnosed?

Managing (coping with the condition/adherence to treatment)

Can you tell me about what kind of treatments or medications you have been advised to take?

How do you manage taking your medications on a daily basis?

How do you feel about having to manage your own medications?

Living with the illness (impact on wider social life)

Can you tell me about what living with liver disease is like?

Has your life changed at all since you were diagnosed with liver disease?

In what ways, if at all, has liver disease impacted your relationships with family?

In what ways, if at all, has liver disease impacted your relationships with friends?

Can you tell me about what going to school is like?

How did you feel about returning to school?

Transitions (growing into adulthood)

What is it like growing up as a teenager with Liver Disease?

How did it make you feel moving to another hospital? / How do you feel about moving to another hospital?

Health Services (relationships with health professionals, transitions and changes in health services provision)

Can you tell me about the last time you were in hospital?

Have you ever been hospitalised?

When did you move to the adult services?

Can you describe what it was like moving to the adult services?

What was it like moving to the new hospital?

How did you feel about having a new doctor?

What would you like from the new liver disease services?

Is there any information you think would be helpful before you move to the new hospital?

Difficulties (unmet needs)

What kinds of things did you find helped when you were in hospital?

Was there anything that you felt didn't help when you were in hospital?

What has been the most difficult thing you have experienced?

Is there anything in particular that you thought was really useful when you moved hospitals?

Looking back, can you think of anything that would have helped you settle in better?

Did you feel you were given enough information about moving hospitals?

Are there any positive aspects of having liver disease?

Another defining feature is semi-structured interviews are arranged in advance and take place 'at a designated time and location outside of everyday events' (DiCicco-Bloom & Crabtree, 2006, p. 315). In order to complete my project, three methods of data collection were available to participants; face-to-face interviews, telephone interviews and online Skype interviews. The participants made the decision as to which interview method they preferred.

3.13.1 Use of Skype

'Skype software is available to download for free and provides a variety of communication options, including audio and video calling with other Skype users, telephoning landlines or mobile phones as well as providing messaging and file transfer capabilities.' (Deakin & Wakefield, 2013, p. 4).

Vulliamy and Sullivan (2000, p. 239) highlighted 'using Skype as a research medium can allow the researcher to reap the well-documented benefits of traditional face-to-face interviews in qualitative research' alongside the benefits of telephone interviews. There is a growing body of research which has explored the feasibility and benefits of using Skype as a research medium; notable advantages include offering flexibility and convenience to participants, overcoming possible geographical constraints whilst maintaining access to nonverbal cues (Deakin & Wakefield, 2013; Hanna, 2012; Janghorban, Roudsari, & Taghipour, 2014). However, Weinmann, Brilmayer, Heinrich, Radon, and Thomas (2012, p. 960) concluded; 'it is still too early to use Skype as an interview technique, phone interviews continue to be the more viable option as a substitute to in-person interviews'. Their study invited young people (classed as a hard to reach group) to take part in a Skype interview, whilst some participants did not have Skype installed, generally there was a lower participation rate for Skype interviews compared to telephone interviews (Weinmann et al., 2012). However, I felt offering Skype was practical and suitable despite any potential drawbacks (Janghorban et al., 2014).

Interestingly, one participant turned his webcam off once the Skype call commenced as he wished to restrict his visible presence throughout the interview so I did the same. This experience resonated with previous research which has found online interview methods make it easier for participants to withdraw or at least decide what level of participation they are comfortable with by simply clicking with a button.

3.13.2 Telephone interviews

Block and Erskine (2012, p. 428) documented the increasing popularity of using 'telephones as a medium for conducting interviews'. The reasoning behind opting for telephone interviews is based on literature which shows participants may find it more convenient to schedule in the interview call alongside their work and home life, providing them with the flexibility and opportunity to take part (Trier-Bieniek, 2012). Telephone interviews have been successfully used to overcome long distances in previous qualitative research with paediatric liver disease patients (Wise, 2002). Participants in previous research have been comfortable to discuss issues such as 'relationship breakdown, ill health and bereavement' through telephone interviews (Hinton, 2013, p. 241). Mobile phones in particular are commonly used by young people and allow participants to be free from spatial fixation by moving around (Hinton, 2013). However, as documented by Hinton (2013), there are a number of ethical considerations associated with interviewing young people who may be using a mobile phone to participate, these include the participants' responses being audible to those around them should they wish to answer in a public space and their understanding of what is acceptable to discuss in public spaces. As a precautionary measure I always ensured participants were comfortable to talk before commencing the interview and reiterated their right to withdraw.

3.13.3 Face-to-Face Interviews

The advantages of face-to-face interviews have been well-documented and include the non-verbal paralinguistic cues and increased participant motivation (Curasi, 2001, p. 370). The face-to-face interviews took part in various locations ranging from the homes of participants, a hotel room, cafés and on the hospital premises. According to King and Horrocks (2010, p. 44), "Public spaces can have the advantage of being comfortable and relaxing, and their neutrality may be an advantage". I preferred meeting up in public spaces such as cafés compared to home interviews but the drawbacks included high levels of background noise which made transcription difficult. On one occasion the café we had agreed to meet at closed early and the interview was completed on a nearby park bench facing a busy road (the park was empty so nobody could overhear the interview).

The interviews were audio recorded. Some participants were very expressive with their facial expressions and gestures and I felt this could not always be captured by the audio. During the interview I would sit with my interview schedule on the table in front of me or on my lap. I would also keep a piece of paper and a pen available to make notes during the interview. Researchers such as Burke and Miller (2001) have suggested taking notes

whilst participants are speaking is a useful source of data in addition to an audio recording. I experienced the process of making notes during the interview a difficult one to negotiate. Some participants stopped talking as soon as I began writing things down and in order to maintain the rapport I felt obliged to stop making notes. Making notes was also challenging due to the individual characteristics of the participants. Some participants' emitted nonverbal disapproval of my notetaking as it meant I had to momentarily cease eye contact with them. This was often in the form of temporary frowning and a sudden termination of the conversation midsentence. These particular interviews were difficult as I was not used to sustained eye contact of such intensity. One participant moved my notes to face her so she could see what I was writing. Once the interview had terminated she made remarks about how powerless I was to influence any changes through my PhD research.

The post interview rapport proved to be interesting. Once the audio recorder had been turned off many participants opened up about topics they did not want on tape but wanted to talk about. Many participants offered to show me around their local surroundings and some participants offered me a lift back to the train station.

3.13.4 Educational Background

I feel it is important to acknowledge my own background as a researcher and highlight some of the obstacles I have encountered whilst completing this study. I have developed my academic abilities against a backdrop of 'positivism' which was constantly reinforced through my former Psychology degrees. I have spent many years developing my approach to data collection to find better ways of searching for 'The Truth' with a hidden agenda of being 'objective'. This desire I believe stems from the constant battle for the recognition of Psychology as science and to protect my education from being demeaned as an advanced form of 'pop psychology'. I recall many incidents where mainstream science students have mocked Psychology as well as the social sciences in general. This has reinforced the idea of searching for 'The Truth' and creating 'facts'. Throughout the interviews I noted I had to make a conscious effort not to say 'and how do you feel about the fact...' as I have come to assimilate the idea that there is no singular 'truth' waiting to be found into my way of thinking and these 'facts' are not really facts.

Kirsch (1999, p. 13), in her book discussing ethical dilemmas in feminist research, raised the point of how former researchers may have in their desire to remain 'objective and detached' from their participants stuck to a set of predetermined questions. Had the researchers used the opportunity to find out more about the participants' daily lives, the

richer contextual background could have aided the researchers to provide valuable feedback and assistance to their participants (Kirsch, 1999). I have selected this point because during the first few interviews I too chose to remain detached from my participants. I did this by offering minimal input into the conversation apart from asking questions and acknowledging I was listening through nonverbal communication and the use of the utterances such as 'm-hm'. Immediately this became problematic as my first face-to-face interview was one where I was faced with a harrowing account of isolation and violence whereby I had to restrain myself from commenting or offering sympathy. My decision not to share my own emotional solidarity with the participant was in fear of corrupting the research by not remaining objective. As a result it took me many days to overcome the grief which followed this particular interview and I was unable to move past what I had heard. Perhaps if I had interjected at that point I would have found it less troublesome in the subsequent days.

3.13.5 Dramaturgical Sociology: Roles and Costume

In relation to my own experience of feeling like I was putting on a performance when in the hospital or whilst conducting fieldwork, I found Kivisto and Pittman's (2007) work on Goffman's Dramaturgical Sociology very potent. According to Kivisto and Pittman (2007, p. 272), Goffman viewed "the metaphor of life as theatre [sic] is rich in meaning" and he viewed "all human interaction as, in some ways, very much like a grand play". They viewed the role a person plays one of the important aspects to this dramaturgical metaphor, further stating "individuals in social settings must adopt the traits necessary to the understanding of reality they want to project" (Kivisto & Pittman, 2007, p. 274). In order to portray myself as a legitimate researcher in the field of liver research, I had to present myself as knowledgeable and professional when I first met participants or whilst I tried to gain access through gatekeepers within the hospital setting. However, my role during the research process was fluid and I alternated from researcher, an inquisitive 'student' and a 'young person'. I felt the latter two roles afforded me a level of 'naivety' to gain more detailed data and be seen as less of an authoritative person (often participants were willing to tell me what medicines were for rather than listing them as they accepted I was not an expert).

Continuing with aspects to the performance one might engage in, Kivisto and Pittman (2007, p. 278) state "one element that is crucial to actors is the potential impact of their costumes. This is because what people are wearing is probably the quickest way to form an impression of them and their social status." As part of my legitimate researcher role,

I had an NHS identification which I had clipped onto my student lanyard which was printed with my university name. My NHS identification card formed an important part of my 'costume' as it was a marker that I had earned the right to ask these questions at the hospital and clearly stated I was a "PhD Researcher". I further had official study documentation which was branded with my institution's details to foster authenticity in my invitations to the research and reinforce I was not working for the hospital but affiliated with a university. Whilst on hospital premises I opted for a smart-casual dress code which would neither be seen as inappropriate for the setting or too smart to alienate me from the young people. This is particularly important as previous research has reported "the style of clothing adopted by the worker was cited by most of the young people as a significant factor in whether they felt able to relate to them and comfortable talking to them. More specifically 'suits' were often identified as 'uniforms' that symbolised authority, control and professional detachment, in a negative way, for the young people" (National Collaborating Centre for Mental Health, 2013). The ability to remain fluid between my roles as a 'researcher', 'student' or 'young person' was important in order to establish rapport with the young people taking part in the study.

According to Robson, Porter, Hampshire, and Bourdillon (2009, p. 475) some young researchers may prefer to interview "children younger than themselves, because they were more compliant and less insistent on demanding to know the benefits of their being interviewed; thus, in some ways resembling adult – child power differentials based on age". It is important to have an exploratory study when researching young people's health to facilitate the identification of features of their healthcare that are important and relevant to them. According to Manning, Hemingway, and Redsell (2014, p. 4), 'despite concerns apparent in the literature with regard to the power dynamics of undertaking interviews with children and adolescents, there continues to be prolific and effective use in child health research'. I tried to break down the adult-child power relationship by refraining from using certain language and on fieldwork trips to see young people, dressing how I would normally dress. One parent participant was critical of the purpose of my open-ended questions whereas I did not find the young people were critical of my questions and I felt the parent was establishing an adult-child power relation. I felt this particular participant who possessed a highly authoritative job position had felt uncomfortable being asked questions by a young researcher, who was not much older than their own children. I, in turn, felt uncomfortable, intimidated and unwelcome in their presence. Another young adult participant of the same age, who was also more accustomed to quantitative research, questioned the impact my project would have and she did not feel the funding charity were in a position to bring about change. This shows

power-relations can work in many ways and are not just confined to adult-child power relations.

3.13.6 Building rapport

Occasionally during the interviews, despite my interview schedule in front of me and an audio recorder, the interview did not feel like an interview. The formality of meeting a stranger for research purposes was not there and it felt like I was meeting a friend for coffee. This may have something to do with the location of the interviews in coffee shops and the similarities in age between myself and the participants.

The interview process was varied and there are many interviews which led to rich and detailed data. Some participants had only briefly met me when they received the information packet yet had disclosed many personal things in the interview.

“Interviews, I want to caution, can sometimes lead participants to divulge information against their better judgement, perhaps even against their will. Feeling the warmth, undivided attention, and sincere interest shown by skilful interviewers (something we rarely experience in daily life), participants can easily reveal intimate details about their lives which they may later regret having shared” (Kirsch, 1999, p. 29).

This is quote is one which I can relate to as I often experienced the interview as coffee with a stranger rather than as fieldwork. At times I felt uncomfortable with the amount of trust participants had in me and recognised I was in a privileged position; I did worry about if they would later regret what they had disclosed. I can relate to the idea of a researcher as a “friendly stranger” used by Kirsch (1999, p. 30) to encapsulate the way researchers disappear after data collection. One challenge was establishing the boundaries between being friendly and being a friend especially due to the commonalities between myself and the participants. However, it is important to consider “close friends do not usually arrive with a tape-recorder, listen carefully and sympathetically to what you have to say and then disappear” (Cotterill 1992, p.595,599 cited in Kirsch, 1999, p. 30). After an interview I never made contact with the participants but occasionally participants decided to maintain contact. On one occasion the contact was persistent as this particular participant had assumed after we had been for coffee we were now friends demonstrating the drawbacks of building rapport. Although many researchers do go on to form friendships with their participants, I had made an active decision not to maintain friendships.

Overall, my age was distinct advantage when it came to building rapport with younger participants. For many participants I was someone they could relate to and talk openly with. One participant commented on how she would not have shared so much information if I was an 'adult'. Being of a similar age to my participants meant I was familiar with the social pressures they faced around alcohol, relationships and drugs. It was interesting how there was a difference between when a young person participant started talking about a 'bad thing' and after I mentioned the term 'weed', to demonstrate my knowledge, it opened up that conversation. Previous research has also reported; "The interpersonal style of the worker was also cited as important by many of the young people. This included the worker's capacity to demonstrate an understanding of the young person's world and to enable the young person to feel at ease and be able to talk about themselves or their problems and concerns" (National Collaborating Centre for Mental Health, 2013, p. 411).

I did not ask participants about their motivations for taking part in research but on inquiring about their research experience overall some shared they were pleased they felt worthy of study. Initially I had been perceived as an 'outsider' to the lives of young people and many were surprised I was similar to them in many ways, thus, they disclosed things they would not otherwise have disclosed. The boundaries of what constitutes being an adult were blurred as many of the participants my research would label as 'young adults' did not see themselves as 'adults' and equally I was not seen as an adult. However, when interviewing people who were younger than me I was the adult in the situation, even if I was viewed by some as a peer.

As the interviews went on I became more confident with the role of the 'interviewer'. Although the work of Goffman (1989, p. 128) focused on ethnography and fieldwork, I found many useful examples of how I would have to get a 'mix of changing costume' in order to complete my fieldwork. Goffman (1989, p. 128) revealed how some researchers mimicked accents, stating 'people don't like to have their accents mimicked'. Although I never mimicked anyone's accent intentionally, I did find my own accent had changed over the course of conducting fieldwork as I had assimilated different ways of talking about topics and new language.

I struggled with self-representation when I began fieldwork and my age was a crucial aspect throughout my PhD. I began this PhD in my early twenties and I felt proud of my academic achievements which I felt did justice to the effort I had put in to reach this stage in my life. However, my main concerns were embedded in identity and legitimacy; there was an inherent desire to reinforce I deserved to be there as researcher in the hospital

to myself. This echoes the 'imposter phenomenon' which highlights how many able female academics 'maintain a strong belief that they are not intelligent' and do not deserve to be in the positions they are (Clance & Imes, 1978, p. 241). At first I was trying to act older than I was in a bid to gain legitimacy and achieve the selfimposed markers that good researchers are older people with a wealth of experience. I soon realised that this was not going to work and I would be better off being myself. In an interview with an 18 year old female I was asked how old I was, and she responded with "What - *you're 23 - that's way too young to be doing a PhD!*". She later went on to say I must have been a 'genius'. Often I was misconceived to be someone with a medical background or a high level of expertise in liver disease; a few participants made reference to me 'knowing' certain things. An incident which I remember very profoundly was with a 17 year old male participant who assumed I would know what would be the impact on his health if he did not take his medicine.

Participant: ...I think one thing I'd like to know like say if I was, I don't think you'd know but if

Me: I might not know (laughs) I probably won't (laughs)

Participant: (laughs) erm, I think I've been told before like if I was to ever miss my medicine what would happen?

Me: I'm not sure

The participant later went on to say he would not deliberately abstain from taking his medicine but I felt very uncomfortable to be placed in a position of a 'liver expert'. I wondered afterwards had he been considering not taking his medication what ethical duties I would have had to report this and if so, to whom. This practical dilemma has also been noted by Hiriscau et al. (2014) who highlighted the lack of clarity when it came to directing researchers as to whom and when they should disclose child and adolescent risky behaviour in order to avoid harm to the participant.

One parent participant asked me if I knew of any ways to get her financial support to help with travel costs associated with attending hospital appointments which put me in a difficult position as I had not anticipated the question ever arising. It also raised questions about what the participants were going to gain from taking part in my study especially if I could not offer any instant reciprocation. There were no incentives for the participants and I did not ask them why they decided to take part. On one occasion, after the interview, a participant told me he almost did not turn up as he was unsure what a qualitative research project entailed but after talking to his mother he soon realised it

was about 'thoughts and feelings'. This particular participant was worried he would not 'know the answers' and often participants stated they hoped they had been 'helpful'. Another participant stated "I should have revised, innit" when I started the interview indicating she felt as if it was a test situation. For nearly all of the participants, their interview with me was the only qualitative research project they had taken part in. One participant had previously been involved in other medical research by donating blood/urine samples so was surprised there would be no needles. The nature of qualitative research was novel and many expected a questionnaire, which in some ways was satisfied by the demographic questions but the interview came as a surprise.

3.13.7 Insider/Outsider Dynamics

"Dichotomised rubrics such as 'black/white' or 'insider/outsider' are inadequate to capture the complex and multi-faceted experiences of some researchers, such as ourselves, who find themselves neither total 'insiders' nor 'outsiders' in relation to the individuals they interview" (Song & Parker, 1995, p. 243). Reflecting on the article by Song and Parker (1995, p. 244) which discussed the many complex 'positionings' such as gender, race, accent and language between the researchers and the participants, I believe this quote aptly sums up my experience whilst conducting the interviews for this research and the multifaceted experience I had. The obvious dichotomisation would be to distinguish me as a young adult without liver disease or as someone without a child with liver disease, however, in the course of conducting the fieldwork many other dichotomisations were unearthed primarily centred around my ethnic origin. I will begin by discussing Black and Minority Ethnic (BME) population access within UK health research and significant occasions where my language skills were of an advantage.

3.13.8 BME population access

Szczepura (2005) drew on statistics from the 2001 census to demonstrate the growing Black and Minority Ethnic (BME) population in the United Kingdom, predominantly located in England. More recently figures from the 2011 census show 7.5% of the population in England and Wales identified themselves as Asian/Asian British (5.7% were of South Asian heritage; Indian, Pakistani or Bangladeshi) and 3.3% as Black/African/Caribbean/Black British (Office for National Statistics, 2011)

According to Szczepura (2005, p. 146)

‘A substantial research base now exists to show disparities in access to healthcare services for ethnic minority populations in different parts of the world. Healthcare organisations and their staff need to be culturally, as well as linguistically, competent when delivering services. Improved responsiveness to the health beliefs, practices, and cultural needs of patients is clearly required to provide equitable access to health care for diverse populations. Such provision should also recognise that the provider and the ethnic minority patient each bring their own individual learned patterns of language and culture to the healthcare experience’.

Szczepura (2005) highlighted language and literacy could potentially be major barriers to accessing healthcare. For example, South Asian women are less likely to speak English than South Asian men and are less likely to be literate in any language (Szczepura, 2005, p. 144). This is particularly important as “even if letters or patient information leaflets are translated, people may not be able to read their own language” (Szczepura, 2005, p. 144). This is key to the issue of obtaining informed consent and the importance of viewing informed consent as more than a single event requiring a signature on a piece of paper but an ongoing process between the participant and the researcher (Dein & Bhui, 2005). The cultural significance of written consent may not be applicable to certain BME groups who may view such a practise as offensive (Dein & Bhui, 2005). If someone cannot read English and it is not possible to produce a written equivalent in their mother tongue, it would be unethical to ask them to sign the consent form. In such cases consent was obtained verbally by explaining the nature of the research.

My personal interest in the role of language stems from my exposure to the language Mirpuri which, like the example of Sylhetti raised by Szczepura (2005), has no agreed written form. Other research has highlighted the challenges of developing data collection methods for speakers of languages such as Mirpuri and Sylhetti in the context of Type 2 Diabetes, where certain terms did not have an English equivalent (Lloyd et al., 2008). Lloyd et al. (2008, p. 461) highlighted that ‘research has shown it is difficult to recruit and collect information from minority ethnic groups and difficulties may be even greater in groups whose main language is spoken and does not have an agreed written form’. Being a researcher from a BME background was an advantage to helping me recruit those from BME backgrounds. My ability to speak Mirpuri meant I was in privileged position to recruit from this community. However, I faced similar barriers whilst carrying out these particular interviews such as those described in Lloyd et al. (2008) where

certain terms did not exist within the scope of Mirpuri. Nevertheless, the use of Mirpuri meant I had the opportunity to build rapport in a different way. The use of this language was a cultural marker and meant I had more in common with my participants.

Pert and Letts (2003, p. 269) raised crucial aspects about the language of Mirpuri, such as it being regarded as a 'low-status language', and the reluctance of people willing to admit they use it at home despite recognition from other sources and the existence of radio programmes in this language in the UK. Pert and Letts (2003, p. 284) suggested 'parents may feel that monolingual professionals will have heard of the language Urdu but be unfamiliar with Mirpuri'. I encountered this during data collection when the first time I met one participant he asked me if I could speak Urdu in order to converse with his partner who was unable to speak English. However, during the course of the home interview it became apparent his partner spoke Mirpuri, not Urdu. An interesting point to note is that with no standard written language for Mirpuri, often multiple dialects are spoken without any one dialect being perceived as more 'correct' (Pert & Letts, 2003, p. 269). However, this did mean at one point during an interview, the participant also present in the room changed the order of my sentence in order for his partner to understand my question.

According to Pert and Letts (2003), Mirpuri speakers, who could be considered as second or third generation migrants to the UK, may have altered dialects stemming from their exposure to a new culture and language. An example of this was during an interview with a young adult who interchanged between Mirpuri and English terms. My language barriers became evident whilst conducting an interview with a native Bengali speaker who spoke little English and the only mutual language we had an understanding of between us was Hindi. The participant shifted between Hindi and English throughout the interview and she expressed her difficulties in translating what she wanted to say into Hindi; "I have things to say but how can I explain them to you! [Laughs]". I felt at that point if I could speak Bengali the interview would have led to more rich data but could not deny that if I was unable to speak Hindi this particular participant may not have had the opportunity to take part in this study.

King and Horrocks (2010), in their book on conducting interviews in qualitative research, raised the point that when conducting interviews in other peoples' homes, often participants may request or insist a family member also be present in the interview room. Although, they further state that if this is going to be problematic for your research you should state this at the start of the interview; I did not feel like I was in a position to make

such a statement as I was a guest in participants' homes. On one occasion a female participant had several family members in the room, including her brother. Although she stated she was happy for her family members to be there, I did not feel comfortable asking her questions around sexual health and made the decision to exclude these from the interview. I further chose to omit these questions during an interview with a 15 year old Muslim participant of South Asian heritage whose mother was present in the room. I made this decision based on my own knowledge of South Asian culture, where sex was considered a taboo subject and the only information conveyed by parents was centred around messages advocating abstinence before marriage (Kim & Ward, 2007).

“South Asian cultures ascribe a high value to women's purity. This is especially understood in terms of premarital virginity. Most women are socialized to believe that loss of virginity prior to marriage means shame, loss of family honor, and resultant social ostracism if it becomes known” (Abraham, 1999, p. 596).

I was conscious not to create difficulties for the participant and feared if I began questioning her on her sexual behaviour or intentions I would create problems for her at home which would be unethical. I justified my decision based on the assumption that even if the participant was sexually active, she most likely would not disclose this information in front of her mother. Overall, the presence of her mother during the interview made me feel uncomfortable as she insisted if this interview was going to go ahead she would sit through it. I could see the presence of having her mother there was uncomfortable for the participant as she repeatedly glanced over at her mother. I do believe her mother's presence had a negative impact on the interview and had she not have been present, the participant would have opened up more. At the time I felt I did not have much choice apart from complying with the demands of the mother.

3.13.9 Participants

In total, 62 participants took part in this research study; 20 young people, 21 young adults and 21 parents, exceeding the original target; Table 1 shows the breakdown of the number participants in each category and their gender. The additional two participants who did not meet the exact requirements but were still interviewed were; a young person who had turned 26 by the time the interview took place and a parent, whose child had passed away. The decision to include these participants was to increase the diversity of the sample and to honour their keen interest in this project. I was in a position of power to decide who could participate in the study and decided to allow these participants to

take part. I had already interviewed Declan at this point who had told me '*once you get to 25 the doors come down on you*'; he mentioned feeling discriminated against because of his age and I was conscious not to discriminate against the young person. Letherby (2003) highlighted the complexity of power issues within research; it cannot be assumed the researcher is always in a position of power. Subjective experiences of power within research contexts 'can be ambivalent for both the researcher and the respondent' (Letherby, 2003, p. 114).

TABLE 1: PARTICIPANT CATEGORIES AND GENDER

Participant Category	Number of participants	Males	Females
Young People (14 – 17 years old)	20	5	15
Young Adults (18 – 26 years old)	21	8	13
Parents	21	2	19

There were more female participants than male participants overall. This is something I cannot explain and did not notice whilst collecting data, however, potential reasons could be perhaps female participants were more likely to want to take part given I was also a female. The young people who participated in the research study reported a variety of different liver conditions/combinations; these can be seen in Table 2, three participants were unable to name their condition and were not able to find this information out at the time of the interview. Table 3 indicates parental breakdown for each liver disease type.

TABLE 2: TYPE OF LIVER DISEASE

TYPE OF LIVER DISEASE	N
Unknown	3
Alpha 1 Antitrypsin Deficiency	1
Autoimmune Hepatitis	11
Autoimmune Hepatitis/Primary Sclerosis/Ulcerative Colitis	1
Biliary Atresia	11
Biliary Atresia /Hepatic Fibrosis	1
Biliary Atresia/Denovo Autoimmune Hepatitis	1
Chronic Liver Disease	1
Congenital Hepatic Fibrosis	1
Gilbert's Syndrome	1
Non Alcoholic Fatty Liver Disease	1
Autoimmune Hepatitis/Primary Sclerosis/Ulcerative Colitis	1
Progressive Familial Intrahepatic Cholestasis	1
Severe Combined Immune Deficiency	1
Tyrosinemia Type 1	1
Wilson's Disease	4

TABLE 3: PARENT PARTICIPANTS AND TYPE OF LIVER DISEASE THEIR CHILD HAS

TYPE OF LIVER DISEASE	N
Progressive Familial Intrahepatic Cholestasis	2
Alagille Syndrome	1
Alpha 1 Antitrypsin Deficiency	2
Auto Immune Hepatitis	4
Autoimmune Hepatitis/Primary Sclerosis/Ulcerative Colitis	1
Biliary Atresia	3
Biliary Atresia /Hepatic Fibrosis	1
Congenital Hepatic Fibrosis	1
Critigenic Liver Disease	1
Gilbert's Syndrome	1
Non Alcoholic Fatty Liver Disease	1
Primary Sclerosing Cholangitis	1
Tyrosinemia Type 1	1
Wilson's Disease	1

Table 4 shows the majority of participants identified themselves as 'White British/White European'. The 'Asian/Asian British' category refers to South Asian backgrounds (Pakistan, India, and Bangladesh).

TABLE 4: PARTICIPANT ETHNIC BACKGROUND INFORMATION

ETHNICITY	N
Asian/Asian British	13
Black/African/Caribbean/Black British	1
Dual Heritage White British/White European and Black/African/Caribbean/Black British	1
White British/White European	47

TABLE 5: YOUNG PEOPLE PARTICIPANT DEMOGRAPHIC DETAILS

Young Person Name	Age at interview (years)	Age at diagnosis (years)	Gender	Ethnic Background
Saima	14	14	Female	Asian/Asian British
Beatrice	14	<1 YEAR	Female	White British/White European
Jodie	14	12	Female	White British/White European
Simon	14	<1 YEAR	Male	Asian/Asian British
Thomas	14	12	Male	White British/White European
Emma	15	<1 YEAR	Female	White British/White European
Freya	15	8	Female	White British/White European
Gary	15	9	Male	White British/White European
Shalima	15	8	Female	Asian/Asian British
Chloe	16	<1 YEAR	Female	White British/White European
Lydia	16	14-15	Female	White British/White European
Nicole	16	11	Female	White British/White European
Raheema	16	15	Female	Asian/Asian British
Steven	16	<1 YEAR	Male	White British/White European
Annie	17	16	Female	White British/White European
Fiona	17	<1 YEAR	Female	White British/White European
Florence	17	<1 YEAR	Female	White British/White European
Jessica	17	13	Female	White British/White European
Lyndsey	17	5	Female	White British/White European
Nathaniel	17	<1 YEAR	Male	White British/White European
Alice	18	<1 YEAR	Female	White British/White European
Imran	18	5	Male	Asian/Asian British
Mia	18	7	Female	White British/White European
Shantaya	18	14	Female	Black/African/Caribbean/Black British
Tahir	18	<1 YEAR	Male	Asian/Asian British
Dominic	19	<1 YEAR	Male	White British/White European
Dylan	19	<1 YEAR	Male	White British/White European
Ethan	19	<1 YEAR	Male	White British/White European
Kaylee	19	16	Female	White British/White European
Harpreet	21	14	Female	Asian/Asian British
Leah	21	<1 YEAR	Female	White British/White European

Molly	21	12	Female	Dual Heritage White British/White European and Black/African/Caribbean/Black British
Shabana	21	<1 YEAR	Female	Asian/Asian British
Leo	22	14-15	Male	White British/White European
Julia	23	16	Female	White British/White European
Shane	23	<1 YEAR	Male	White British/White European
Naheed	24	11	Female	Asian/Asian British
Declan	25	9	Male	White British/White European
Keira	25	<1 YEAR	Female	White British/White European
Kylie	25	<1 YEAR	Female	White British/White European
Jenna	26	3 YEARS	Female	White British/White European

TABLE 6: PARENT PARTICIPANTS' DEMOGRAPHIC DETAILS

Parent Name	Age	Child's age at diagnosis	Gender	Ethnic Background
Scarlett	32	14	Female	White British/White European
Audrey	39	14-15	Female	White British/White European
Vicky	39	13	Female	White British/White European
Fahima	41	8	Female	Asian/Asian British
Hayley	41	12	Female	White British/White European
Natasha	42	<1 YEAR	Female	White British/White European
Cassandra	43	15	Female	White British/White European
Chrissie	44	11	Female	White British/White European
Jacob	45	16/17	Male	White British/White European
Zoe	45	<1 YEAR	Female	White British/White European
Madison	46	14-15	Female	White British/White European
Nusrat	46	<1 YEAR	Female	Asian/Asian British
Gloria	49	12	Female	White British/White European
Eileen	50	<1 YEAR	Female	White British/White European
Erin	51	<1 YEAR	Female	White British/White European
Bianca	52	8	Female	White British/White European
Rosa	55	<1 YEAR	Female	White British/White European
Farooq	57	<1 YEAR	Male	Asian/Asian British
Fozia	57	<1 YEAR	Female	Asian/Asian British
Mary	58	<1 YEAR	Female	White British/White European
Martine	61	14	Female	White British/White European

3.14 Chapter Summary

In this chapter I have explained my methodological choices and reported the process of collecting and analysing the data. I have covered a range of important aspects such as my reasoning for adopting a post-positivist, critical realist approach and the use of thematic analysis. I have also discussed the ethical issues which were raised during this project such as issues in relation to power whilst interviewing children, issues of anonymity and conducting fieldwork as a lone researcher. In total this project accumulated over 134 hours of audio which were transcribed and I kept my reflections on the interview process in a diary. For me, the process of collecting data was very important and I routinely reflected on how I was perceived by participants as a researcher, as a young adult and as someone from a BME background. Moreover, I noticed things during recruitment and interviews which helped contextualise some of the experiences young people reported. I began this chapter with a piece of reflection to highlight the multiple issues I encountered whilst collecting data. I will share some of the narrative from my reflections at the start of upcoming data chapters; in light of my ontological and epistemological approach, the narratives will serve the purpose of illuminating chapter content and key issues. In this chapter I have drawn attention to my experiences of collecting data in a hospital environment, the various challenges I was presented with whilst trying to recruit participants and how I attempted to negotiate access, including embracing the 'language' of my participants during my struggle with self-representation. Building on from the issues of recruiting participants in a hospital environment and the assumptions from some health professionals that I would only be focusing on the transition from paediatric to adult services, the next chapter will focus on young people's experiences of communicating with health professionals and the clinic/health services.

4 Experiences of the 'clinic' and health services

February, 2014. I'm sat waiting in a consultation room and I can hear some commotion outside. I ask the nurse what is going on and she explains the doctor had been concerned about the behaviour of the mother of one of the patients so had asked her to leave the consultation. A few minutes later a young, South Asian individual walks into the room and I proceed to explain the research. This young person is chatty, polite, and comes across as confident. They agree to take part but explain they are very busy with their studies so cannot guarantee a time. The mother then walks in and stands frowning over us both until I ask her to take a seat. 'What is this for?' the mother demands in her native language, staring at her child who signs the consent form. I start to explain the study in her language to her but the mother seems disinterested and does not even reply. Then, a female walks into the room and the first young person leaves. The second person is a young adult who will go on to take part in the study. As I begin to explain the study, she asks her mother to leave in her native language and her mother mutters something angrily before walking out. 'I can't talk in front of her', she explains to me, which confirms for me the nurse's comments. She is different from her sibling; her speech is slurred and she is very abrupt. 'Don't look at me', she warns, 'I can't write while you're looking at me'. As I turn away from her shaking hands, she fills out the consent forms, 'I've got handwriting like a baby'. She asked me a lot of personal questions and began to share her liver story whilst we were in the room; I am taken aback by her fixation on marriage. 'All the decent guys are married or dead', she proclaims, 'I can't find a rishta (marriage proposal)'. After she leaves I am chatting to the nurse who is suggestive that her mother favours her sibling over her. A month later I agree to meet her in town and I turn up on time; she claims she was very early and was annoyed she had waited 'for ages'. I apologise but I am not sure why she was so early. We go to a nearby coffee shop, music is blaring and I have to really concentrate to understand her. During the interview I ask her if her mother always comes with her to her hospital appointments. Her response takes me by surprise; she was annoyed the doctors make her mother wait outside; she tells me her mother gets 'told off' and that she thinks the doctors are racist. She further disclosed her guilt at treating her mother badly for so many years. It was at that moment I realised how easy it is to misconstrue complex family relationships as an outsider; the hospital staff had tried to be helpful in asking the mother to leave but this was against her wishes. As a young adult, the decision in asking her mother to leave had to come from her, for example, she did not mind asking her mother to leave whilst signing up to the research.

4.1 Chapter Introduction

In this chapter I am going to focus on young people's and their parents' experiences (where appropriate) of the clinic and healthcare setting. This chapter has been separated into two sections, "the negotiation of roles in the clinic space" and "the transition to adult services". My reflection at the start of this chapter demonstrates the challenges which can occur within the clinic space, particularly around managing the complex relationships between parents, children and healthcare professionals. As I mentioned earlier in the thesis, Harris (2015) reported adolescence was a period of physical and mental transition, citing characteristics such as greater competency and social autonomy as markers of this change. Some of the issues which can occur during this transition included blurred boundaries between adolescence and adulthood (Mortimer & Larson, 2002; Youniss & Ruth, 2002). This is of importance within the healthcare setting due to the behaviours of parents and healthcare professionals which have been documented within the clinic space; parents may dominate the consultation or young people may feel excluded by the terminology used by healthcare professionals, which can impact young people's participation (Coyne & Gallagher, 2011). Young people's experiences of this broader transition were evident within their experiences of healthcare, one such example is their involvement within the clinic appointment.

Transition has multiple facets, particularly in relation to healthcare. As I mentioned earlier, there is the physical transition to adult services which can be a significant change in a young person's journey with their healthcare as they leave behind the familiarity of their children's hospital and routines, but also as they face new expectations to manage their own healthcare themselves, including taking on a more active role within the consultation. However, as this chapter will show, young people are often constantly transitioning within the clinic space even before the move to adult services as they negotiate their own role within the appointment. Young people's experiences were shaped by their position as children in relation to adults such as parents and healthcare professionals. Young people had to negotiate their participation and role in the clinic setting with parents who were accustomed to speaking for their child and some young people chose not to challenge their parents, whilst others were aggrieved of their situation. Alongside this, young people also had to manage their interactions with healthcare professionals, whose position came with superiority beyond the categories of adults and children. Whilst some young people were able to communicate in a way they deemed satisfactory, others did not have positive experiences and were not satisfied with the communication between themselves and healthcare professionals. Amongst the interactions with adults, young people also were affected by their position as children

when it came to their own competency to convey their symptoms and accounts of their health.

Some young people chose not to participate in their healthcare appointments; they reported they did not communicate with healthcare professionals themselves. This was important particularly as some young people reported their liver disease did not affect them, and others were determined not to be affected by their liver disease, which resembled aspects of biographical disruption. As explained earlier, chronic illness can be viewed as a disruptive event and biographical disruption refers to the rethinking of a person's biography following the onset of a chronic illness, and their utilisation of resources to manage the disruption (Bury, 1982). In both situations the outcome was either self-reported or reported by parents as a distinct lack of interest in the appointment. Hence, this was also why parents felt they were responsible for managing the conversation with healthcare professionals and remembering what was said. This chapter will show how there can be a connection between participating in healthcare appointments and some young people's efforts to minimise the disruption liver disease can cause to their lives. Experiences of healthcare can further be impacted by stigma; either through the stigma associated with having a chronic condition in general or the clinic space being viewed as a stigmatised space.

4.2 Negotiation of roles in the clinic space

Although it is advocated young people actively participate within their healthcare, for example, by communicating themselves during their appointments and that the interactions between healthcare professionals, parents and young people are triadic in nature, what actually occurs in the consultations can differ greatly. This section will explain the ways in which young people seek to participate in consultations through negotiating space with parents and healthcare professionals. Structural factors which impact on the consultation will also be considered.

4.2.1 Participation within the healthcare setting: negotiating space with parents and healthcare professionals

Over one third of participants interviewed reported much of the interactions during the clinic consultations took place between their parents and the health professionals present. Some young people did not like being excluded and thus sought space in the consultation to participate, these young people reported frustrations such as being ignored. One such example is summarised by Dylan;

Dylan: But it was never really talking to me; it was always aimed at mum and dad. (...) I'm just sat there while they're talking in the corner and

they're going 'well that's bad, that's bad'. (...) Sort of make you feel like oh well, not a lot I can say.

For Dylan, this created a conflict whereby although he was the one with the liver condition, he felt the consultation was focused on his parents and any information provided by health professionals was also directed at them. This was in line with previous research which found children were treated as 'passive bystanders' in their own consultation (Tates, Elbers, et al., 2002). Dylan reported this behaviour continued until he was told he was going to be moving to adult services whilst in secondary school. One parent, Hayley, reported her son was ignored by health professionals, "they didn't even look at him when we would go in for an appointment and I found that very rude", which supports the experiences of young people who felt they were ignored in consultations. Similarly, Gary, also stated the consultation was "more to reassure my parents"; Gary reported he did not ask the doctor any questions about his condition. These accounts suggested some young people were not actively involved in their healthcare appointments; their participation appeared to be limited to attending the appointment. Although not all participants felt this way, as I will later expand on.

Another participant, Kiera, reported she "hated being talked over" when her parents were present, she told me she was involved in her healthcare and communicating with health professionals from as early as age five or six. She then described an isolated incident where she was prevented from participating in a conversation about her transplant by a nurse at around age seven.

Kiera: I-I hate how they did this erm but they-my parents had had a conversation with the doctor about me being on the list um and erm and there was a nurse who I didn't really like very much and um and I wanted to- I knew what was happening and I wanted to go and be there so I was trying to get through and go and talk to them and this-this nurse basically tackled me to the ground and I kept running towards to go and be in this meeting and talk to them-to people about it but erm.

Kiera talked about resenting being excluded on this occasion as previously she had been included in conversations at the hospital, suggesting it was the inconsistency which she did not like. Whilst Kiera reported she resisted against the circumstances where she felt ignored and tried to reinstate herself as part of the conversation, other participants did not report taking any such actions despite saying they felt excluded from the consultation process.

Young people's ability to communicate with health professionals was further restricted by practical problems such as the presence of both parents and other family members. Emma told me in the interview her family used to make a daytrip out of her liver consultations but as she got older she began to resent this as it was "stressful". In the interview, Emma talked about her mother "asking every doctor she sees questions" and stated she found the appointments "easier" with only one parent attending in order to reduce the "chaos". Another young person, Alice, told me she did not ask the doctors or nurses questions although she did "really want to ask them". Alice went on to explain when her parents "were bothered they did ask questions and things and their concerns". The actions of adults constraining children's participation has been documented in the literature demonstrating young people may not feel like they are given a chance to communicate with doctors (Coyne & Gallagher, 2011). Being unable to communicate with healthcare professionals is not conducive towards the transition to managing one's own healthcare (Knopf et al., 2008).

In the context of the parent-child relationship, some young people were conscious of their parents' role which afforded them the privilege as spokespeople. Whilst some young people sometimes had to negotiate with their parents when taking up the space in a consultation, especially if their parents tended to dominate, others discussed expecting their parents to communicate; an example of this can be seen in Fiona's account.

Fiona: I think now that I'm older I can obviously communicate more better than what I used to, like, I just used to be shy and things... (Text omitted) Not even shy. My mum would tell them all because I (pause) my mum would say it all because that's just what mums do. They can explain better than I can. But now obviously I would be going with my mum much more and (pause) When I'm older I'll be driving up to (hospital) I won't be getting the trains no more so (pause) I have to.

From Fiona's account, her mother is constructed as having a role in communicating with the consultants. There is further an expectation her mother will manage the communication and she is portrayed as being more competent to fulfil this role as she can 'explain better'. Fiona acknowledges when she is able to make her own way to the hospital to attend appointments without her mother, she will have to communicate for herself and this was also indicated in an interview with Raheema.

Raheema: ... when your mum and dad's there you expect them to do most of the talking than you, but when you're on your own you have to talk more about what's going on and.

This indicates the act of bringing your child to hospital appointments may contribute towards their subsequent experience of communicating with health professionals and sometimes, may even hinder efforts to speak for themselves.

Some participants reported parental intervention in a consultation was unhelpful, for example, Mia indicated she “can’t be bothered correcting” her mother if she reported incorrect symptoms during a consultation, as “if my mum is right, she’s right, so...” When asked to elaborate on her experiences Mia described experiencing “weird stomach cramps” when she was younger that her mother was unable to “tell the doctors where they come from”; instead, she told the doctors Mia had been sick.

Mia: I don’t know I can just explain things better like and like by the process of like symptoms coming out and stuff

Although Mia was confident in explaining her symptoms even as a child, she reported she would not go against her mother’s version of events.

Another participant, Emma, informed me her parents also reported her symptoms on her behalf.

Emma: Erm, he (doctor) mostly talks to my parents. They normally say “yeah, she’s fine. Nothing’s changed since last year” They’ve been saying that for years so I don’t really know what that is. When I was a bit younger they (doctors) used to talk a bit more to me to reassure me.

Emma’s account, like others interviewed, reports her parents as being the primary focus of health care professionals during consultations. She challenged the repetitive answers her parents gave each year claiming she was fine, stating she did not ‘know what that is’. It is interesting how as Emma got older, she felt communication between herself and health professionals declined; this is in contrast to others, such as Dylan, who felt ignored throughout childhood until they got older. The extracts from Emma and Mia’s interviews show how young people can be hesitant to correct their parents, may not be listened to and shed light on how they understand their role within the context of a consultation; ultimately their parents are in a more powerful position. A parental account of symptoms may fail to accurately represent what the young person experienced and highlights contradictions between different perspectives.

In contrast, one young person reported her mother ensured she was given space to talk in consultations.

Nicole: My mum does the talking most of the time, but she always like makes sure that I do say something, and I actually do step forwards, and like say it. I think, as I have gotten older I have like said more, and more about it. Because, when I was younger, I just used to sit back and let her do it really. But now, I think I've become a bit more – like I think I'm better when I'm around doctors, and stuff like that. She's spoken to them about it, and like how it's affecting me, and how the – like what pains, and what's happening, and like she might like two steps back and everything when I'm at the doctors so she lets me explain everything, and they prefer it sometimes when you speak rather than your parents.

Nicole's account suggests her participation in the clinic appointment improved as she got older; she transitioned into a more active role with age. Her account of her participation resembled the "prototypical supportive triadic medical interaction" as described by Bates, Elbers, et al. (2002, p. 6) as she was encouraged by her mother to take an active role. Nicole spoke elsewhere in the interview of her transitionary phase; she was aware she was not an adult but also did not feel "childish", she further indicated a general preference for being treated like a "grown up" by other adults in her life, including school teachers. This particular example highlights how young people, their parents and healthcare professionals can communicate in a way which benefits the young person and facilitates their involvement.

On the other hand, several other participants felt their parents were better placed to communicate with health professionals. One such example was visible in Jenna's interview; Jenna reported when she was younger her mother "would definitely ask questions" and that her mum would "always do most of the talking".

Jenna: I think mum, probably she understood more and she remembered (long pause) so I don't remember being really unwell but she obviously saw me being really unwell (long pause) where I don't remember it at all so I never really know if (long pause) sick or (long pause) kind of the pressure that put on my family so what's happening and such. So yeah, I think she was always intrigued to know, you know, what she should be looking out for and the medications and stuff.

From Jenna's account some of the reasons for not communicating with health professionals and relying on her mother included not understanding the condition as much as her mother and memory problems, e.g. not remembering when she was unwell and lacking sufficient knowledge of the condition. One parent, Rosa, described her daughter experiencing similar problems to Jenna in the consultation and having to prompt her daughter about issues she had wanted to discuss with her doctor but forgotten about whilst in the consultation. For some participants, remembering information whilst in the consultation was challenging and two participants reported writing out their questions in advance as an effective way of securing information at consultations. It is important to note, whilst parents were useful as "reminders", some participants reported sometimes they found their parents' presence as unhelpful, especially when they wanted to discuss things with their doctor that they were not comfortable sharing with their parents, e.g. advice on contraception. These factors, which may pose a barrier in young people's communication with healthcare professionals, will be further discussed in the next section.

4.2.2 Factors which hinder young people's communication with healthcare professionals

Many factors hindered young people's ability to communicate with healthcare professionals themselves including the duration of the appointments, their own ability to communicate confidently with healthcare professionals, and their perceptions of what was an appropriate use of the doctor's time. If young people are not given space within the consultation to voice their concerns, important issues may be overlooked. Where parents act as spokespeople for younger children, they should still have access to space within the consultation for their concerns rather than competing with their parents or time. Whilst several participants noted the short duration of their appointments, some did not mind this especially if they felt there was 'nothing much to say'. However, three participants reported difficulties with the duration of their appointments. Annie reported that due to the short appointment duration she did not feel as if she had enough time to 'process' the information given to her by health professionals, and although she was asked if she 'had any questions' she was unable to utilise the moment. Whereas Jessica reported she felt her doctor would "rush" her and reported once her doctor cut her off while she was trying to ask a question; "went to mention that thing, it's like *all right, we'll see you next time*". Initially, I thought perhaps Jessica's experience reflected on her being a young person and perhaps her mother was given more time but Jessica's mother, who was also interviewed, reported she too felt rushed during consultations by

health professionals. Healthcare professionals are often bound by constraints such as pre-set appointment times which can limit the time they are able to spend with any individual patient (Braddock & Snyder, 2005). Although patients may feel more satisfied with a longer appointment (Howie, Porter, Heaney, & Hopton, 1991), it is not always feasible to provide them with the time they need (Braddock & Snyder, 2005).

Some young people lacked confidence in communicating with health professionals compared to others. For example, whilst Mia was confident in her ability to convey information to health professionals, other young people like Jodie appeared to lack confidence in their own ability to communicate with health professionals, and thus, parents acted as a safety net to support them with communicating.

Jodie: No, I think umm, I think I didn't really speak to the doctors, I just remember always looking to my mum to speak for me whereas now I speak for myself. I think at the start I was scared about not getting something right or they would assume I'm making things up because I think at the start I think I thought I was making things up too, sort of overreacting, I didn't know what to say that in case they through I was again, attention seeking, or umm, making things up but now I know that it's better to tell people and be told that it's probably not that, than to leave something untold, and just making it worse, if it is something bad.

The act of communicating with health professionals was carefully evaluated against potential accusations of exaggerating symptoms or lying; this can be understood by debates within the sociology of childhood literature around children's age and competency, particularly as childhood is constructed as unstable and children are not always deemed by adults as "reliable witnesses" to their own lives (Qvortrup, 2006, p. 439; Walkerdine, 2009). Jodie's account highlights many different power dynamics which come into play during a consultation; she reported hospital staff as being scary, distrustful and judgemental actors with the ability to undermine her account. This is reflective of previous research which recognised children's 'sick status' is often dependant on adult approval and highlights potential barriers children may face when trying to take up the status as healthcare actors (Mayall, 1998).

Several parents also reported they felt health professionals were distrustful of their children's account about their health, sometimes suggesting their children were "exaggerating" their symptoms, and were judgemental. This is problematic as in Jodie's case it indicates this fear led to feelings of self-doubt in her ability to communicate her

experience, and suggests her relationship with health professionals was initially unproductive, stifling her voice. This sense of inferiority has been documented in previous literature on children's communication with healthcare professionals (Beresford & Sloper, 2003). It further highlights the disparity in treatment between adults and young people; her mother was able to 'speak' for her as an adult who would be taken seriously. Jodie's account echoes many other young people's experiences of becoming more confident in communicating with health professionals as time goes on, reflecting the transition they make into a more active role.

Whilst Jodie reported feeling scared of giving the wrong answers to health professionals, Tahir's experiences indicated he felt he was a burden to the doctors. He reported he wanted to find out more about his liver disease as he got older but he asked his parents about his condition rather than the doctors at the hospital.

Tahir: Yeah I asked my parents but I didn't really ask the doctors ... My parents know the story and um they know the story what happened but I don't really ask the doctors. Cuz I don't really wanna waste their time, you know. Yeah.

It is interesting he sums up any questions or concerns about his health as 'wasting' the doctors' time. Similarly, Kylie reported she had many questions about her liver disease she wanted to ask the doctors but felt a "sense of urgency" because the clinic was "chockfull" and "other people need to be seen". A similar account to Tahir's was reported by a young person in another study on adolescents' experiences of communicating with healthcare professionals (Taylor, Haase-Casanovas, Weaver, Kidd, & Garralda, 2010). In current times, society is embroiled in fears of spending cuts and there are many prevailing discourses in society which aim to vilify people 'wasting' NHS resources. Due to financial constraints, commissioners have discussed the need to 'ration' health services (Rooshenas et al., 2015). Tahir's concerns of 'wasting' the doctors' time resemble what Fischer and Ereaut (2012, pp. 20, 48) summarised as entitlement anxiety, which to a certain extent is perceived by society to be a 'public good' as it may prevent inappropriate use of public resources. Some groups in society may have inappropriate levels of entitlement anxiety and health professionals should be aware of this (Fischer & Ereaut, 2012).

Several participants reported they did not understand much about their liver condition until they got older; this reflected their transition into becoming more active participants in their healthcare. As young people they grow older, their own communication skills often improved so they did not need their parents to act as spokespeople. Florence, who

was diagnosed as a baby, reported she felt differently about attending hospital appointments as a 17 year old compared to when she was younger because she understood more about the hospital procedures as a 17 year old; “I sort of did but I wouldn’t when I was younger and I didn’t kind of know”. Nathaniel expressed concerns about what would happen during future treatments, whilst he was not interested in liver disease per se, he was interested or “curious” as he described it, in the procedures that he would undergo at hospital. He reported once health professionals explained the procedures to him he felt at ease (elsewhere in the interview he reported when he was younger he had been nervous about medical procedures); this is another example of how young people were actively involved in their healthcare by drawing on resources available to them such as knowledge obtained from health professionals to minimise their discomfort.

One thing which struck me whilst collecting data was Gary (aged 15), Tahir (aged 18), Ethan (aged 19) and Imran (aged 18, who had also transitioned to adult services), could not tell me the name of their liver disease; not because the diagnosis was unconfirmed like some participants, but because they genuinely did not know. Whilst Tahir and Ethan had congenital liver disease, Gary was nine years old and Imran reported he was five years old when diagnosed. Four participants being unable to name their liver disease signals a breakdown in communication as all of the other young people interviewed were able to name their condition. To not know this basic information warranted further attention to discover why this may be. I would like to mention here that Imran’s parents told me he had been diagnosed as a baby, however, Imran, told me he was diagnosed aged five, the age which he had a liver transplant. Imran told me his parents did not tell him he had liver disease until he was ten years old which may explain why he was not aware of the name of his condition, however, he had been regularly attending hospital appointments throughout his life. Similarly, Tahir explained he was 16 years old when he found out he had liver disease from doctors and prior to being told he did not know. Whilst Ethan had known since he was child he had a liver condition, there is little explanation to as why the other participants did not know the name of their specific condition.

Although I was curious as to how Imran and Tahir did not know they had liver disease prior to being told by their parents, there is a potential culture-bound explanation related to the stigma of having a chronic condition. Tahir’s parents were not interviewed but in the interview he told me his liver disease was kept a secret and not even his teachers or his family doctor knew about his condition. Furthermore, when I spoke to Imran’s parents

his dad recalled how other people, including 'close family' members had wrongly assumed Imran's liver disease was contagious. He described his relatives not bringing their children to his house as they were concerned their children would "catch" liver disease. At this point in the interview his dad drew attention to our shared cultural background "you know how our people..." Therefore, not telling Imran about his liver disease becomes plausible as his parents were aware that having a chronic health condition could lead to Imran being ostracised by others, an example of enacted stigma. Previous research has reported that South Asian parents of children with other chronic conditions like asthma have been resistant to accept their child's asthma diagnosis; whilst many parents were reluctant to disclose the illness to other people, others themselves believed asthma was contagious (Lakhanpaul et al., 2014). Lakhanpaul et al. (2014, p. 7) reported 'there appears to be an ethnicity-specific belief that asthma is contagious and stigmatising'. Other studies have found that indeed people from a South Asian background may believe other chronic illnesses such as cancer or diabetes are contagious (Lord et al., 2012; Rai & Kishore, 2009). One way of managing other's potential negative reactions would be to ensure they did not find out about their child's condition, as explained by parent, Fahima, it was not necessary for those from "outside" to know about her child's liver disease. Whilst South Asian parents were not the only ones who discussed not telling other people about their child's liver disease, there was a clear pattern in the interviews with South Asian parents and young people of maintaining secrecy in relation to the disclosure of liver disease.

Another participant, Raheema, whose liver disease was diagnosed in her early teenage years, told me she had discovered the name of her liver disease after seeing it written on medical notes, reporting no health professional had ever told her the name of her liver disease. Part of me questioned whether the specific name of the type of liver condition was important. Taking one perspective, given that there are over 100 different types of liver disease which vary in treatment, it is of significance, for example in an emergency situation where the young person may suddenly be hospitalised and (in the absence of available medical records) a decision may need to be made on which drugs are safe to administer (Hartwood, Procter, Rouncefield, & Slack, 2003). There are many positives of communicating with health professionals for young people with liver disease which include addressing their concerns about the consequences of their liver disease and enabling them to challenge the boundaries which restrict their activities. However, young people who do not communicate with health professionals may not be able to experience these benefits. More broadly, research into other chronic conditions

such as cancer, has highlighted effective communication between healthcare professionals and patients is vital for providing good care (Fallowfield & Jenkins, 1999)

Some participants did have an understanding of their liver disease, for example, Julia described herself as 'very well read' for someone of her age. What this highlights is individual differences should be taken into account by health professionals. Some young people and children may feel they are able to cope with potentially distressing information (Brady et al., 2015). An example of this is when a participant (who did not wish for these comments to be assigned to their pseudonym) told me that they felt annoyed their doctor deliberately concealed how sick they were to avoid upsetting them. Previous literature with adults has also documented that often patients want more information about their condition and are not always shocked by their diagnosis (Peel, Parry, Douglas, & Lawton, 2004). This raises a question about information provision for young people with liver disease and how the needs of those young people who want more information are managed.

One way in which parental involvement can become problematic during the consultation process, is when young people feel like they are being denied information regarding treatments and procedures. Julia was unhappy as she was under the impression her mother did not convey the information provided by health professionals back to her regarding her need for a transplant.

Julia: Erm, I'd have liked to have known - I do not know- I suspect say 16 year olds, like me, I suspect that mum was given all the information an adult would have been given, had it been her and then she made a decision not to tell me, as opposed to the medics

Julia's mother did not take part in this study, however, another parent (Hayley) reported she was open about the dangers of a transplant to her 14 year old son; "I've just had to tell my son to have an operation that could potentially kill him, when all I want to do is tell him everything's going to be okay". Hayley claimed she was very "matter of fact" stating although she was a healthcare professional herself, she was not qualified in speaking to children "in a manner that they can understand". However, two other young people reported their parents did not talk to them about their condition at all; Emma reported her parents did not like talking about her liver disease and would not tell her she had an appointment until the night before so she would not get "worked up about it". Elsewhere in the literature on childhood chronic illnesses it has been documented parents may choose to limit the information their child has access to; this can be

problematic for children who do want to know more (Young, Dixon-Woods, Windridge, & Heney, 2003).

4.2.3 Reasons for not participating in healthcare appointments

For some young people, refusing to be actively involved in the consultation appeared to be a way of managing their condition as they did not want their liver disease diagnosis to disrupt their lives. This can be understood in light of biographical disruption (Bury, 1982); a decision to not engage with health professionals by some participants such as Tahir, Gary and Thomas may be indicative of a struggle to adapt to a new identity. The third stage of biographical disruption, as described by Bury (1982), referred to a response to the disruption which was categorised by those diagnosed utilising the resources they had available. Drawing on the work of Mills (2000), one possible explanation for the decision made by young people to not communicate with healthcare professionals within consultations could be to avoid moving into the role of the patient within the healthcare setting, particularly if young people wanted to minimise the disruption of liver disease to their biography. This could be a plausible explanation in light of previous research on liver disease which has reported young people's strive for normalcy (Wise, 2002).

To demonstrate this I will present the information from one young person, Thomas, who presented himself as uninterested in the liver diagnosis, claiming he was more interested in asking the doctors "what was for lunch". He told me the diagnosis "didn't really affect" him and was keen to portray himself as unfazed by his diagnosis, portraying his mother as the one who wanted information. When I asked Thomas why he preferred to let his mother do the talking, he told me "I don't really like to talk about it". Thomas is another example of a young person who relied on their parents to communicate with health professionals but also felt his liver disease diagnosis had not changed him "mentally or physically". Although Thomas reported he was initially "shocked" by the diagnosis, he repeatedly asserted he was not affected by it, something which was also apparent in the interview with Gary. Gary told me he was not the "type of person" to let liver disease "affect" him, however, he also stated he struggled to understand what was said during his liver disease consultations, which may have impacted his ability to contribute towards discussions. Previous research has demonstrated that people may reject a discredited or stigmatised identity due to the stigma and negative stereotypes associated with disability (Crooks, Chouinard, & Wilton, 2008; Goffman, 1963). One study reported although some people do not deny the impact of their condition on their lives, they do

reject the negative stereotypes associated with disability and may prefer to focus on 'their shared sense of selfhood with nondisabled others' (Jahoda, Wilson, Stalker, & Cairney, 2010, p. 522). This may explain why Thomas and Gary told me their liver disease diagnosis had not changed them as a person; they may have been rejecting a stigmatised identity.

By describing the consultation as something to reassure their parents, both Thomas and Gary were able to avoid being in the foreground of the consultations and avoided communicating with health professionals. Thomas further stated when talking about his future transition to adult services he was "not bothered" as he didn't "know any of the doctors anyway" and "it wouldn't make a difference". Despite the rhetoric within the literature advocating young people should be communicating with healthcare professionals and actively participating in their consultations, a decision not to participate does demonstrate young people's agency in how they wish to manage their healthcare. It has already been documented within the literature that children's refusal to participate in other contexts can be viewed as failure on their part rather than a decision not to assert their agency (Hartas, 2011). Furthermore, as recognised by Tisdall and Punch (2012), it is important not to demonise children who do not wish to comply or take responsibility. Some parents indicated an awareness that their child was not actively involved in the consultation, e.g. through communicating with health professionals, however, not all parents viewed this as problematic.

One parent, Cassandra, she described her daughter as "not really receptive" and reported "she just doesn't really wanna know" about her liver disease. Cassandra's daughter had been under the care of adult liver services since she was fifteen years old but had been under children's services for a comorbid condition; she stated she did not think her daughter was an adult yet. However, she had observed one occasion where her daughter was receptive and shared her observations about when the doctor communicated with her sixteen year old daughter directly.

Cassandra: And he sat down and talked it through with (daughter) (pause) not, not the whole thing, but he just explained to her what was happening in her - what could be happening in her liver, so that she could understand and she was, she was quite interested (long pause) whereas before it's all been, nothing's really been said. ... I mean obviously for me I-I knew all of that anyway but I was thought it was very interesting to see that (daughter) was, you know, was actually asking questions, and she was, you know, really responsive to it

From Cassandra's account it appears she is advocating health professionals make the effort to communicate with young people. She initially felt even as a parent she was not given adequate information but spoke positively of the doctors efforts to convey information to her daughter. Cassandra did say in the interview "I'm just sort of aware that, you know, she is sixteen and (pause) you know, it's her appointment, not mine". However, it is not known if Cassandra's attempts to take a backseat in the consultation stemmed from the health professional's assumption her daughter needed to be communicated with and his subsequent actions. Furthermore, as her daughter was not interviewed it cannot be taken for granted that her daughter felt that particular appointment was good as other young people have reported they prefer to let their parents do the talking.

In contrast, another parent, Madison, told me she or other family members spoke on behalf of her son and she did not see this as problematic;

Madison: If you knew him [son], he isn't that kind of lad anyway. We've always done the talking for him, so it's easier for him to just sit there, and listen, just answer questions if he has to (...) because he likes to block out what's happened to him. He doesn't listen anyway when we go to appointments.

Madison's son was interviewed separately and told me his liver disease did not affect him or his daily life in the same way as his other comorbid health conditions. Interestingly, Madison stated her son blocked out the past which would suggest it was an active choice not to remember. Whereas in the interview, her son stated he could not remember much of the past, which was more suggestive that it was not an intentional act. In contrast to Cassandra, Madison did not appear to find her son's decision not to participate in the clinic appointments as problematic.

However, it is important to note young people did not share all of their concerns with health professionals despite reporting they were happy to talk to and had space to communicate with health care professionals. Some of the concerns reported by young people could be viewed as resembling anticipated disruption, which previous research has reported as a current issue which affects young people's biographies, rather than one being located solely in the future (Saunders, 2017). For example, Saima, who felt part of the consultation, had some concerns which she had not shared with anybody regarding the intergenerational transmission of liver disease. One explanation for her concerns could be her future identity as a parent being at stake; another study reported women who survived childhood cancer were concerned about the genetic risks in

relation to parenthood (Gorman, Bailey, Pierce, & Su, 2012). Similarly, Fiona, was concerned about the impact of pregnancy on her liver transplant scar but had not talked to anyone about it. Another participant, Nathaniel, wanted to know what would happen if he was to stop taking his medicines. Whilst this is of concern as young people are not getting these particular informational needs met, it is more worrying when young people do not communicate with health professionals matters which are affecting their immediate health. Two parents, who both reported their child preferred not to communicate with health professionals, discussed incidents where their children had been in pain or experienced other pressing medical issues but not conveyed this information to health professionals. This was worrying for the parents, especially as their children were in adult services and their parents could not stay overnight with them to communicate on their behalf.

Participants' communication can be affected by other factors outside of the healthcare consultation, for example, Molly, a young adult, stated;

Molly: I still probably don't talk as much as I should now, but I don't know, I'm just not one to, they ask me how I am, I am not really one to complain. I know it's not complaining, I talked to doctors but, I don't really talk about my illness or anything, really, I usually just say 'fine' and that's it, so.

Molly told me in the interview that most people she talks to in her daily life are not really interested in her liver disease. Molly was alluding to the act of "complaining" being seen as a negative, stigmatising attribute, and one she wanted to distance herself from. She did not see the point of reiterating a detailed account of the symptoms experienced as a result of her liver disease even within hospital consultations because it was mostly "just normal" for her. Patients not wanting to 'complain' about symptoms they are experiencing has been widely documented within the literature (Davidson, Feldman-Stewart, Brennenstuhl, & Ram, 2007; McDonald, McNulty, Erickson, & Weiskopf, 2000; Wells, 1998). One particular study found women were keen to avoid being seen as whining or complainers, and undertook a significant amount of 'work' to appear credible in front of healthcare professionals (Werner & Malterud, 2003). This highlights how a person's broader identity can be impacted by how they manage their health condition. Scenarios like these highlight the complexity in young people's transitions into adulthood and their transitions to becoming active participants in their own healthcare; their journeys are varied and complicated by a number of issues ranging from feeling shy/anxious to not wanting to engage in conversations with health professionals.

4.3 Transition to adult services

So far, I have demonstrated the different experiences of young people with regards to communicating with health professionals, highlighting how tensions may exist between young people and their parents. Family dynamics can have an impact on whether young people actively participate in their appointment as young people weigh up the pros and cons of participating, sometimes being cautious of not being at odds with the roles they perceive their parents have. It is important to consider how young people experience the transition to adult services in light of the differing ways they communicate with health professionals and the challenges they may face. It is not uncommon for the transition from child to adult services to be difficult; this has already been discussed in literature regarding other chronic illnesses, in particular, diabetes for instance (Beskine & Owen, 2008; Kipps et al., 2002). However, there is a crucial difference between the experiences of children with type 1 diabetes transitioning and the experiences of children with liver disease; type 1 diabetes is not stigmatising in the same way that liver disease is (type 2 diabetes has been reported as a stigmatised condition) (Browne, Ventura, Mosely, & Speight, 2013). Liver disease comes with accusations, for example, of alcohol and drug misuse, a lack of deservingness of transplants, and the depiction of those with the condition as a drain on precious resources. There is a shift for young people from being innocent victims of an unfortunate disease to suddenly feeling judged and being held accountable for a condition they have no control over. Hence, I would argue young people transition not only to adult services, but into stigma as described by Goffman (1963). Outside of the protected bubble of paediatric services is a more judgemental world that they had previously been sheltered from. The move to adult services may not only physically locate them in a space where they are exposed to wider societal views on liver disease and stigmatising beliefs, but also bring them face to face with the new, negative labels and identities thrust upon those with a liver condition.

I will now discuss the experiences of young people with liver disease and their parents in relation to the transition from child to adult hospital services, which is one of the transitions they make during the broader transition into adulthood. The numbers presented are indicative of the experiences of all sixty two participants rather than just young people aged 14-17 years. Prior to the transition to adult services, one third of the overall sample reported feeling scared or nervous about the move to adult services; this included a mix of those who had made the transition and those who had not. The first theme “concerns about changes to service provision” encompasses young people’s views regarding the care they will or did receive at adult services and the loss of relationships with the health care professionals at children’s services. This theme

predominantly focuses on the physical transition to adult services. The second theme, “ready to move to adult services”, demonstrates the experiences of those young people and parents who felt their child was ready to make the transition to adult services, demonstrating how young people can grow out of the environment at the children’s hospital. This theme draws on the broader transition young people make into adulthood. The third theme, “fear of sharing the clinic space at adult services”, refers to young people’s and parents’ concerns regarding the adult clinic space which they will share with those who did not have childhood liver disease. This theme draws on the concept of stigma to demonstrate how the adult liver clinic can be viewed as a stigmatising space.

4.3.1 Concerns about changes to service provision

A theme which was evident was participants’ fear of changes to their current health provision; this fear spanned across both the standard of care and a new hospital environment. Eleven participants (four of whom were parents) indicated they needed reassurance that the care they would receive at adult services would be as good as the care they received in children’s services. As one participant, Shane, who was diagnosed as a baby explained;

Shane: I think that was one of thing I was a bit nerved about because Dr (name omitted) was a very good doctor and you know I just as I mentioned earlier I had her since I was very young (pause) I knew things would be different (pause) well, I think this is the thing I needed reassurance about. I think things were a bit up in the air.

Later in the interview Shane reflected on his experiences post-transition;

Shane: I think the professionalism is the same. Yep. I think you know despite my concerns I think the standard has been the same. You know it's been a very high standard.

As can be seen in the quote from Shane, although some young people may be fearful of losing the ‘good’ care they receive from their children’s doctor, they discovered after moving to adult services the care was just as good.

However, one third of the overall sample interviewed (the majority having transitioned already to adult services) indicated they felt adult services were not as supportive or caring as children’s services. A number of explanations were put forward as to why they felt this way including perceptions of staff at adult services being unable to see things

from “a child’s view”, not being as sympathetic to the desires of young people during hospital stays, and differences in the way concerns were managed e.g. taking longer to respond to concerns or arrange medical procedures. For example, Steven reported at adult services the way some of the procedures such as blood tests are done “seems a lot less thoughtful and caring and more of a job”. Drawing on literature presented earlier, these experiences could be due to the absence of child-friendly methods which were employed at children’s services (Koller & Goldman, 2012).

Nearly half of the participants who took part in the study indicated they wished to remain in children’s services.

Tahir: Going to be different, I'd love to stay in the same hospital but I can't. (...) I'm used to it and erm I wouldn't mind staying at the hospital for longer.

The quote from Tahir demonstrates how for some young people it appeared to be the familiarity of children’s services which was important; they were uncomfortable with the changes which would follow when they moved to adult services. The main reason for this was the familiarity of children’s services and trust they had with their children’s service doctor. Eighteen participants reported it was important to know someone at adult services which reinforces the importance of familiarity. The presence of the same Clinical Support Nurse and transition specific staff from the children’s hospital were cited as reassuring for those moving to adult services.

Another concern raised by young people included overnight hospital stays; three young people expressed concerns about no longer being able to have a parent stay with them overnight at the adult hospital. Most participants did not mind staying in hospital overnight alone although some participants, such as Shabana, reported feeling “scared” and “bored”. Similar sentiments about hospitals have been reported elsewhere within the literature (Dalke et al., 2006).

Kiera: “having someone with you is erm a good distraction of what’s going on and it’s also-it helps you make sense of what’s going on cos you have someone to talk it though with that’s on your team so your team feels less erm you have a slightly less stronger team, when you’re the only person on the team”

As can be seen in the quote from a young adult who was reflecting on their experience of staying overnight in hospital alone, having someone with them can have an important role in making the young person's stay more comfortable.

For other young people, moving to adult services meant they would experience a loss of the relationships they had with the children's services.

Chloe: I can't trust this doctor (in adult services) is gonna be perfect straight away. He might be, I don't know that... I just feel like (pause) I'm a little insecure about it (pause) I'd rather stay... It's hard to let go.

Chloe is one example of a young person who spoke highly of her children's services doctor, in the interview she told me how she felt her paediatric doctor saved her life on multiple occasions. Another participant, Kiera, who had transitioned told me;

Kiera: I think continuity is vital when you have a long term condition. It's very, very important that you have someone who knows you, who you can go back to erm who understands your perspective

One thing that was important for young people was the duration of time they had known their paediatric doctors; often young people discussed the doctors as knowing them since they were babies and thus, these doctors had earned their trust. These findings reflect previous research which reported continuity of care and relationships with healthcare professionals were important for young people with liver disease (Wright et al., 2016).

Fifteen participants reported it was important to them to have a transition clinic to meet their new healthcare team. Examples of this include Alice, aged 18, who had already transitioned at the time of the interview who said the transition appointment was helpful;

Alice: "Because I just met a few people and we got to know everybody before I moved out. But I think it helped me because I just met the people before. I was more nervous though, yeah".

Several young people who had not yet transitioned reported they would like a longer transition appointment to get to know their new doctor and how to navigate the new hospital. Those who did not have a transition appointment reported feeling upset about the sudden move to adult services as they did not get the opportunity to say goodbye to their children's hospital doctor. As one young adult explained;

You know, these pivotal care givers that had been there throughout my entire life, I didn't even get a chance to say goodbye to so yeah (text omitted) I didn't feel great about it.

Nearly one quarter of participants felt unprepared for the move to adult services; they wanted further information about the transition process.

4.3.2 Ready to move to adult services

Whilst for some participants there was a strong desire to remain in children's services, 12 participants indicated they did not mind having to transition to adult services. Two of these were parents, Eileen and Mary, who reflected on the transition as an inevitable event. A commonality between both of these parents' interviews was that they both reported their children had good health.

Eileen: Erm (pause) well she can't stay at the children's hospital for the rest of her life (laughing) can she? It's just a transition that she, she erm, she has to do really, it'll be sad leaving the children's because erm we've been there for so long, but erm (pause) yeah, as I say she'll look silly in her twenties if she's still going back to the children's hospital isn't she? It has to be done.

Mary, felt the transition would be a positive event for her daughter; something echoed by nine other participants who reported they were ready to move to adult services.

One of the reasons reported by young people for feeling ready to move to adult services was the desire for a more mature environment; they felt they had outgrown the toys at the children's hospital and were looking forward to "somewhere without the screaming" of younger children. This reflects the broader transition young people make into adulthood, where material manifestations of childhood, such as toys, may not be as appealing (Brookshaw, 2009). Those who had infrequent appointments at the hospital or did not anticipate many changes at the new hospital did not have any reservations to moving. What this highlights is differences in the importance of the children's hospital to different young people; some young people do not feel as attached.

Kylie: At the adult hospital I felt a bit more relaxed. Kind of like being more myself... I feel that you have to do it (transition) in order to understand it. It's all right having a new doctor. Someone new to me.

The main thing that I was worried about was the journey, took me longer to get to the adults than to the children's hospital

Declan: I wasn't really too bothered. Erm, you know, a hospital's a hospital (...) I found it quite easy. The first liver appointment that I went to at the adult hospital, the doctor at my children's, the doctor who looked after me at the children's was there to do the official handover. That didn't help me personally. I think it was just a medical thing. Erm, you know, more for the doctors, rather than myself.

Both of the young adult accounts demonstrate their positive experiences of transition were down to their own individual feelings about hospitals. For Kylie, it was not a new doctor or the loss of a relationship that concerned her but the practicality of getting to a new hospital site, which was a challenge she faced in the broader context of growing up and having access to transport. The new hospital site had disadvantages as it meant Kylie was no longer able to get a lift from somebody she knew who worked close by to her children's hospital. Kylie talked about how the journey, which consisted of two separate buses, took "forever".

Declan's account differed from other participants in that he did not appear to have formed any attachments to hospital staff and thus did not experience the loss of relationships other participants, such as Chloe, experienced. One of benefits of not forming attachments with hospital staff at children's services for him was that he was able to transition smoothly. However, it is important to note that liver disease affected Declan's life in many ways and the transition to adulthood more generally had been difficult; he struggled with other life transitions such maintaining friendships, forming intimate relationships and gaining financial independence. Earlier in the thesis, I discussed literature on how growing up with a chronic condition can result in struggles to achieve financial independence (Grinyer, 2007) and young people with liver disease may struggle to fit in with their peers (Wise, 2002). For Declan, the transition to adult services was a manageable life transition. Overall, these particular accounts suggest some young people may be better placed to manage the hospital transition.

4.3.3 Fear of sharing the clinic space at adult services

The transition to adult services forms one of the life transitions young people go through as they reach adulthood. This should be a period where young people take responsibility for their own health through communicating with health professional themselves and may also be reflected in practical changes such attending hospital appointments alone rather than with parents. However, some young people and their parents had several

reservations about adult services. There were a number of things which participants feared, for example, seven participants (two parents, five young people) expressed concerns or were fearful about the presence of 'alcoholics' at adult services. They felt this was not an appropriate environment for them and as one parent explained the two groups "have different needs". At the start of the thesis I explained how historically alcoholics have been stigmatised as deviants within society (Macfarlane & Tuffin, 2010). Some participants explicitly distinguished between those present at the clinic due to alcoholism and themselves and the role of alcohol this is something I will discuss in more detail later on in the thesis. Whilst many young people reported being sympathetic to the individual circumstances which lead to alcoholic liver disease, other young people felt they had not 'done anything' to cause their liver disease, this was suggestive that alcoholic liver disease was self-inflicted. These accounts were indicative that participants felt there was a stigma attached to adult services, many commented on "old people" attending the clinic in addition to alcoholics and a few participants raised concerns about 'criminals' attending the clinics in handcuffs. Amongst those concerned about alcoholics, only one of the participants was Muslim and generally fear of sharing clinic space with alcoholics did not feature in the same way in Muslim participants' accounts. This is something that I will discuss in more detail later in the thesis; given alcohol-induced mortality is predominantly lower amongst those who are Muslim (Cojocariu, Trifan, Gîrleanu, & Stanciu, 2014). A potential explanation could be that Muslim participants did not associate liver disease with alcohol. For other participants, this suggests although the transition was due to be a period of change within young people's lives as well as in their healthcare provision, it also became a transition into a stigmatised space (the adult clinic).

Another condition where young people may become exposed to stigmatising beliefs is Human Immunodeficiency Virus (HIV). Wiener, Battles, Ryder, and Zobel (2007, p. 6) described 'transitioning paediatric HIV patients' as carrying 'the extra burden of social stigma and transmissibility' as a result of their illness. Whilst Wiener et al. (2007, p. 13) predominantly employed quantitative methods to collect their data, the free text box at the end of their questionnaire reported the following reoccurring sentiments; "loss", being "upset," feeling "frightened about future," feeling "abandoned," being "concerned about receiving lower level of care," and a "lack of HIV knowledge" in other places. Interestingly, they did not find any links between disease severity and readiness to transition/anxiety, alternatively suggesting a young person's lack of readiness to transition to adult services was more likely to be influenced by their "strong emotional attachment" at the children's service (Wiener et al., 2007, p. 3). Another study also

reported young people with HIV who were less involved in their healthcare decisions in their paediatric service “were more positive and ready for transition than those who had been more involved” (Miles, Edwards, & Clapson, 2004, p. 305). What these studies suggest is that young people’s investment into their involvement with paediatric services may be crucial for understanding their feelings towards transition and may explain why some young people may not view the transition to adult services as a significant event compared to others.

Other previous research looking at the transition of paediatric HIV patients has reported some interesting findings in relation to stigma and the transition to adult services. For example, Vijayan, Benin, Wagner, Romano, and Andiman (2009, p. 1222) reported “issues of stigma played a prominent role in both the challenges to care and barriers to transitioning care” for young people with HIV. They found families had “negative perceptions of and experiences with stigma of HIV disease” and this made them reluctant to meet new healthcare providers, something the authors reported as a barrier to transition (Vijayan et al., 2009, p. 1222). Referring to the population who attended adult HIV clinics, some participants in Miles et al.’s (2004, p. 309) study reported they were disappointed to see a “predominantly gay, male population” as this was not something they had previously considered, and others were disappointed there were not many young people attending. This finding was important because it draws attention to how young people may become aware of stigma associated with their condition through the transition to adult services.

Whilst gay males may be the stigmatised population for HIV, I would argue alcoholics are the stigmatised population for liver disease (e.g. through lay beliefs around liver disease associating it with being linked to alcoholics and drug abusers). Sharing the same clinic space as those usually stigmatised for their condition can bring to the forefront for young people the stigmatising beliefs associated with their respective conditions. The compounding issue is young people transition into this stigma (for conditions such as HIV the stigma may be more prevalent throughout the life course) which can make the transition to adult services more challenging for those with liver disease. Being exposed to stigmatising beliefs regarding liver disease may have an impact on young people’s biographies, particularly as adolescence in itself is recognised as a period of transition where their identities are being developed (Harris, 2015).

4.4 Summary

In this chapter I have demonstrated how experiences of healthcare and the clinic space are impacted by the multiple transitions young people make within the clinic space. These transitions include moving into a more active role within consultations (which can involve negotiating space to participate with parents), the transition into adulthood, and the physical transition to adult services which can mean being exposed to stigmatising attributes associated with liver disease. I have further demonstrated how young people's experiences of the clinic space and their healthcare can be explained through the concept of biographical disruption, and their own way of managing their liver disease.

An observational study by Bates, Meeuwesen, et al. (2002, p. 115), focusing on General Practitioner (GP) appointments, reported;

“Parents obviously regard matters of the child's health as their own responsibility and, therefore, they usually treat their children in medical interviews as if they were absent”.

Drawing on the sociology of childhood literature, the parental behaviour found in the data can be understood in light of the changing role of the family being responsible for ensuring children's wellbeing (Qvortrup, 1987, p. 16). Mothers in particular are impacted by cultural expectations to protect their children (Young et al., 2002), and the findings showed some young people expected their parents to communicate with healthcare professionals on their behalf.

Young people's need to communicate with health professionals will change over time and whilst health professionals and parents need to be responsive to these changes, a young person's age might not always be the best guide to these changing needs. Scenarios such as that presented by Cassandra highlight the problem with both administrative and legal fixations on age being the decider for allocation to children's or adult services. It can be difficult to assess Gillick Competence (Williams, 2006) in young people under age 16 and once they reach 16, it might not be very useful in determining whether or not they are ready to assume the responsibility that comes with managing their own health. Whilst there are legal provisions in place which can allow 16 year olds to request information is not shared with their parents, the interviews with young people and their parents have suggested age 16 is not the best guide for determining when a young person is ready to assume more responsibility. This is due to some young people wanting to be involved and treated like 'adult' patients before they turn 16 and some young people older than 16 not wanting to be spoken to like 'adult' patients.

Applying the medical model of transition, young people make this transition between ages 16-18, which is problematic for young people who cannot conform to the expectations placed upon those in adult services such as asking more questions and actively participating in their healthcare, and for parents who are not ready to let go of their role. A better approach would be to provide ways of communicating which can meet the individual needs of young people irrespective of whether they are in child or adult services. Further research would be needed to operationalise such an approach to determine how health professionals would recognise which style of communication would suit each of their patients. This is particularly important in the context of liver disease as young people may have congenital liver disease or have been diagnosed later in childhood.

If young people with congenital liver disease are routinely ignored as children, like Dylan, this can then lead to frustrations with consultations and the young person becoming a 'passive bystander' in their own consultation (Tates, Elbers, et al., 2002). It is important young people do not feel like the consultation is simply there for the benefit of their parents as this can then become problematic when they move to adult services and are expected to take responsibility for their own healthcare, especially if they rely on their parents to communicate on their behalf. When young people are diagnosed later in childhood, they can have very different responses to the diagnosis. For example, in the case of Thomas and Gary, they may wish to maintain their sense of normality by ignoring their liver disease to minimise the disruption on their lives, or in the case of Julia, they may want to know the details of their condition. Those who are diagnosed later in childhood and do not wish to be in the foreground of the consultation may not have the same opportunity to drift into the background as those with congenital liver disease, who have become accustomed to their role in the consultation over time.

Young people who are diagnosed with liver disease later in childhood and who straight to adult services may need extra support as they have to contend with the unfamiliarity of being in hospital alongside going straight into adult services. With reference to addressing young people's concerns about the transition to adult services, a number of key concerns may need to be addressed such as the fear of sharing clinic space with those whose liver disease stems from issues with alcohol misuse, concerns of changes to service provision, young people's desires to remain in children's services and desire to move to adult services. Reflecting back to the start of this chapter with the extract from my interview notes, it was evident the difficulties health professionals face when negotiating sometimes complex family dynamics and how easy it is to make the wrong

decisions. However, the best way of understanding young people's preferences is to ask them.

5 The role of alcohol in experiences of stigma across different transitions

After the first few interviews, I was already very aware of how the restriction on alcohol consumption was problematic for young people who were trying to fit in with their peers. "I want to live" one participant told me when reflecting on how alcohol interfered with his social life. Some participants told me about being singled out publically by peers for not drinking, the hurtful comments with ensued and their own sadness at being excluded from social situations. However, there were other participants who challenged the stigma associated with being the one consuming soft drinks instead of alcoholic drinks. They were not going to be pressured into doing something that would potentially put their health into 'jeopardy'. Irrespective of the stance young people took, it was clear that alcohol was a significant issue for them, marking them as different.

However, the very questions associated with alcohol consumption became uncomfortable to ask during some interviews, especially when I was almost 100% confident the participants would not consume alcohol. Seven of the South Asian participants with liver disease I interviewed identified themselves as Muslim and I knew their religion prohibits alcohol consumption. None of these participants expressed a desire to consume alcohol. I remember vividly arriving at a participant's house and seeing the remnants of an important religious occasion stacked in piles around the room. His parents apologised for the clutter and explained he [their child] had organised the event which ended the day before; they discussed how seriously he took his faith and the fulfilment he received from religious activities. When the participant entered the room to be interviewed he was wearing distinctive religious clothing. As the interview progressed I asked him if he had ever been in a situation where his peers may have been consuming alcohol - to which his replies were short. "No", "drinking was not right", he did not "like it" and if his peers were to drink he would not go "close to them". The questions on smoking, alcohol and drugs made him sigh as none of these activities appealed to him. Another participant told me drinking alcohol was "gunah" [a sin].

I was conscious not to make assumptions about the lifestyle choices of any of the Muslim participants when it came to consuming alcohol as I know the extent to which individuals adhere to certain practices vary. However, it could not remain unnoticed that Muslim participants had very different experiences around alcohol to non-Muslim participants. Only one young adult, Muslim participant discussed some of their close friends were drinking alcohol but made their position clear that they did not partake in drinking. Another young person explained that most of her friends are Muslim and would not drink because their families would not let them. This made me think about a joint interview with a Muslim mother and daughter where as I began to explain I had some questions on alcohol, smoking and drug use, the mother sharply answered for her daughter, "no" before I had even asked the questions! Sometimes you have to pay attention to what is unsaid in interviews and within the interview context it was drinking alcohol which held potential stigma for Muslim participants rather than abstaining.

5.1 Chapter Introduction

In the reflective piece at the start of this chapter I have set the scene for a difference in relation to experiences of alcohol-related stigma amongst young people; that is certain ethnic minority participants, notably those from a South Asian, Muslim background did not experience alcohol-related stigma in the same way as non-Muslim participants. In the first section, I will explore the experiences of Muslim participants in more detail, showing how their religious beliefs and the abstinence of alcohol served as protective factors against the stigma non-Muslim participants experienced during the transition to adulthood. I then present the other side to the ambivalent attitudes towards alcohol consumption in the United Kingdom, where young people were stigmatised for not consuming alcohol whilst making the transition into adulthood and how it affected their identities. I will then discuss how in the context of individualised responsibilities for one's health, young people managed societal governance on their alcohol consumption. This was particularly pertinent in relation to transitioning into an adult and taking responsibility for their health condition. I then present the ways in which the stigmatising reputation of liver disease manifests itself within young people's accounts as they seek to differentiate themselves from 'alcoholics' as a response to the stigma surrounding liver disease. In the subsequent sections, I will present the experiences of participants who felt their liver disease had impacted on their employment prospects, those who had access to resources to manage any stigma, and finally how alcohol can affect some young people's transition into employment. The final section addresses the ways in which parents have experienced stigma in relation to their child's liver disease, both as a spectator and personally through direct stigma questioning their behaviour throughout pregnancy. Here, I also demonstrate how parenting identities can be affected by stigma associated with liver disease.

I am going to begin this chapter by outlining data from the interviews relating to alcohol consumption by participants. In the current study 26 young people (by young people I am also referring to young adults here) reported they did not drink alcohol, 14 reported they occasionally consumed alcohol and one participant did not answer this question. Of the 26 young people who reported they did not drink alcohol, five had tried alcohol and three of these participants felt they were discontented by their lack of alcohol consumption. An additional young person who did not drink alcohol, nor had ever consumed alcohol, reported they also were discontented with the amount they could consume in comparison to others. Of the 14 young people who reported they consumed alcohol, eight of these participants reported they were discontented with not being able to consume as much alcohol as their peers. In total, 12 young people were bothered by

their limited alcohol consumption; this is just under 30% of the overall young people sample. Earlier in the thesis, I explored the ambivalent attitudes towards alcohol in the UK; alcohol was seen to have an integral part in society yet those with alcohol misuse problems were equally ostracised by others. Not all young people viewed alcohol as an integral part of society, I will discuss this further in the next theme.

5.1.1 South Asian participants and non-drinking culture

Seven participants aged between 14 to 24 years, identified themselves as Muslim, all were from South Asian backgrounds, whose families originated predominantly from Pakistan, but also Bangladesh and India. None of these participants reported consuming alcohol nor expressed a desire to consume alcohol. Only one of these participants was interviewed with a parent present. Islam, the religion which Muslims abide by, forbids the consumption of alcohol and within South Asian communities this abstinence of alcohol, particularly for females, is also governed by close-knit familial networks where deviation is discouraged in order to save the family's izzat (honour) (Valentine et al., 2010). However, although the figures are generally lower than other populations, some Muslims do consume alcohol regularly, often with young Pakistani men citing alcohol facilitates their confidence in talking to women (Valentine et al., 2010). Although the figures are not recent, Cochrane and Bal (1990, p. 762) reported Muslim men who regularly drank alcohol consumed the highest units of alcohol compared to Sikh, Hindu and White men in the West Midlands; although these were few in number with 90.5% of the Muslim sample having never drank alcohol or consumed alcohol in the past year. Furthermore, there was a relationship between being a less religiously observant Muslim and being more likely to consume alcohol (Cochrane & Bal, 1990). Whereas, for other Muslims, even being in a space where alcohol is served is considered as potentially 'contaminating' for them (Valentine et al., 2010, p. 17).

An older, female participant told me she would not "do anything out of context" and that consuming alcohol was a sin. However, she also told me she had a "cigarette problem" and blamed her friends for pressuring her into trying smoking in the first place. It was interesting when narrating her story about how she started smoking, she told me she kept telling her friends smoking was a sin, but eventually started smoking. This shows how the relationship young Muslims have with 'forbidden' activities such as drinking and smoking is complex and can be subject to change in the future as young people are exposed to peer pressure. It appeared for that particular participant, alcohol was more of a sin than smoking, as she was firmly against alcohol consumption and even drug

use. Generally, it is acknowledged during the transition from adolescence to adulthood, young people may partake in behaviours such as smoking and drinking alcohol; healthcare professionals may be worried about the specific health implications for young people with liver disease (Dhawan et al., 2016). I was aware that perhaps Muslim participants were conscious about revealing their drinking behaviours to me given how alcohol is prohibited within their religion and consumption may portray them in a negative light, or perhaps my cultural background influenced their answers as they may have been conscious not to say anything which could damage their *izzat* (honour). Although I cannot be completely certain, participants were happy to disclose other behaviours such as smoking and curiosity about 'medical marijuana', thus, I do not believe the participants were concealing their drinking behaviour.

Raheema, aged 16, is an example of a participant who recognised that her experience of growing up with liver disease was different to that of other young people living in the United Kingdom because she did not drink alcohol for 'religious reasons'.

Raheema: If I was like someone else, like partying all the time, I guess that would be harder on me 'cuz there's alcohol. But I don't really drink so it doesn't really affect me in that way 'cuz if it was someone who did drink obviously it goes through your liver and stuff that would be harder but with me - no.

When asked about a hypothetical situation where her friends were drinking around her, Raheema stated she would be the "sober friend" and she joked about being the "designated driver". Raheema was also the only Muslim participant who mentioned at the adult hospital there may be "alcoholics"; it could be other participants did not register the stigma associated with liver disease and alcoholism in the same way given consuming alcohol had never been 'normal' for them. Both Tahir (aged 18) and Shalima (aged 15) told me in the interview that drinking alcohol was bad for your liver if you have liver disease, with Shalima solely citing this as the reason for not consuming alcohol. Shalima did not mention her religion as a reason for abstaining from alcohol, it could be because she felt in the presence of a BME researcher with a shared cultural background it was already obvious. Similarly, Imran seemed perplexed in the interview as to why he was being asked questions about alcohol. Imran said he had never considered drinking alcohol. When asked about why he would not drink alcohol, he refused to answer, simply going 'mm'.

Another 14 year old participant, Saima, laughed whilst being asked questions on alcohol as the idea that she or her friends would consume alcohol seemed absurd as "they're all

Muslims so they wouldn't drink". It was important to ask these questions as other non-Muslim participants had reported consuming alcohol around age fourteen. Saima was the only participant who reported familial regulation would prevent her friends from consuming alcohol; this was similar to the findings in the research by Valentine et al. (2010) which suggested South Asian communities govern behaviour to discourage 'deviant' behaviours such as alcohol consumption. None of the participants reported ever being in an environment where alcohol was being consumed which is in line with previous literature highlighting how entering a place where alcohol is freely consumed is frowned upon amongst South Asian Muslims (Valentine et al., 2010). Tahir initially said none of his friends consumed alcohol, however, he later said some of his friends did consume alcohol although he distanced himself from them.

Tahir: I don't really mind when they drink but I don't go with them, obviously I don't.

When Tahir was asked if he had ever consumed alcohol he replied, "No, I'm not really an alcoholic" and that he would never consider drinking alcohol in future. Tahir stated he did not think drinking alcohol was a good idea for people without liver disease even "once" as it "messes your head up". There are several potential ways to understand Tahir's comments, for example, Tahir may be trying to distance himself from alcoholics who historically have been a stigmatised group (Macfarlane & Tuffin, 2010) or he may generally associate alcohol consumption with the undesirable trait of an alcoholic.

Not all of the South Asian participants interviewed were Muslim, in particular, one Sikh participant, Harpreet (aged 21), also discussed how some members of her family did not approve of alcohol consumption. Harpreet was diagnosed whilst in secondary school where she did not "go out" so was not exposed to the peer pressures associated with drinking culture. Not "going out" to see friends after school and at weekends is not uncommon for female, South Asian adolescents due to the cultural values which influence their upbringing discouraging certain activities (Basit, 1997). However, Harpreet told me she was allowed "one drink" at the age of 17 with her cousins at family weddings and reported drinking with her friends from university. This appeared to be done in secret as she told me she currently does not drink whilst living at home, "because my family don't allow it (text omitted) mum and dad have always disapproved of drinking". Harpreet was careful not to drink too much not only because of her liver disease, but also because she did not want her family to find out she had been drinking.

Whilst none of the Muslim participants in the interview mentioned people associate liver disease with alcohol, Harpreet reported explaining to people her liver disease was not caused by alcoholism. This is interesting as it suggests Muslim participants may not be exposed to the same societal views which do view those with liver disease negatively. Perhaps because of their religion, people may assume their liver disease is unrelated to alcohol as they are not likely to be consumers of alcohol. Whereas non-Muslim, young people with liver disease, such as Harpreet, may be viewed under a suspicious lens when people find out about their liver disease. This can be explained by the stigma associated with alcohol consumption and liver disease (Bathgate, 2006; Macfarlane & Tuffin, 2010). What I do know from the interviews is Muslim participants were less likely to disclose their liver disease to others and this may have been the reason why none of the participants could answer any questions on societal attitudes towards liver disease, other than Raheema, who explained there was not enough awareness about liver disease for there to be any attitudes.

Overall, this theme demonstrates how the transition to adulthood varied for South Asian participants in the context of their cultural background, whilst some experienced pressure to consume alcohol, others were not exposed to drinking norms within their social circles and therefore did not report experiencing any stigma for not consuming alcohol. In the next theme I will present other participants' experiences of pressure to consume alcohol.

5.1.2 Experiences of pressure to consume alcohol

Numerous studies have documented the popular trend of young people drinking excessively in the UK, something often referred to as 'binge drinking' in the media, a term which has varying definitions but generally consists of drinking high volumes of alcohol in one sitting (Davies, 2005; Ormerod & Wiltshire, 2009). Previous research has highlighted the contrasting messages young people may experience; 1) they should be exercising responsibility when drinking; 2) drinking is necessary to have fun and be integrated into a group of friends (Szmigin et al., 2008). Many young people reported experiencing both felt and enacted stigma in relation to alcohol consumption (Scambler, 2007). Participants perceived pressure existed to drink alcohol; some young people felt that their peers would not be accepting of their alcohol restrictions despite not actually having been rejected by their peers. An example of this includes participant Annie, who talked about her former friendship group who she was no longer in contact with. Annie told me about one former friend, who used to be "quite a big party girl and she loves to drink a lot", who she felt would pressure her to drink; "I'd be like stuck on the coke and you know, they're like "oh, come on have a sip"...". When I asked Annie if this had ever

happened to her she told me it had not but she anticipated it would with time, for example when she “went to university and met new friends”. Another participant, Thomas, reported he would “keep his head down” in future at parties where his peers were consuming alcohol so not to draw attention to himself; this suggests he was conscious of the reactions of others. Participants were conscious about the future disruption restrictions on alcohol consumption would have on their lives; the idea of a recurrent biographical disruption during adolescence has been reported in the context of other chronic illnesses where biographical disruption was not experienced as a one-off event, but tied to past, present and future experiences (Saunders, 2017).

Other young people with liver disease reported they had experienced what could constitute as enacted stigma as a result of their limited alcohol consumption. Examples of their experiences included others publically raising their lack of alcohol consumption during social events or not inviting them to social events where drinking was deemed to be an important activity. For example, Declan reported not being able to drink was a “big time” problem and he had experienced others reacting negatively to his lack of alcohol consumption at social occasions, something also experienced by others, such as Dominic. For Dominic, like many other young people, only when they met new people did their lack of alcohol consumption become stigmatising in social settings, this is because their “old friends” (people they grew up with) knew about their liver condition and would not offer them alcohol. Whilst their former friends appeared to have made an exception to their lack of alcohol consumption, new people did perceive their lack of alcohol consumption to be undesirable. This may be because of perceptions held in society that those who do not consume alcohol are dull individuals (Herring et al., 2014). The act of publically outing those who do not consume alcohol is reminiscent of the third stage of the development of stigma as described by Abbey et al. (2011, p. 2) as *separation*, that is the “us and them effect”.

Another participant, Kaylee, reported her peers stopped inviting to her social events and from her account it was clear her peers had also created categories of drinkers and non-drinkers, reminiscent of the *separation* stage of stigma as described above (Abbey et al., 2011);

Kaylee: People would stop inviting me to house parties, they knew I had liver disease and stuff, like, “Oh I wouldn’t invite her ‘cause she doesn’t drink”. I don’t care to be honest. I love just hanging out with my friends. I don’t care that they’re drinking and I’m not but they wouldn’t invite me ‘cause they don’t want to hurt my feelings.

Whilst for Kaylee the important thing was spending time with her friends and being present at social events, her peers valued participation in drinking. Kaylee, however, was determined not to drink “to fit in”. Many participants described alcohol-based activities with their peers such as drinking in the park or at parties in people’s houses as being common ways of socialising. Being excluded was reported as “upsetting” by participants such as Leah who reported feeling “like an outcast” in her friendship group once they all began drinking alcohol in order to socialise.

Leah was amongst many young people with liver disease who reported facing stigma associated with alcohol as their friendship groups grew older and alcohol became embedded into their social activities. For some younger participants such as Freya, aged 15, and Chloe, aged 16, close friends within their social circles were not consuming alcohol so they did not experience their lack of alcohol consumption as stigmatising. Drawing on Goffman (1963), this can be explained by the abstinence of a discrepancy between the expected attributes of these young people and their actual attributes, for example, the young people’s drinking behaviour was congruent with their friends’ expectations. Whereas for other participations such as Kaylee and Leah, not drinking alcohol was perceived to be an undesirable attribute by their friends and their avoidance of alcohol was incongruent with their friends’ expectations. The experiences of Leah and Kaylee also highlight how stigma is not automatically or periodically experienced by young people; only when consuming alcohol became imbedded within their social circles did they experience stigmatisation. Thus, young people experienced themselves shifting away from their social circles and experiencing “othering”.

The accounts of young people demonstrated alcohol was an important component in the social events young people engaged in and young people who did not drink were often excluded or made to feel different by their peers through public disapprovals. One way of situating such experiences is to contextualise them within the earlier definition of stigma presented by Goffman (1963, p. 3), in which stigma was a tool to highlight the undesirability of not consuming alcohol, or what Goffman described as the ‘disgrace itself’. Taking this definition, we can unpack why liver disease may be a stigmatising condition for young people and break down the components which enable stigma to be experienced, such as the labelling of alcohol avoidance as an undesirable trait.

Participants’ experiences of alcohol can be viewed as a form of biographical disruption. For those who were not born with liver disease, sometimes biographical disruption was more evident later on in life. The disruption manifested in many ways as young people grew older and engaged in new behaviours such as drinking alcohol which would not

have impacted their lives when they were younger. In this study, eight young people who reported consuming alcohol also stated they were bothered that they were not able to drink as much alcohol as their friends. For these young people alcohol appeared to symbolise fun as well as being a sociable activity for young people. Three participants in particular reported feeling the restrictions on alcohol consumption negatively affected their social lives. Ethan reported wanting to 'live the life everyone else does' and Declan described being stigmatised by his peers. Shantaya explained prior to being diagnosed with liver disease she used to drink alcohol;

Shantaya: "well, I was drinking before I had it. Like there was a lot of parties and stuff like that, I was fourteen. And then as soon as I got it, no drinking, none at all".

She ceased attending parties after her diagnosis and recalled a noticeable change in her behaviour. Her account demonstrates how young people may have built themselves an identity within their social circle and the sudden diagnosis of an illness can disrupt that. In order to conceal her illness, she refrained from the social activities she used to take part in and felt isolated.

In order to understand why not being able to drink was a form of biographical disruption it is useful to understand the connections young people made between consuming alcohol and their identity. According to Foster, Yeung, and Quist (2014, p. 2) 'drinking identity can be described as the extent to which a person views alcohol use as a defining characteristic of their identity'. Indeed for some young people drinking was not reported as part of their identity; they drew on religious identities which prohibited alcohol consumption or aligned themselves as non-drinkers focusing on the potential detriment to their health (22 young people reported they did not drink alcohol and did not mind this). However, for many young people drinking alcohol was a common social activity for other young people their age and some felt it was part of their identity as a young person.

Ethan appeared to associate alcohol with living. He told me in the interview 'I wanna live', indicating he currently did not feel like he was 'living' compared to his friends who could consume alcohol without restrictions. He constructed two identities in his account, one of an exciting young person who can socialise and drink alcohol freely (this appeared to be his preferred identity) and another of a boring person who begins their night out with soft drinks like 'Coke' (his current identity). Alcohol consumption is used as a status symbol by Ethan to signify how sociable a person is and it is linked to personality traits; a lack of alcohol consumption deemed a person 'boring'. Previous research has highlighted some young people may misuse alcohol for social reasons and

due to peer influence (Davies, 2012). One young person, Gary, aged 15, who reported he had never tried alcohol anticipated he would drink in future on social occasions; “maybe at the weekend kind of thing, maybe with your mates if there's a football game on”. His account draws on discourses regarding the ‘masculine’ identity in relation to alcohol and football; previous research has observed alcohol as being central to the experiences of those watching football and allowing males to integrate into the football community (Ayres & Treadwell, 2011; Clayton & Harris, 2008). Given the function of alcohol in facilitating male friendships, it explains why young males with liver disease may feel ‘frustrated’, as stated by many, by the restrictions on alcohol consumption, thus experiencing biographical disruption as they grow older and are exposed to these social norms. Although, it is important to note alcohol was not solely a facilitator of male friendship as many female participants also reported alcohol playing a crucial role in their social relationships.

Earlier in this thesis I drew attention to some of the characteristics which defined adolescence as a period of transition, such as greater ‘biological and sexual maturity’ (Harris, 2015, p. 64). Research has shown contrary to beliefs that primary schools are asexual environments, male children can be affected by the need to be seen as a ‘proper boy’, which involved the establishment or an investment in ‘projecting a recognisable (and hegemonic) heterosexual identity’ (Renold, 2003, pp. 189-190). Previous research has reported connections between alcohol consumption and engagement in sexual behaviours in young people (LaBrie, Hummer, Ghaidarov, Lac, & Kenney, 2014). This was seen in the account of Dominic, who discussed how being unable to get drunk meant he could not engage in the same behaviours as his peers. This became an issue for him around the age when he began to “get interested in girls” and he talked about other young people’s behaviour.

Dominic: Get drunk and like get off with each other randomly because they were like drunk and that sort of stuff and I was always, I don’t know if I was (long pause) I could never really do that, at least not to the same extent that other people did because I felt I didn’t have an excuse to do that, if you see what I mean. Other people are like, *oh I’m drunk, I can do whatever I want* and I was just like, I’m not drunk, I can’t really validate that, which in hindsight I’m quite glad about but at the time it was a little bit frustrating.

Dominic had observed a connection between this ‘random’ physical exploration and alcohol, noting a lot of his friends “only do that sort of thing when they’re drinking so I

kind of put two and two together and said well I don't drink so maybe it's that". Dominic speculated that his inability to be "good with girls" was linked to him not consuming alcohol, although he was not sure that this was the case. This particular account can be understood in relation to what Livingston, Bay-Cheng, Hequembourg, Testa, and Downs (2013, p. 38) described as a 'depiction of the combination of alcohol and sexuality as carefree fun' within the media that young people are exposed to. Although their research focused on the views of female adolescents, the benefits of alcohol included 'facilitating social and sexual interactions and excusing unsanctioned sexual behaviour', which is similar to what Dominic described (Livingston et al., 2013, p. 38). However, the relationship with alcohol in the United Kingdom is ambivalent and the consumption of alcohol can be viewed negatively, particularly in light of a pre-existing liver condition. This will be discussed further in the next theme.

5.1.3 Good citizens do not misuse alcohol

This theme, entitled 'good citizens do not misuse alcohol', encompasses participants' views regarding excessive alcohol consumption and their decision to moderate their alcohol intake in light of their liver disease. In particular, from the interview data it was apparent that some young people felt having a liver transplant came with a responsibility to look after it, for example, Beatrice, a 14 year old, who was diagnosed as a baby stated:

Beatrice: ...I wouldn't (pause) drink every day because it would probably be bad for me to do that. And probably quite disrespectful to the doctors if you know what I mean (pause) if I was to be drinking all the time (pause) especially this early (...) I would have died if I didn't have a transplant. So I wouldn't wanna ruin this liver if the doctors have done this for me (pause) and then (pause) just for it to be thrown away, you know.

Beatrice's account is reflective of the 'good citizen' narratives, like many other participants she was conscious she had a duty to avoid 'risky behaviour' which could damage her liver, something she defined as regular alcohol consumption (Harris et al., 2010). Other examples of this include transplant recipient Nathaniel reporting he "didn't want to mess up his liver" by drinking alcohol and Shane being conscious of "damaging" his liver. However, these sentiments were not solely shared by some transplant recipients; many young people who did not have liver transplants, such as Steven, reported they did not think alcohol would be "worth the risk". These accounts demonstrate young people were managing the risks associated with alcohol

consumption, and arguably, demonstrating their agency in managing their liver disease (Uprichard, 2008).

An additional component of being a good citizen which should not be overlooked is where the expectations of being a good citizen stem from, and who decides what constitutes a good citizen. Earlier, as part of the literature review, I demonstrated how historically negative attitudes towards alcoholics exhibited during the temperance movement, deeming those who drank excessively as flawed characters (Macfarlane & Tuffin, 2010). Whilst young people with liver disease in this study did not have alcoholic liver disease, the majority were aware of the misconceptions associating their liver disease with alcohol misuse. Furthermore, many sought to actively differentiate between themselves and those who they felt had 'caused' their own plight. Growing up amongst misconceptions regarding disease aetiology in a society geared towards individual responsibility for one's health may explain why in turn, young people alluded to expectations from others not to drink alcohol in light of their liver condition (Harris et al., 2010). There were many societal expectations governing the behaviour of young people with liver disease and young people had to manage these expectations.

For some young people, other people in their lives, such as family members or friends, were viewed as monitoring their alcohol consumption. One such example is from Leah, who reported she felt her father monitored her alcohol consumption; she recalled he would often say "no more" to her after "a couple" of drinks. Leah was resentful of being monitored as a 21 year old, drawing on examples of her younger sister who did not have liver disease being able to drink as much as she wanted. This demonstrates how living with liver disease can affect young people's transition into adulthood, particularly if they have to negotiate their alcohol consumption with their parents. Leah rationalised her parents' behaviour as a form of their care towards her as they were "trying to look out" for her having witnessed her plight as a child. Similarly, Ethan reported his parents were "supervising" him when he first started drinking alcohol but as he grew older he began to learn how to manage his alcohol intake himself. Other participants, such as Fiona and Molly, reported their friends would "keep an eye" on them whilst drinking and socialising, or would verbally chide them for drinking too much, something they appreciated and viewed as their friends' concern for them. What all of these examples demonstrated is that there are wider societal expectations which dictated those with liver disease should avoid drinking excessively or drinking at all in order to preserve their livers.

One source of governance on young people's alcohol consumption behaviour appeared to stem from health professionals. Several young people cited medical advice as being

one of the main reasons they did not consume alcohol. From the earlier quote from Beatrice it is clear she felt indebted to the 'doctors' who she would be doing a disservice to by not fulfilling her role as a good transplant recipient and avoiding drinking excessively. Pinter et al. (2016, p. 1534), in their literature review, also reported that kidney transplant recipients experienced a 'moral responsibility to maintain health', to obey medical advice and that lifestyle recommendations were viewed as 'sacred' by some recipients. Sometimes, young people received ambivalent advice from different health professionals regarding alcohol consumption. Alice, aged 18, reported her nurse specialist at her children's hospital had "always" told her she could not drink alcohol, however, her new nurse specialist at adult services had informed her she could consume certain units of alcohol. Alice was insistent she would follow the advice of her former nurse specialist; elsewhere in the interview she also stated she preferred her former nurse specialist over her new one at adult services. As discussed in the previous chapter, young people can feel strong attachments to their children's hospital. For some young people, their consultants occupied important positions for them for 'saving their lives'. Another study, exploring the views of kidney transplant recipients, reported the participants also described their doctors as their 'saviours' (Kamran, 2014, p. 10). This might explain why some young people were keen to execute the behaviours expected of them.

Embedded within young people's awareness of their responsibilities to minimise or avoid alcohol consumption, transplant recipients in particular described themselves as "grateful" or "lucky" to have received a liver transplant. Similar sentiments amongst other transplant recipients have been reported elsewhere in the literature (Kamran, 2014). This was often contextualised within the risk of death without the transplant and suggested young people were aware of the donor liver shortage (Neuberger, 2016). Furthermore, young people reflected on being privileged compared to those who did not have a transplant. This further reinforced the need to look after their liver by actively avoiding risky behaviour, in this case drinking alcohol (Teghtsoonian, 2009). Kylie reported she did not want to 'tempt fate' by drinking alcohol, suggesting she was actively managing the risks of damaging her transplanted liver through alcohol avoidance. Whereas Chloe reported she would feel "ungrateful" if she ever consumed alcohol and "upset" if she ever "wasted" her liver through alcohol consumption.

The majority of young people interviewed disapproved of those who they felt were causing their own liver damage through behavioural choices such as alcohol consumption. Mia felt "frustrated" by those who "jeopardised their health for like no reason" and questioned their motives for "ruining" their "healthy livers". Similarly, Declan

quoted an example of a woman who refused to stop drinking despite medical advice, something which “irritated” him because he was born with liver disease. One participant, Kylie, felt very strongly about people she felt were “wasting” their transplanted livers through alcohol consumption stating she felt like “kicking them” because “someone else had died” so they could have that liver and they were “throwing it away”. Another young adult, Jenna, likened drinking alcohol with liver disease to smoking after a cancer diagnosis; “the best way I could explain is if I tell you, is if you’ve been told you’ve got lung cancer and then you continue to smoke. You have lung cancer, you continue to smoke - I just think it’s stupid”. This demonstrates young people’s perceptions of a notion of responsibility existing to look after one’s liver.

However, the findings also demonstrate how young people with childhood liver disease may engage in “othering” those who have had a liver transplant due to alcohol issues, which further reinforces the stigma associated with liver disease. Young people’s annoyance at those who were wasting their livers went beyond the demand for donor livers outweighing the availability; they wanted to actively differentiate themselves from those deemed to be responsible for their liver disease. This became apparent through young people’s discomfort of sharing hospital clinic space with alcoholics in adult services, something which, as explained in the previous chapter, seven participants reported they were fearful of. One 14 year old drew on ideas of responsibility by stating “she had not done anything” to cause her liver disease unlike those with drinking problems, something which was echoed in many other accounts. Young people were conscious of how others would perceive them for sharing the same space as those with drinking problems, for example, Jodie worried that when she was older people will “automatically think she drank and now she has a disease about it” and she felt “judged” by this. Whilst Jodie’s fears of stigma were felt rather than enacted, other young people had experienced direct stigma as a result of misconceptions about the causes of liver disease by the public, particularly in relation to employment, as I will discuss in the next theme.

5.1.4 Employment as another transition into stigma: understanding the connection between alcohol, liver disease and stigma

Another transition young people make in their lives is the transition into employment. In this theme I will explore the connections between alcohol, liver disease and stigma in relation to employment. This is what I would argue is another important transition in terms of living with liver disease as young people may branch out from their current, protected social circles where they may have a network of supportive friends. There are two main

ways in which living with liver disease meant young people experienced some form of stigmatisation, the first is that they felt they were not as desirable to employers because they had an illness, and the second, that the workplace became another potential space marking them as different due to their lack of alcohol consumption.

Before I delve further into this, I would like to explore the connections between stigma and discrimination. According to Thornicroft, Rose, Kassam, and Sartorius (2007, p. 192) “the term stigma refers to problems of knowledge (ignorance), attitudes (prejudice) and behaviour (discrimination)”. In relation to employment, as explained by Vickers (2008, p. 153), organisations may unknowingly demand homogeneity in employees, that they should possess *sameness* e.g. should ‘look, behave, think, feel, or do things’ in similar ways to other colleagues. When employees deviate from a norm, this can lead to provenances of stigma i.e. they are discredited and then may be subject to discriminatory behaviours (Goffman, 1963; Vickers, 2008). Statistics show that those with a disability are less likely to be employed than those without a disability (Barnes & Mercer, 2005). There have been various pieces of legislation which aimed to prevent people from being discriminated against, notably the Disability Discrimination Act 1995 and Equality Act 2010 (Griffith, 2008; O’Cinneide & Liu, 2015). Disability is what is described as a ‘protected characteristic’ on the United Kingdom’s government website which aims to deliver information to the public (Gov.uk, 2016). It further lists two ways in which discrimination can be played out; 1) ‘direct discrimination - treating someone with a protected characteristic less favourably than others’; 2) ‘indirect discrimination - putting rules or arrangements in place that apply to everyone, but that put someone with a protected characteristic at an unfair disadvantage’ (Gov.uk, 2016).

I will begin by presenting accounts from young people who felt they were experiencing stigma in relation to employment; these were young people who felt they were less likely to be employed than someone without a chronic illness. Some young people recognised and accepted that there were certain jobs they would not be able to physically do as a result of their liver disease and the impact it had on their health. For others, this was more difficult to accept. Declan is an example of a participant who felt strongly he was being stigmatised due to his health conditions.

Declan: I'd say any illness but I'd say yeah. You tick on a form you have disability and the employers going to go chuck it. And I don't. You know - like I said I have am very cynical about certain things. Certainly the Anti-discrimination Act is one, I think it is - quite frankly it's not worth the paper it's written on. You know, I've been to employment agencies,

high street employment agencies. It's started 'well you know, you've not got two years of previous paid employment so we're not going to take you on our books'.

For Declan, it was a 'them vs me' situation; he constructed employers and employment agencies as powerful and discriminatory against him, a young person with health problems. He also highlighted how he felt the legal frameworks for enforcing equality were ineffective. It is important to note, Declan had been employed for a short period of time in the past but had ended up resigning as he could not cope with the work and felt very overwhelmed. Declan identified he should have had extra support in the past to help him transition into his former role which was not available. Crucially, it was not simply having liver disease which was responsible for the experiences of stigma Declan felt; rather, it was an accumulation of consequences resulting from the liver disease e.g. poor health and an incomplete education, which have been reported within the literature to impact the employment opportunities of young people with chronic illnesses (Yeo & Sawyer, 2005). Being unemployed can be classed as a stigmatising attribute (Karren & Sherman, 2012) and Declan appeared keen in the interview to demonstrate he had tried on multiple occasions to secure employment. The discourse of 'scrounging' used to stigmatise those on benefits has been argued by charities to be stigmatising for those with a disability (Baumberg, 2016). Furthermore, previous research has reported that claiming benefits has been linked with feelings of personal shame, affecting a person's pride, which could explain Declan's dissatisfaction with his employment status (Baumberg, 2016).

For some participants, previous incidences of stigma in relation to employment opportunities impacted their anticipated future career options. For example, another young person, Lydia, wanted to become a liver nurse but reported being unable to. Lydia told me, "but they won't let me because of the liver and the problems". When I asked Lydia who told her she could not become a liver nurse, her mother challenged her account, stating; "nobody actually said you can't be a liver nurse". Lydia then referred to a past experience of applying for a job where she was told she would be rejected due to her health.

Lydia: Originally, I wanted to join the army, the job I wanted to do was be an army medic. But I was told I couldn't do that because if I was to suddenly go ill it would cause problems.

She justified her fear of being stigmatised or discriminated against by using a previous example where she was denied the opportunity to take up a certain job because of her

illness. The similarities between Declan and Lydia's accounts are that they both allude to the stigma being due to differences in their physical health compared to applicants without liver disease. This in contrast to other young people whose experiences suggested the stigma they faced from employing organisation was not so much to do with their physical health, but rather the connotations and stigma associated with liver disease.

Some young people reported experiencing the negative reactions of others upon the revelation of their diagnosis. Shane had developed an impairment during the course of his childhood, something he attributed to his medicine-taking. He recalled an incident where during an interview a potential employer questioned his lifestyle and accused him of drug abuse, blaming him for his condition. He reported being "insistent" that "drugs or other illegal substances" were not responsible for his current condition. Shane drew attention to the point that the accusations were coming from an organisation that was meant to help people with that particular impairment; this piece of information is significant as it highlights the discrimination he faced and hypocrisy of the accusation. Especially since the organisation was meant to be supporting those with that specific condition to overcome barriers to leading a 'normal' life. Shane made references to wider discourses regarding 'bad youth' where he highlighted the reputation of young people as making irresponsible choices regarding their health. Shane's comments are reminiscent of findings from previous literature which have noted the excessive drinking habits of young people, something which frustrated participants like him who did not drink (Szmigin et al., 2008). Shane presents those who choose to take drugs and drink excessively as 'foolish', thus constructing himself as a sensible person. This is an example of young people constructing 'alcoholics' and 'drug users' with liver disease as different to themselves; through this categorisation young people were rejecting a stigmatised identity.

Whilst some young people experienced or envisaged facing difficulties in securing employment as a result of their liver disease, there were other young people who had already secured employment or anticipated securing employment without such difficulties. Three young people in particular were able to use their connections to secure employment or plan their future employment. All three of these young people were either working in businesses owned by family members, or planned to work in a business where their family members were in a senior position. Having access to resources which can be utilised to one's advantage is defined as 'capital' and the premise behind the functioning of 'social capital' is founded on the membership of a group being used by the person (or agent) to achieve certain goals (Bourdieu, 1986; Potts, 2005). Drawing on

Bourdieu (1986, p. 52), we can understand how the families of these young people may have invested into hiring them to “reproduce lasting, useful relationships that can secure material or symbolic profits”. I would argue here a symbolic profit would be seeing their family member in employment, thus enjoying the economic and social rewards of employment.

To demonstrate this, I will present data from Kaylee, a young adult who reported working for her family business.

Kaylee: ...they [colleagues] understand-well they’ve kind of seen me through it, ‘cause it’s my parents’ company so when I was ill they saw how my parents were with it and they’ve seen how I’ve been ‘cause I’ve been popping into the office since I was 14 (laughs)

Working for her parents afforded Kaylee the flexibility to feel secure in her employment, work fewer hours and manage her work in relation to the “energy” she had. Kaylee reported her work colleagues were understanding and “accepting” of her liver condition. Whilst without interviewing her colleagues it would be difficult to know for sure, it may be her colleagues’ behaviours were influenced by their own relationships as employees within a family-run business. That is, they would have had a vested interest in being supportive of Kaylee given her parents were employing them; a body of literature exists addressing the factors affecting the relationship between employees and managers, including offering complements to those in superior positions in the workplace for personal rewards such as promotion (Chinoy, 1952; Sibunruang, Capezio, & Restubog, 2014). By working for family members, this enabled some participants to avoid any potential stigma from employers.

However, it is important to note not every young person has access to resources like family businesses. As seen earlier in the quotes from Declan, not every young person has the opportunity to choose their working hours and tasks around their health. One participant, Jessica, considered being self-employed as a way to overcome her health interfering with potential employment.

Jessica: I can kind of work it around me and when I’m feeling well rather than work for someone else, all these hours, or whatever. (...) It could get complicated or something with all the medical stuff and then being able to do the hours, of waking up or not feeling rough halfway through

Like Kaylee, Jessica also wanted the flexibility of being able to adapt her working hours around her health, however, Jessica did not have the same access to resources, or

social capital, as Kaylee. During the interview both Jessica and her mother discussed the difficulties she faced securing employment.

Vicky (Parent): ... and she's been honest on the forms and put her medical conditions which she never got anywhere ... So I'd be inclined to not to put it in, to be fair. They can't discriminate against you if you've got job and then you tell them. They can't certainly can't say 'we wouldn't have given it to you if you had that' because that's discrimination.

Vicky was more inclined to encourage her daughter to conceal her illness because she felt in the past her daughter had been unfairly discriminated against because of her liver disease. This was a way of reclaiming power, especially if Jessica got the job as she would then be able to use her legal rights to not be discriminated against because of her illness. As seen in the example from Shane, employers can sometimes openly discriminate against those with a chronic condition.

Another way in which liver disease enabled some young people to experience stigma in relation to employment manifested through their inability to consume alcohol with their work peers, thus, excluding them from a common networking activity. In an earlier theme, 'experiences of pressure to consume alcohol', young people discussed their perceptions of perceived pressure to consume alcohol in social situations with their peers, similarly, this also applied to the transition into employment where stigma was both perceived and enacted.

Emma: Erm I'd quite like to go into a career in musical theatre or drama and after parties for shows could be interesting if I can't drink erm, other than that I don't really think it's going to impact my life that much because it's not really within my character to drink anyway so [text omitted] Erm I don't really know. I think it's (pause) it's just after shows and stuff it's nice to completely relax and that's where alcohol comes into it.

According to Allison (2009, p. 101) 'corporate drinking augments and humanizes work relations'. Going for alcoholic beverages can play a part in securing employment promotions. Drawing on the work of Allison (2009), Ginsberg (2000, p. 263) states;

'Alcohol serves to lower inhibitions and blur hierarchical boundaries in the office. Although the drinking parties can be enjoyable at times, after-hours

socializing with the boss and office colleagues is also a requisite for promotion and success along the corporate ladder’.

Some young people living with liver disease are excluded from this activity and thus may not benefit from the ‘economic rewards’ of drinking with colleagues (Ginsberg, 2000). Emma described the after-show drinking as a ritual to relax; one she felt obliged to ‘out’ herself in as she did not want to drink. She justified her inability to consume alcohol as an intrinsic choice stemming from her ‘character’. Whereas another participant, Mia, reported being able to “comfortably turn down” alcohol at the end of long shift working at premises which sold alcohol. At her workplace, alcohol was also used as a celebratory tool; this is consistent with wider societal patterns of drinking alcohol becoming the norm. Mia reported concealing her liver disease from her employer; this is interesting as other participants also suggested withholding their liver disease diagnosis as a way of securing employment.

Another form of enacted stigma in relation to employment was experienced by Jenna who talked about her experiences of managing her work culture which centred on alcohol consumption. Jenna’s occupation required her to socialise with new clients in bars or other venues where the primary activity was to drink alcohol. She described her techniques to conceal her liver disease and restricted alcohol intake, which included managing the bar bill so she could conceal what she had ordered, and lying about drinking “gin and tonic or vodka and soda” when it was really “fizzy water”. She constructed the pressure to masquerade as consuming alcohol as deriving from the industry she worked in.

According to Schweitzer and Kerr (2000, p. 47), in many cultures, alcohol consumption ‘is considered an essential element in building business relationships, and managers across a wide range of functional areas are likely to encounter opportunities and even pressure to consume alcohol with business colleagues’.

Jenna: And just because when there’s sort of situations where it is work related and I’m talking to new people who I don’t know, I don’t want to say the whole thing and go into it and explain why I’m not drinking because it’s a big thing. You know people (long pause) I feel like (pause) at my age now and obviously the industry I’m in people drink a lot and it’s like it is kind of like the thing to do - everybody’s drinking, it’s all social, going crazy, like myself and something like that and I obviously don’t fit into all that like everybody else because I feel

guilty if I drink too much. So (pause) yeah, I try to keep it from people I don't know.

Although being employed in an industry which was focused on alcohol consumption made it difficult for Jenna to conceal her liver disease, she demonstrated her ability to control the situation, in particular who to disclose her illness to. For Jenna, her liver disease diagnosis was a 'big thing' in light of her age and the social norms regarding alcohol around her. It is interesting Jenna reports feeling guilty for consuming alcohol as this can be understood in light of the changes towards viewing health as an individual's responsibility (Harris et al., 2010). Young people are expected to take ownership of their liver disease in that they should avoid partaking in any activities that could have an adverse effect on their health. Arguably, in Jenna's case, there is the added factor of alcohol being related to her livelihood, thus, her decisions to conceal her consumption were made in the context of transitioning into adulthood.

5.1.5 Parental experiences of liver disease stigma

The current research project also interviewed parents of young people with liver disease in order to understand their experiences in relation to stigma associated with liver disease. Parents were asked about what attitudes towards liver disease they came across in society. Although parents discussed stigmatising experiences throughout the interviews across various points in their lives, it was at this stage those who had not touched upon the subject shared their views on liver disease stigma. In line with the rest of this chapter I am going to focus on examples related to alcohol consumption and drug use.

There were several themes which occurred within parental interviews, the main themes were; society assumes liver disease is self-inflicted by young people, society feels mothers caused their child's liver disease, and the pressure on young people to consume alcohol to fit in with peers. In the interviews, some parents talked about their perceptions of how society associates liver disease with alcohol misuse or drugs, both of which were viewed as stigmatising behaviours. When other people made the association with liver disease and alcohol misuse, liver disease was deemed an 'unfavourable' trait (Goffman, 1963). Some parents presented the rationale for such beliefs that liver disease was 'self-inflicted' through 'drug use or alcoholism' as stemming from a lack of public knowledge about childhood liver disease. Both Gloria and Mary discussed that 'an ordinary person' who had not been affected by liver disease would be unaware of the causes of childhood liver disease, as prior to their child's diagnosis, they

too, were unaware. Another parent, Madison, also reported prior to her son's liver disease diagnosis she too assumed liver disease was 'a drinker's illness' and her son had 'got something like alcoholics can get'. Madison's son had non-alcoholic fatty liver disease and the name of his condition was viewed by her as a useful tool to dispel any associations with alcohol.

Courtesy stigma refers to the spread of stigma from the individual with a stigmatised attribute to those closely connected to them (Goffman, 1963). As this theme will show, being a parent of a child with liver disease exposed some parents to courtesy stigma due to the stigmatising attributes associated with liver disease. This manifested in a number of different ways, for example, one of the stigmatising attributes of liver disease, accusations of alcohol misuse, was transferred to the mothers themselves. Two mothers reported incidents where they had been directly accused of drinking alcohol during pregnancy and causing their child's liver disease; this is also an example of the enacted stigma parents experienced (Scambler, 2007). By exploring their accounts and those of other parents, the accusations appeared to be situated within a wider discourse of control and the shift towards individual responsibility for one's health (Harris et al., 2010). Bell, McNaughton, and Salmon (2009, p. 164) explored how foetal exposure to alcohol embodied a 'moral panic' as this was seen to be a public health crisis and in many of the public health responses, the emphasis on 'protecting' the foetus lies with each individual mother. However, according to Armstrong (2003, p. 2013) 'this emphasis on individual responsibility may deny broader social responsibilities for health and disease'. In her book, Armstrong (2003) explores the role of the 'pregnancy police' allegedly protecting the foetus from harm caused by the mother, when in reality the pregnant women's choices are being policed. This stigma draws on wider discourses of the 'good mother' which can position mothers who smoke or drink alcohol during pregnancy as 'bad mothers'. According to Lupton (2012, p. 329), in this present time in society 'pregnant women and their foetuses are such potent focal points for regulation, monitoring and control'. The foetus has been labelled as 'precious cargo' and thus women have received, what Lupton (2012, p. 330) described as, a 'bewildering array of risk-averse behaviours to ensure the health and optimal development of their foetuses', which included avoiding the consumption of certain foods.

Gray (2002) discussed how courtesy stigma worked to produce a biography of parents of children with a disability or illness which was sensitive to the situation they were in. Exploring the accounts of the two mothers who experienced the accusations revealed they began to review their own behaviours during pregnancy, this can be understood in light of the pressures to be a 'good citizen' and assume responsibility for their own health

and the health of their unborn child (Harris et al., 2010; Lupton, 2012, p. 330). Hayley reported her mind “just kept flashing” back to when she was pregnant; both Hayley and Zoe reported they questioned whether they were risk-averse enough, e.g. did they consume the right foods or was their baby affected by their choice of oral contraception method?

In the interview Hayley told me “luckily” she did “behave herself” whilst pregnant; this is an example of the way wider societal pressures govern pregnant women’s behaviour. In contrast, Zoe disclosed she had a “couple of tipples” whilst pregnant but maintained she did not “drink like an alcoholic”. Zoe told me she was blamed by other people for her daughter’s liver disease. Over time, the health messages around alcohol consumption during pregnancy have changed from low consumption to zero tolerance (Bell et al., 2009; Lumley & Astbury, 1982). This increasing focus on abstinence during pregnancy in combination with a general lack of knowledge about the cause of childhood liver disease could explain why mothers, such as Zoe, experienced accusations. Like the young people interviewed in the study, Zoe distinguished her drinking behaviour from that of an ‘alcoholic’; young people also rejected the ‘alcoholic’ label and differentiated themselves from ‘alcoholics’ which reinforces the stigma associated with being an ‘alcoholic’ and having liver disease. Being accused of being a “drinker” whilst pregnant made the mothers feel “awful” and “guilty”. Hayley reported she was also angry as experiencing stigma was another strain she did not have the “energy” for; she felt having a child with liver disease was already “unfair”. These findings could be understood in the context of a disruption to their biography as mothers, and the roles they played as mothers or mothers-to-be (Mills, 2000). Zoe may have been attempting to repair her biography as a mother and contextualise her alcohol consumption (Felde, 2011; Kaufman, 1988).

Another form of stigma which affected parents of children with liver disease focused on their parenting; parents were accused of failing to bring up their children properly e.g. poor parenting is why their children damaged their livers by misusing alcohol. Several parents reported they/their child had directly faced stigma related to liver disease, the stigma usually insinuated that liver disease was caused by alcohol or drug misuse. One parent, Gloria, in a family interview with her daughter, jointly recalled an occasion where a member of the public had assumed childhood liver disease stemmed from alcohol misuse and had ‘laughed’ about it. Similarly, parent Cassandra, recalled an incident where her daughter had been accused by her friend’s mother of being responsible for causing her own liver disease as a result of misusing alcohol. She went on to explain that her daughter knows “if you mention liver people think, you know, you’re an

alcoholic". Following the "unpleasant" things which were said to her daughter, Cassandra stated she ensured that she mentioned her daughter had an "autoimmune" liver disease when discussing it with other people. This is another example of the ways in which parents felt liver disease was stigmatising and reinforces my earlier points on how being viewed as an 'alcoholic' was an unfavourable trait.

One reason why liver-related stigma existed was put forward by Mary who described 'bad publicity'; this referred to her own experiences of coming across media reports linking alcoholism and liver disease. This was similar to the young people's experiences of feeling stigma existed despite never having encountered it personally (an example of felt stigma). Similarly, Eileen acknowledged liver disease was associated with alcohol by other people although she had 'never experienced it first-hand'. Bianca talked about the media putting across the message that liver disease was caused by alcohol misuse either through maternal consumption during pregnancy or by young people with liver disease themselves. When I asked Bianca if anyone had insinuated these things to her about herself (drinking in pregnancy) and her child (misusing alcohol) she reported she personally did not feel people think this is what happened to her son. What these parents' accounts reinforce is that stigma is not always enacted and draws attention to how parents' interactions with the society they live in, either through the media they are exposed to or conversations with others, shape their experiences of felt stigma.

Parents' accounts also acknowledged that their children were facing pressure to drink alcohol or anticipated as their child made the transition into adulthood they would face pressure consume alcohol. Martine, who reported her son consumed alcohol, described alcohol as a "social sort of thing" which was reflective of previous research which reported that alcohol was viewed as part of social life in the United Kingdom (Heath, 1995). This was in contrast to other parents who emphasised despite their worries about peer pressure, they believed their child would never consume alcohol. One such example is Eileen, who told me;

Eileen: "She's [daughter] never (pause) touched alcohol and I don't think she really will. I think she knows that er (pause) her liver is very precious and she can't hurt it in any way, can she? She's a very, very sensible girl".

Eileen's account reinforces wider views on alcohol consumption being viewed as a reckless activity for those with a transplant. Other parents acknowledged once their children were old enough they would make their own decisions around alcohol

consumption and some parents felt uncomfortable with the reality their children's decisions may not be the same as theirs.

Erin recalled an occasion where hospital staff had been unsympathetic in her eyes when her daughter had ended up in hospital unconscious due to excessive alcohol consumption. Erin talked about a doctor saying "I hope you're proud of yourself. You let your daughter drink so much she got cirrhosis". This is an example of where parents were held responsible for their child's alleged actions and experienced courtesy stigma. Erin initially reported her daughter's university friends had "spiked" her drink but later on attributed her daughter's drinking behaviour to peer pressure and wanting to "fit in" with her peers; something she felt healthcare professionals should be more understanding of. I felt this was interesting as it showed Erin's own issues with her daughter's drinking behaviour; she later told me "I was angry that she done it but (pause) well, she's gonna make mistakes". Erin had experienced what would be classed as enacted stigma in relation to her daughter's drinking behaviour. Therefore, it was likely Erin did not want me to form a negative opinion of her daughter which would explain the shift in narrative. The message Erin and many other parents of children with liver disease were trying to convey is that the scrutiny of their children's drinking behaviour was unfair given that in other circumstances, drinking is viewed as a normal part of growing up and is embedded into the social fabric of the society in which their children are growing up in.

5.2 Summary

In this chapter I set out to explore young peoples' experiences of living with liver disease in the context of a society which exuded ambivalent attitudes towards alcohol consumption through the lens of stigma (Goffman, 1963). Many misconceptions about the cause of liver disease were reported ranging from alcohol and drug misuse, to mothers being accused of harming their child in utero through "bad behaviour"; in both cases the blame for having liver disease was attributed to certain individuals. This fed into wider sentiments in society which advocated individuals should take responsibility for their own health (Harris et al., 2010). My reason to focus on alcohol stemmed from participants' reports of liver disease being routinely associated with alcohol misuse. On one hand, misconceptions regarding the cause of liver disease existed and on the other hand, society exhibited ambivalent attitudes towards alcohol, advocating the consumption in order to facilitate social cohesion. This created an unfair situation for young people who were being advised by health professionals and their parents not to consume alcohol, who were aware of the shortage of donor livers but also faced pressures within their social group to not stand out.

However, not all the participants were affected by the ambivalent attitudes towards liver disease in society. In the theme titled “*South-Asian participants and non-drinking culture*” I demonstrated how South Asian, Muslim participants, who abstained from alcohol for religious reasons, did not report their lack of consumption of alcohol as a stigmatising. Furthermore, none of the participants associated their liver disease with alcoholism, with only one participant acknowledging other people at the adult clinic may have liver disease because of alcohol misuse. To date there has not been any research with South Asian, Muslim young people with liver disease specifically exploring their experiences of alcohol and this theme has shown how their experiences around stigma associated with alcohol consumption can differ to non-Muslim young people with liver disease. It is important to take the cultural and religious experiences and upbringing of young people into account.

In the theme “*experiences of pressure to consume alcohol*” I discussed the role alcohol consumption in relation to young people’s experiences of stigma. The stigmatisation of not consuming alcohol was either felt or enacted. Whilst some young people feared being singled out for their lack of consumption in social situations as they got older, others reported being ostracised within friendship groups for not consuming alcohol. I also discussed the impact of drinking identities on young people’s experiences of growing up.

In the theme “*good citizens do not misuse alcohol*” I demonstrated how the individual responsibility for one’s health manifested through young people’s self-monitoring of alcohol consumption and their experiences of being monitored by others. Young people discussed the pressures on them to regulate their alcohol consumption, especially if they had a liver transplant, a rare commodity given the extensive waiting lists and shortage of donor livers. I further presented data from young people which reinforced their disapproval of those who were seen to be causing their own liver disease. This theme untangled the frustrations of young people who were often at the centre of societal misconceptions about a condition they had no control over. As a response, young people formulated different categories, separating themselves from those who they felt caused their own liver disease, e.g. through alcohol misuse. Through this response, it was reinforced by participants that there are negative attributes associated with alcoholic liver disease.

In the theme “*Employment As Another Transition Into Stigma: Understanding The Connection Between Alcohol, Liver Disease And Stigma*” I presented the different experiences of young people in relation to their attempts to gain employment or their

actual employment. For some young people, it was having a health condition or disability which led to them feeling they would be undesirable candidates in comparison to people without one. These young people reflected more broadly on the impact of a chronic illness on their employment prospects. One way of buffering the negative effects of being stigmatised was young people's access to social capital and being able to secure employment through their families. I highlighted how this was not a realistic option for many participants and how some participants sought to conceal their illnesses from employers. The second part of this theme was dedicated to the role of alcohol in the workplace and I drew on examples of young people concealing their lack of alcohol consumption in order to manage in environments where alcohol was ubiquitous.

The final theme titled "*parental experiences of liver disease stigma*" reported on the parental perspective of liver disease related stigma. Parents echoed young people's accounts of the misconceptions surrounding the cause of liver disease, shared their fears of their child being pressured to consume alcohol and mothers discussed their experiences of being held responsible for their child's liver disease as a result of their behaviour whilst pregnant.

Referring back to the explanation of stigma presented by Abbey et al. (2011) we can understand young people's experiences in light of how stigma is carried out; young people with liver disease are labelled as different to candidates applying for the same job without liver disease; connections are made between having liver disease and being an undesirable candidate; employers distinguish between 'healthy' and non-healthy applicants; young people may feel an emotional reaction to this rejection or anticipated rejection; the stigmatisation takes place in the form of young people with liver disease being rejected for jobs or they may feel unsupported in a role suggesting structural inequalities exist; and finally, young people may feel that employers are in a powerful position compared to them.

In this chapter I have shown how the stigma young people with liver disease may face in relation to employment can be both felt and enacted. This is something which has not been documented within the literature before due to the scant research in this area. Following on from the research of Wise (2002), which suggested young people wanted to fit in with their peers, I anticipated young people would face peer pressure to consume alcohol during their school years; it was interesting that the data showed some young people face similar pressures in the workplace. Combined with participant reports of societal misconceptions about liver disease, the transition to employment is an area where young people may need further support, especially if they feel like their liver

disease diagnosis could be a reason for their rejection from employment. The rejection would appear plausible given the negative attributes associated with alcoholic liver disease. Employment is not only important for financial reasons but also for social benefits such as friendship; research has shown people identify their friends as colleagues and former colleagues (Methot, Lepine, Podsakoff, & Christian, 2016; Pedersen & Lewis, 2012). For young people who are isolated, having friends at work could be a way to begin new friendships, something one participant highlighted as being a disadvantage of struggling to find employment.

To conclude, there are multiple ways in which liver disease can affect the lives of young people. For some young people, liver disease not only impacts their health but the stigma associated with the condition affects their school life, relationships, and their employment opportunities. Young people face various challenges whilst growing up including negotiating the desire to fit in with their peers either at school or in the work place, whilst having a condition that is accompanied by accusations of having a bad, moral character. Thus, having liver disease left some participants vulnerable to the misjudging of others. In the next chapter, I will expand further on how the role of stigma can impact on young people's identity.

6 Feeling and being visibly different

March 2014. I have a telephone interview to do with a participant I had met a few weeks earlier at the hospital. When I first met him I noticed his physical appearance; he had many of the visible signs of liver disease I had read about in journal articles and textbooks. However, during the interview he does not mention any of the visible signs associated with his liver disease. In the interview he talks about not usually telling other people about his liver disease. I asked him about the reactions he received from others when he did disclose his illness and he told me people are usually shocked because he looked 'alright' and they do not believe he has liver disease. He said he felt bad inside that people accused him of making his liver disease up and he felt 'different' because he expected people to believe him. This particular participant stood out to me because he was the only one who did not talk about his physical appearance when I expected him to. The majority of young people I interviewed did not have any visible markers of their liver disease. I did not probe physical markers of liver disease in the interview; if he did not discuss his appearance or feel he was visibly different to other teenagers, then why should I?

I thought about other interviews which had taken place, including a face to face interview with a young adult. She talked about a "very noticeable" side effect of her medication causing her to lose eyelashes and eyebrows. "Really? I hadn't noticed", I told her. I was surprised as to me it was not obvious she was missing facial hair, even when I was sat opposite her, yet she was very self-conscious about it. She told me it was the worst thing about having liver disease. Some physical manifestations associated with liver disease were more noticeable than others to 'outsiders' like myself. Yet, through the interviews I witnessed the most important thing was how these young people felt about these physical manifestations, and that would classify whether or not they were indeed visible differences, not what I could observe.

Not all young people did have physical manifestations of their liver disease but they experienced many difficulties which were not visible to the naked eye including pain, fatigue, sickness, and difficulties which affected them emotionally and socially. It is important to note often we only see a snapshot of a participant's life. In the earlier reflection I talked about how what I and the nurse observed about a young adult and her mother was different to what she experienced. Whilst we were all there in that physical space, each of us interpreted the events differently. In the first reflection I talked about my own difficulty in coming to terms with the difficulties the participant I interviewed had endured on a daily basis. I was not prepared for that. Things change; while many of his visible differences were no longer there, he still felt so different compared to people without liver disease.

6.1 Chapter Introduction

In the previous chapter I focused on young people's experiences of stigma around alcohol, as their alcohol consumption was one element of their life as a young person with liver disease that marked them as different. This was particularly pertinent given the society in which these young people were growing up in which had ambivalent attitudes towards alcohol; drinking alcohol was a "normal" activity to integrate with peers but alcoholic liver disease was a stigmatised condition. In this chapter, I will focus more on visible and invisible differences associated with growing up with liver disease, and how the stigma associated with these differences has an impact on young people's identities across various life transitions. Young people are exposed to sociocultural beauty standards which dictate how they should look and transplant scars can be viewed as a blemish (Goffman, 1963). However, whilst it is perhaps plausible to understand the transplant scar as being stigmatised in that context, it is important to acknowledge the complexity of the ways and contexts in which the transplant scar is stigmatised.

The first section of this chapter will explore experiences of the liver transplant scar. In this section I briefly address the problems associated with invisible differences, drawing on assumptions that disabilities are confined to wheelchair use. I then explore the functions of the transplant scar as evidence of liver disease for young people who were struggling to gain legitimacy for their experience of their illness. This section also demonstrates the differing reactions from others towards the transplant scar following the transition from primary to secondary school. Drawing on the concept of stigma, I demonstrate how experiences of felt and enacted stigma had an impact on young people's perceptions of future relationships. Within the context of adolescence as a period of transition, young people with transplant scars were affected by gendered expectations related to body image, clothing, behaviours and identity.

The second section of this chapter will focus on experiences of biographical disruption. I demonstrate how young people can experience biographical disruption in similar ways to adults (Bury, 1982). This section addresses how living with liver disease affects young people's transition into adulthood, particularly the pace in which they feel they are growing up, with the hospital environment being reported as a catalyst to maturity. The impact of growing up with liver disease and managing the condition is discussed in the context of the loss of the adolescent identity, which becomes a marker of difference for young people. Finally, I discuss parental experiences, both in light of witnessing their child's biographical disruption, to experiencing a form of vicarious biographical disruption themselves following the impact of their child's diagnosis on their own lives.

6.2 Transplant scars and visible markers of difference

At the start of this chapter I reflected on some of the interviews where visible and invisible markers of difference were discussed, or I anticipated they would be discussed, but they were not raised by participants. As I explained earlier on in the thesis, liver disease itself and the treatment side effects can lead to visible differences in those diagnosed. Taylor et al. (2009) reported the frequency of symptoms young people with liver disease experienced did not necessarily determine how distressing they perceived them to be; an infrequent symptom can be viewed as more distressing. What this suggests is young people can place a different value on certain aspects of their condition, for example, as the reflection demonstrated, for one female participant it was the loss of facial hair she deemed to be the worst aspect of having liver disease. This could be understood in light of sociocultural beauty standards which dictate how people should look, which can have more of an impact during adolescence (Mieziene et al., 2014). Wise (2002) reported the importance of paediatric liver transplant recipients being able to fit in with their peers and visible differences can prevent this from happening. Atkin and Ahmad (2001) emphasised when trying to understand young people's experiences of chronic illness it is important to situate those experiences within the wider context of growing up; at some stages in their lives, differences may have more of an impact. It is further important to recognise how young people's perceptions about their liver disease can impact on their identity; as I mentioned in the reflection, for some participants, feelings of difference can remain even after their visible differences are no longer there.

Some of the misconceptions surrounding chronic illnesses and disability are linked with visible differences, for example, wheelchair use is stereotypically associated with disability. According to Goldman and Lewis (2008, p. 20), 'it took the Disability Discrimination Act 1995 to bring the concept of disability out of the wheelchair'. However, some young people highlighted the complexity of having a chronic illness without stereotypical, visible markers.

Mia: You know like disabled is – if you got an ongoing life-threatening illness. And it's like what I have. But I don't like (pause) like, I'll never, ever tell people that I'm disabled. It's like I'm, I don't know, it just doesn't fit there because I look like kinda healthy, I suppose. So I don't (pause) I don't (pause) I wouldn't want anyone to call me disabled. [Text omitted]. It just feels like I'm insulting people who are like in wheelchairs and stuff. Because they obviously are disabled. I just feel like (pause) I don't know, like I'm not. I can walk fine. I can do like baseball and stuff.

Mia's educational institution recognised her liver disease as a disability, however, she did not see herself as a 'disabled person' despite acknowledging the nature of her illness was compatible with the definition they used. Being labelled as disabled has stigmatising connotations and previous research has shown those classed as disabled may reject the label, focusing on the ways they are similar to those who do not have a disability (Watson, 2002). The use of young people's comparison of their own condition to others has been documented within the literature, for example, Monaghan and Gabe (2015) reported participants in their study compared themselves to those who they felt were worse off. This was understood as contributing towards the portrayal of the condition as minimally disruptive on their lives (Monaghan & Gabe, 2015). Mia further mentioned she did not look unwell, hence her hesitation to accept the disability label, which also emphasises the importance of visible markers in claiming legitimacy. For liver transplant recipients, the liver disease scar is a visible marker of their condition.

6.2.1 Experiences of the transplant scar at school

Fifteen interviews talked about transplant scars; transplant scars marked some young people with liver disease as visibly different from their peers at school. However, the impact of the scar varied across the participants. Whilst Mia did not have a transplant scar, the idea of the transplant scar serving the purpose of "proof" of liver disease was brought up in a joint interview with Chloe and her mother, Zoe.

Zoe: The icing on the cake for me were when I had had enough, one day, her teacher didn't believe you - that she'd had a transplant-

Chloe: I know

Zoe: She said to her she's a liar to her face

Chloe: I showed her my stomach [laughing] it was quite funny actually seeing the look on her

Zoe: She showed her her stomach and her scar and left her speechless but there was quite a few episodes like that.

In this situation the scar legitimised Chloe's illness as it was a visible indication of her disease. Interestingly, in a study by Ware (1992), participants with chronic fatigue syndrome which is deemed to be an invisible illnesses, drew comparisons with those in wheelchairs receiving legitimacy of their illness. This stresses how a lack of visible markers of an illness can also result in stigmatisation as other people may accuse those without visible markers of fabricating their condition. Interestingly, in Chloe's case, it

was a school teacher who did not believe she had a liver transplant; Mayall (1998) discussed how within the school environment children were denied legitimacy in their illness status until an adult, such as a teacher or a parent, approved. This is indicative of the adult-child power imbalance (Kitzinger, 1997). Physical markers when trying to claim legitimacy for an illness can serve as evidence for other people around the young person, as even very young children pair physical representations, such as wheelchairs, with illness (Diamond & Kensinger, 2002).

Transplant scars were a physical reminder that young people were different compared to their peers and that they had a chronic illness. Participants reported a range of reactions from others to their scar from shock, disgust, to curiosity. Nathaniel and Dylan both described other people's reactions beginning with the word 'woah' to really emphasise the shocked reactions.

Nathaniel: You know people might make jokes about it and stuff so whereas secondary they were just like "Woah, where's that scar from?"

Dylan: Erm (pause) it would be the first swimming lesson, everyone was sort of like "woah, what's that?"

Most young people talked about physical education classes being the first place where others saw their scar. This is because children get dressed in one open space rather than separate cubicles, and it can be a situation where young people realise that they look different. As these classes were compulsory, there was very little young people could do to manage the situation, although, a few participants reported turning to face the wall or going to a corner to get changed. This demonstrates young people's attempts to exercise agency within an everyday situation, although, they inherently lacked the power to avoid being in the situation in the first place (Alanen, 2001, p. 21).

An interesting observation within some young people's accounts indicated that the stigma related to transplant scars changed over time; that is, it was context dependant and the stigma young people felt either increased or decreased depending on certain life transitions. One such example is where participants reported the stigma attached to transplant scars varied depending on whether they were in primary or secondary school. Examples of participants who reported this included; Beatrice, Nathan and Kylie, who stated in secondary school people were more inquisitive about their scars. Nathaniel talked about his reluctance to let people see his scar, especially in primary school, which he described as being 'immature' as opposed to secondary school. Nathaniel explained

when he got to secondary, his peers' reactions were more of shock and curiosity rather than ridicule by default.

Nathaniel: Whereas primary school “aha, you got a big scar!” and stuff

By describing instances of teasing/bullying from other children as 'immature' Nathaniel was able to contextualise the bullying as being located as a product of younger children's lack of awareness. Although, this does demonstrate how the transplant scar can be a stigmatising attribute for young people with liver transplants.

A similar experience was reported by Beatrice who reported she noticed a shift in the change of attitudes from her classmates when she got to secondary school. Beatrice talked about her scar initially prompting negative reactions in her primary school class amongst peers; “some of them were a bit like urgh”, however, stated afterwards people were like “oh okay” and “accepted it”. Beatrice noted her secondary school class peers were more concerned about how she got her scar.

Beatrice: “they were like ‘oh my God, what happened?’ Like (pause) more concerned ‘cause (pause) as you’re older (pause) you’re more aware of operations (pause) so that was erm I just told them and they were like okay.

When probed about how she felt about her classmates' reactions to her scar, Beatrice told me she was “used to it” and “wasn't sad or anything”. She told me she was “quite happy to carry on” and there was “nothing to be ashamed of”. Eileen (Beatrice's mother) confirmed her account that initially other children did question her daughter on her scar in primary school but there were less adverse reactions to her daughter's scar in secondary school.

Eileen: she doesn't like it particularly but she's doing really, really well. Nobody says anything about her scar at secondary school (pause) and erm (pause) people just accept, don't they?

Eileen described her daughter starting school as “another step in life” that her daughter “has got on with”.

Whilst the majority of young people who had a liver transplant who talked about their scars had undergone transplantation whilst still in primary school, one young person had been in secondary school when she had her transplant. Lydia was a sixteen year old

who had her liver transplant aged thirteen. Lydia did not have a transplant scar when she started secondary school, which may explain why her experience differed to those participants who started secondary school with a transplant scar present. She reported being bullied about her scar, which she stated affected her 'psychologically' and impacted on her desire to disclose her illness to other people.

Lydia: Um, it made me feel quite down, I didn't really want to get out of bed. Just lay there all day. I didn't want to get out of bed, I wouldn't wanna move, I wouldn't wanna interact with anyone. [Text omitted]. When I was younger, before the transplant I never really had a problem with it [telling others about liver disease] so it was once the bullying started I would shy away from talking about it or get embarrassed.

Bullying from peers can be seen as an example of young people experiencing enacted stigma as a result of their transplant scar (Scambler, 2007).

Lydia and her mother, Audrey, gave a joint interview. Audrey discussed how the stigma towards her scar was exacerbated by Lydia's time off school.

Audrey: it was the scar and the amount of time she had to have off, saying she was faking it and she was putting it on 'cause she didn't want to be there.

This is important because it highlights the wider impact of the transplant and how factors such as being away from school contributed towards the stigma development. Previous research has demonstrated that spending time away from school can affect young people's quality of life, particularly as they are away from their friends and can feel isolated when they return to school (Winger, Ekstedt, Wyller, & Helseth, 2014).

6.2.2 Becoming adult with embodied insecurities

Another way in which young people's experiences of stigma related to their transplant scar changed was in relation to future intimate relationships. Some participants were fearful of how other people would react to their scar, indicating they were experiencing felt stigma. Kylie told me in the interview she was not bullied vocally by other children at school about her scar, however, the quote below shows she recognised her scar could be seen as stigmatising.

Kylie: I would like to [be in a relationship] but again I am, I don't know if afraid is the right word. (Long pause) Self-conscious maybe a bit

more accurate. Obviously with scars, you know everyone's (long pause) a lot of people see scars and they're like *yuck, no*. I'm more afraid if they see the scars because they'll eventually run away. So on the other hand, I'd rather stay single and not risk being hurt like that. Depending on how it's received, it can make you feel really ugly about yourself.

Kylie had never been in a relationship, telling me she has been "single since the day I was born". Like another participant, Fiona, Kylie was concerned about how future partners would react to her scar. Both participants reported felt stigma attached to their scar and the scar appeared to be disrupting their anticipated future lives as partners (Saunders, 2017; Scambler, 2007). Fiona told me in the interview she had never shown her scar to any of her previous boyfriends, although, she was confident her last boyfriend would not have "gone off" her because of it. These experiences can be understood in light of previous research I discussed earlier, which reported the influences of wider sociocultural beauty standards which have been linked to body dissatisfaction in young females (Clark & Tiggemann, 2006; Clay et al., 2005; Mieziene et al., 2014). Young people may face pressure to look perfect and have perfect bodies', this is something the transplant scar can potentially compromise.

One parent suggested the transplant scar could be viewed as a positive asset; Eileen used humour by making a joke about the scar being a good icebreaker for her daughter's future relationships.

Eileen: Basically I just said it's a small price to pay to have a scar on your tummy, and now she isn't, it's a small price to pay isn't she never mentions it at all (pause) well its one way of getting a boyfriend isn't it, you can say do you want to look at my scar? (laughing) (long pause) she never mentions it, I mean we bought some bio oil once and someone said if you rub it in (pause) it can save the scar (pause) but she never bothered doing it.

Eileen concluded her daughter cannot be bothered by her scar as she has not taken any steps to reduce the visible appearance of the scar which reinforces her view that the scar was insignificant.

For some participants, in the interviews there was an emphasis on minimising the appearance of the scar or concealing the scar through clothing. One participant reported having surgery to minimise the appearance of her scar, throughout the interview she

talked about her scar, stating her scar bothered her more than the liver disease itself. Adolescence has been described as a time of vulnerability for adolescents as they make their transition into romantic and sexual contexts, particularly as they can be sensitive to peer norms (Emmerink, Vanwesenbeeck, van den Eijnden, & ter Bogt, 2016). Rahimi and Liston (2009) reported dressing fashionably was a way for adolescents to reduce feelings of isolation and current fashion trends included midriff exposure. Within the literature, it has been reported young girls have exhibited a preference for 'sexualised' clothing, such as cropped tops, indicating the internalisation of the sexualised messages they are exposed to through various platforms (Slater & Tiggemann, 2016). Several female participants reported they felt unable to wear the clothes wanted to, notably swimwear or tops which would reveal the transplant scar/midriff area, as they were concerned about other people's reactions. This suggested they felt the scar was stigmatising.

One parent, Zoe, described herself as "quite aware of how much importance" her daughter's multiple scars were having on her whilst she grew up. Her daughter, Chloe, confirmed this; Chloe told me she tried to conceal her scars initially through her clothing and her main concern was not receiving any additional scars in future following medical procedures.

Chloe: When I was in counseling, I found out that I was being a little insecure of my body, and eventually, so I wore a bikini, which was quite massive ... I feel a little more comfortable with my body 'cause I feel like 'if you don't like it, so what?' It's not harming you.

Chloe told me she felt her scars prevented her from 'looking good' and restricted her clothing choices. For Chloe, receiving counselling was useful to manage her feelings about her scar. Not all female participants felt self-conscious about their transplant scar in certain clothing. For example, Beatrice said "it's just something I've got and it saved my life really" and that her scar was "just there but I really don't mind".

It is important to note that some male participants also talked about trying to conceal their scars. One issue with the transplant scar was it restricted young people's abilities to hide their illness from their peers. For example, Dylan explained he did not "just go telling everybody" about his liver disease, although all of his classmates had seen his scar from swimming lessons. He emphasised that although the scar was visible, it did not necessarily mean he was going to have to disclose his transplant status. Dylan was relieved his liver disease was predominantly invisible.

Dylan: Um (long pause) pretty glad actually, 'cause it was always there and you couldn't pick out and say what's that, what's wrong with you, so I suppose from that aspect - say you had like a really visible (pause) formation on you, it's like "woah, what's that?" but with mine it's just a scar. Unless I lift my top up it's not visible for people to see. So I suppose in that way it's alright. You don't just see it every day and get somebody come up to you.

From Dylan's account, it seemed unlikely that he would be frequently quizzed about his scar but having a visible scar did make him vulnerable to questioning from others. He also compared his concealable scar to a 'visible formation' suggesting there are other visible markers of illness which would perhaps be more stigmatising. Dylan did not feel exclusively singled out because of his scar and trivialises the impact it has on his life.

6.2.3 Reclaiming the scar and managing stigma: shark bites

Occasionally, transplant scars were referred to as 'shark bites' by participants. A recent study looking at young, liver transplant recipients reported participants referring to a shark story as a way to avoid telling people about the liver transplant and to shock them (Wright, Elwell, McDonagh, Kelly, & Wray, 2015a). Whilst there is very little research looking at young people's experiences of liver transplants and their feelings towards their scar, quantitative research focusing on scars reported young burn survivors reported positive feelings about their appearance and evaluated others would perceive their appearance positively compared to non-injured controls (Pope, Solomons, Done, Cohn, & Possamai, 2007). Whilst it is important to note visible scars do not always result in body dissatisfaction, a case study of a patient with facial disfigurement following an accident in childhood, reported the patient was teased and given an undesirable nickname; this particular person withdrew from social situations and became very shy during interaction with their peers as they grew up (Bolton, Lobben, & Stern, 2010).

Dominic, Dylan, Ethan, Nathaniel and Shane all made 'shark bite' references when talking about their scar. Interestingly, all of these participants were male. However, it is important to stress that not all male participants who had had a liver transplant mentioned the scar or used the 'shark bites' analogy, examples of such participants include; Imran, who had his transplant during early childhood, and Simon, who had been transplanted two years prior to the interview aged 12. Those participants who made references to 'shark bites' sometimes used the 'shark bite' analogy as a way of managing other people's reactions to their scar.

Dominic initially talked about his scar being an indication for him that he had liver disease. He subsequently mentions other children are 'gullible' for believing his shark bite story.

Dominic: probably towards the end of primary school in year five or six, I don't know because I still have a scar on my stomach so I knew about that, I knew I had had an operation before that and I knew my parents were always very open about the fact that I might need a transplant at some point in the future. But it was never really (text omitted) so I knew kind of that much but that was about it really (text omitted) I quite liked it [the scar]; I wasn't that self-conscious about it to be honest. Mmm. I used to quite enjoy telling people that like I had been attacked by a shark or whatever, something.

Dominic presented his scar as relatively inconspicuous stating it is not something he is 'self-conscious' about.

Nathaniel described the shark bite story as deriving from his concerns about other people's reactions. This suggests there was an element of felt stigma attached to the transplant scar (Scambler, 2007).

Nathaniel: Just worried about what people's reactions would be but they didn't mind it even, you know, that's where I got the shark thing from (laughs)

Nathaniel used the 'shark bite' analogy as a humorous way to manage the interest people showed in his scar.

Nathaniel: When they ask me "Oh what's that scar from?" I just I make up some sort of joke like "Oh I got bit by a shark" ... So I've always said to them when I was little and then my teacher would always call me shark bait like when I got to secondary school.

Dylan also referred to his transplant scar as an indication that he had liver disease and he recalled asking his parents about it when he was younger.

Dylan: I remember, the rest of the kids used to ask about it (pause) never never bothered me them asking about it, I always used to say it's a shark bite... [laughs] Then they found out, never really bothered about it, just gave them the answer they wanted to

Dylan did not immediately refer to his scar as a 'shark bite' when he was discussing it during the interview, he first described it as an 'upside down grin'. Dylan was able to recognise the 'shark bite' story had certain social rewards, such as people being interested in him; once he told the truth about the scar, he reported the interest waned.

The use of humour could be seen as a way of participants regaining control of a visible part of their condition. Both Dominic and Nathaniel constructed themselves as enjoying their opportunity to describe their scar as a shark bite. By doing so they constructed themselves in a positive way, emphasising information which is positive about them such as their ability to be 'funny' or make 'jokes'. Previous research by Wanzer, Booth-Butterfield, and Booth-Butterfield (1996) indicated people who were seen to be humorous were also seen to be more socially attractive. According to Kehily and Nayak (1997, p. 83), 'humour creates and consolidates heterosexual hierarchies in male peer groups through: regulation of self and others, enhancing reputations, disparaging reputations, demarcating those who belong from those who do not'. This suggests a potential relationship between humour and power in the context of establishing heterosexual masculinities. Whilst this research did not explore heterosexual masculinities directly, participants did occasionally contextualise behaviours by drawing on their perceptions of normative masculine behaviours. An example of this would be Nathaniel's reference to his fear of being unable to defend his friends in a fight because of the potential consequences for him following his transplant and liver biopsies.

Nathaniel talked about an incident where his friends defended him in a fight at school and he expressed his friends would not expect him to get involved in a physical altercation, indicating they were mindful of his condition. However, Nathaniel still expressed his difficulty in accepting he could not repay the loyalty.

Nathaniel: And if my mate, if my mates cause trouble and that and I'm with them. It's a bit hard to like, it's like I wouldn't know what to do if someone was to start on my mates or whatever cos your first - my first reaction if someone was to start on my mates for no reason or whatever, then it's like when I'm with them like they're my mates so I can't let them, just stand there and let get beat up or whatever. So I think I would try and join in but I know it wouldn't work if there was a lot of them they'd be - it wouldn't work out cos like I'd probably end up in hospital but I don't know. It's hard, it's a hard situation (pause) I wouldn't know what to do.

Arguably, this extract shows the 'masculine' thing to do would be to defend friends in a fight, which is not possible for Nathaniel due to his liver condition. Whilst the transplant would be seen as a negative attribute in such situations, Nathaniel is able to regulate his image through his use of the shark bite analogy.

Data suggests at least for one participant, the shark bite analogy went beyond the physical similarity of a shark's mouth to the actual scar; to have been bitten by a shark would portray the transplanted person as a survivor. This is because 'shark attacks are rare but are associated with a high morbidity and significant mortality' (Caldicott, Mahajani, & Kuhn, 2001, p. 445). Previous research which discussed men's experiences of mastectomy scars found 'some men asserted the mastectomy scar as a masculine feature' (Butterworth & Sparkes, 2014, p. 12). Examples of how this was achieved included referring to the scar as a war wound (Butterworth & Sparkes, 2014) or a battle scar (France et al., 2000). Interestingly, one study found a male cancer survivor's children referred to his scar as a shark bite which made him look 'hard' (Iredale, Brain, Williams, France, & Gray, 2006, p. 337). Although breast cancer in males is very different to liver disease due to lay beliefs which label breast cancer as a women's condition, which may explain the need to assert the scar as a masculine feature, there are some similarities with regards to how surgery scars are talked about by male participants (France et al., 2000). Discourse around shark bites and surgical scars seems to suggest the analogy goes beyond a mere physical representation of the scar but can be seen as a way of asserting oneself as a 'survivor' rather than a victim of a health condition.

Shane talked positively about his transplant scar and emphasised the longevity of the scar in relation to the rest of his life.

Shane: Um. Um. I mean I think my scar does mean quite a lot to me actually. I mean, I think it shows what I've been through. Um. (pause). I'm quite fond of it actually. Um. (pause) Yeah. Um I still have it, I think it's going to be something I'm going to have for the rest of my life. I'm not taking that as a negative thing but um, you know, it's going to be with me forever.

Sabo and Thibeault (2012) discussed the embodiment of scars in female breast cancer survivors and found scars can be seen to symbolise strength and courage. Their paper explored ways in which the participants re-authored their life story following a key turning point such as the initial loss of breasts and found people may 're-examine the meaning of self and embodied self through a lens colored by social norms associated with body image' (Sabo & Thibeault, 2012, p. 209). Rather than seeing his transplant scar as a

cosmetic flaw, Shane's account presented his scar as a physical representation of his difficult journey with childhood liver disease and what he had 'been through'; the scar was something to be proud of.

Kylie: Erm (long pause) I'm in two minds [about the scar]. (Text omitted). When people look at me I feel self-conscious but also proud, getting through it all

Similarly, Kylie also recognised her scar was something to be proud of as it represented her survival of liver disease. Although she also reported as a child she experienced "stares" from other children when they saw her scar, her account shows how young people's feelings about their scar can be mixed.

6.3 Medical environments and growing up

I will now focus on the changes young people reported following their liver disease diagnosis using the lens of biographical disruption to make sense of their experiences (Bury, 1982). Some participants reported they struggled to come to terms with their liver disease. Lyndsay, a 17 year old diagnosed aged five, reported she began to question her illness aged nine and experienced 'anger issues' whilst growing up.

Lindsay: ...the questions I was asking when I was nine was just like what it was. I think, you know ... know, yeah, I didn't really get it. Like I didn't get why I had it and like what is involved and like it deeply upsets me.

Several other young people reported their diagnosis was life-changing and reported questioning why they were diagnosed with liver disease. These accounts highlight the struggles young people without congenital liver disease face which resemble adult literature on biographical disruption and chronic illness (Bury, 1982). One of the changes which occurred for those diagnosed later on in childhood was the assimilation of hospital visits into their lives and I will now discuss how some participants felt this impacted on the pace they grew up at.

6.3.1 The hospital environment as a catalyst to growing up

Earlier in the thesis, I discussed children's awareness of the material manifestations of childhood; certain cultural products, such as books and toys, are associated with childhood (Brookshaw, 2009; Hunt, 2004). However, being diagnosed with liver disease

exposed young people to the hospital environment and medical artefacts. For those participants who were not born with liver disease, the hospital environment was not something they would have been traditionally exposed to in comparison to older people, who may frequently be exposed to this environment due to ill health (Roland, Dusheiko, Gravelle, & Parker, 2005). To illustrate how young people felt liver disease hastened the onset of growing up, I will begin by discussing participants' experiences of being exposed to the hospital environment.

One participant found going to his children's hospital unpleasant;

Declan: "I think if you want someone to grow up quickly, you-you take them to hospital erm for something like that where they have to go regularly. 'Cuz you do grow up quite fast, you know."

Other participants described their children's hospital as 'protective' and 'colourful', which was in line with the literature stating efforts were made to make the hospital environment more child-friendly (Dalke et al., 2006). However, for Declan, the hospital environment was a place where he was faced with the stark reality of his "lifelong illness" and underwent a "galore" of tests. For Declan the hospital environment spilled over into his home; twice he mentioned his parents needed to keep "biohazards and sharps bins" and other medicinal items in the fridge and kitchen cupboards, something he described as "horrible stuff". Such items would not be classed as material manifestations of childhood and by highlighting this Declan was emphasising that he felt that having these items in a kitchen was not normative. Declan, like many others, also reported he very quickly "mastered" administering his own medicines rather than relying on his parents, further indicating he began taking one of his medicines by himself whilst still in primary school; again suggesting a level of responsibility and maturity. For Declan, another indication of a hospital being a place for adults was evident in his perceptions of health professionals not "mincing their words" and communicating in ways which were not child-friendly; referring to his initial diagnosis, aged nine, he stated he would have taken a "gentler attitude" himself. What Declan's experiences indicate is how the hospital environment was incongruent with what he deemed appropriate for childhood, hence contributing towards his early maturity.

Being in hospital exposed young people to circumstances they perceived they would not normally have been exposed to had they not been diagnosed with liver disease. Examples of this included exposure to an environment where there were a lot of visibly sick people. As one participant explained;

Annie: It wasn't very nice you know, it was a little bit annoying and frustrating cos it's not the right environment to be in for a 17 year old, being on that ward with all the old people that have like bags and catheters and you know you're with like alcoholics, drug addicts, old people – cardiac arrest ... I got used to it but you know, a 17 year old shouldn't get used to it, you know, I'd just be like on the phone to my mum and like "oh another blue box has gone by" you know, it'd be like everyday life kind of thing now.

Annie's account demonstrates another way in which the hospital environment was incongruent with what she felt was appropriate for someone of her age. While previous research has reported people may be "terrified" after witnessing cardiac arrest (Holm, Norekvål, Fållun, & Gjengedal, 2012), and younger people may find them confusing (McDonough et al., 2012), Annie shows how she became accustomed to being exposed to those around her having a cardiac arrest. A similarity between Annie and Declan's accounts is how both reported adjusting to the adult-centred environment despite feeling they should not have been exposed to it. Like many others, Annie and Declan had to take on responsibilities for their health and be in an environment which involved physical intrusions such as "needles" for blood tests.

In contrast, not all participants felt negatively about the changes they experienced as a result of their exposure to hospital. For example, Steven had congenital liver disease and for many years his liver disease had been in the background of his life. This resembled what Monaghan and Gabe (2015) referred to as *biographical contingency*, that is, the condition was minimally disruptive to his life. However, the sudden onset of liver disease-related complications were disruptive to his life and he wanted the comfort of one of his parents with him at the hospital. Steven initially reported staying overnight at the adult hospital was scary and on one particular occasion he told me he was "the youngest on the ward while the others were 60 years or so". He described having "definitely more solitary feelings" as there were no other young people on the ward and that he "didn't really talk" to the older people. However, the experience did have some positive outcomes for him.

Steven: The experience of being in the hospital, and I find that being severely ill, helps you to deal with it in the future, and also help other people through it.

Steven talked about being able to empathise with other young people with liver disease following on from his experience and being able to give them advice. His account suggested he felt he had developed personally as a result of his experiences.

Being exposed to the hospital environment was more difficult for some young people for various reasons, for example, they were in an environment which highlighted for them that having liver disease was not normative for someone of their age due to the demographics of the other patients present. Furthermore, the medical artefacts young people became accustomed to seeing in their homes and within the hospital environment were not congruent with the material manifestations of childhood (Brookshaw, 2009). Whilst previous research reported experiences of chronic illness could bring a “young adult’s life trajectory to a standstill” (Grinyer, 2007, p. 266), these findings suggest young people *felt* they had to mature more quickly. In the next theme, I will demonstrate further how living with liver disease impacted on young people’s transition to adulthood, focusing on how experiences of biographical disruption were viewed as speeding up their transition.

6.3.2 Mourning the loss of a “reckless teenager” identity

This theme will explore the ways in which experiences of biographical disruption acted as a catalyst to speed up the life course of young people with liver disease. Speeding up of the life course consisted of a loss of the expected adolescence trajectory and the behaviours associated with being a teenager (Arnett, 1992). Alongside this, was a removal of the supposed protective factors adolescence afforded young people, for example, not having a heightened awareness of one’s own mortality and being kept away from a decline in physical health and a reduction of daily activities, something which the literature on older people found they often expected as an age-related issue (Faircloth et al., 2004).

In many interviews, ‘planning’ was raised; young people either had to plan their daily activities carefully to accommodate their liver disease and health, or found planning things “risky” due to the unpredictable nature of their condition. Young people talked about the teenage years as a period where other young people could be “reckless” (Jodie). Adolescence has been associated with sensation seeking and recklessness, although, in reality this period in the life course is perhaps exaggerated (Arnett, 1992; Arnett, 1999; Arnett, 2003). However, some participants felt liver disease prevented them from experiencing adolescence in the same way as their peers without liver

disease. Indeed, across the literature it has been documented that those with chronic illnesses may not participate socially at the same levels as those without chronic illnesses (Anderson, Clarke, & Spain, 1982; Winger et al., 2014). The consequences of this meant young people experienced biographical disruption, which contributed towards accelerating the life course, as young people compared their lives with liver disease to this utopian version of adolescence.

One such example was evident when Shantaya described things as having “slowed down”. She recalled her life prior to her liver disease diagnosis as facilitating spontaneous outings with her friends, reporting she could “just do it” and make plans “on the day”. However, following her liver disease diagnosis she could no longer make spontaneous plans.

Shantaya: “Because I don’t know how I’m going to feel on that day. If I’m not feeling well I’m not going to go and I found out if don’t plan stuff now I get a headache, I get really (pause) for some reason. I have to plan everything”.

Some young people reported feeling tired very easily and struggling to keep up with the pace that their peers socialised at, commenting they would need “naps” or “sleep” after school. Although daytime sleep is culturally specific, with many cultures engaging in daytime napping (Devine & Wolf, 2016), some young people signalled needing daytime sleep interfered with their identities as young people by compelling them to incorporate behaviours into their own lives that they felt were usually present in older adults’ lives. Research has demonstrated some older adults may be unaware of how many naps they actually have; this suggests to a certain extent napping is uncontrollable (Nguyen-Michel et al., 2015). Furthermore, napping during the day is resisted by some older people who view it as a ‘negative marker of the ageing process’ (Venn & Arber, 2011, p. 197).

One parent, Cassandra, described her fifteen year old daughter’s struggle with fatigue and attempts to conceal her illness. Her daughter was diagnosed with liver disease aged nine.

Cassandra: I think it's her friends [that she is trying to hide her illness from], she doesn't want anyone to, to know, she just wants to be absolutely normal and of course she then pushes herself probably, then gets very tired because she tries to live at the pace other people live at.

Prior to this point in the interview, Cassandra recalled a period in her daughter's life where she used a wheelchair and continued to maintain social activities; this is something Cassandra believed her daughter would no longer be able to do if she was to use a wheelchair again, stating she would be 'mortified' as being in a wheelchair at her current age would be 'so obvious'. Cassandra was of the opinion that it was easier for younger children to 'forget' about their physical differences to their peers and she further noted her daughter's outlook had now changed. Taking the definition of biographical disruption by Bury (1982), Cassandra is reporting her daughter is struggling with the taken for granted behaviour of her peers such as maintaining social activities and her strive to be normal may be indicative of her trying to mobilise resources to reduce the impact that the fatigue caused by her liver disease was having.

A consequence of being unable to commit to planned social activities meant young people often felt left out of social plans and sometimes peers misunderstood them. For example, Molly described having to cancel pre-planned events "all the time" despite having paid for tickets and reported her peers and previous partners had often not been very understanding of the impact of her liver disease on her health. This suggests it was not only friendships but intimate relationships which were impacted by periods of ill health. A few participants reported a difference between their friends who had chronic illnesses (mostly also had liver disease) and their friends who did not have any illnesses; those who had similar health statuses were more understanding when young people had to cancel plans due to unanticipated health reasons. Young people's experiences indicated that having to plan their lives was a marker of difference between their peers who did not have liver disease and themselves. The unpredictability of their health can be understood as a stigmatising attribute for young people with liver disease as it prevented them from maintaining their social relationships (Goffman, 1963). This is important as previous research has demonstrated the importance of friendship for young people with chronic illnesses to reduce feelings of difference; one study in particular reported 'adolescents described the feeling of loneliness as overwhelming, and sometimes the meaning of life was questioned' (Winger et al., 2014, p. 2652).

Other participants reported having to plan their activities in advance to ensure they had enough resources to manage their health. One participant, Jessica, told me she had to take "extra precautions" in everything she did following her diagnosis and she has "to leave the house prepared". She gave an example of how if she was to go on a long walk she knew she would "obviously" be "the first one that's worn out or tired or wants a break

or need some drink". To manage this, she would have to pack "anything she can think of", including an array of items such as drinks, food, medicines and hand sanitiser to prevent infections; this was something which bothered her. A few young people appeared to be in a state of heightened awareness as a result of their liver disease. Jessica reported when she was younger and did not have liver disease she had "nothing to worry about". However, following the onset of her liver disease things changed.

Jessica: soon as I get a bug now or feel like a headache or something straight on Google, so it's not oh (pause) so I'll panic and say should we go to the doctor and should we go to the doctors, what do we do? So I don't know whether any of the symptoms I have were from the medication, other problems (pause) any of my problems I'm actually diagnosed with, or everything.

Similarly, Freya told me that both she and her parents were concerned that if she was to get "a cold or flu" it would worse compared to what she described as "a normal person". She took precautionary measures to keep away from potential sources of infections. Therefore, periods of ill health or anticipated ill health were biographically disruptive and impacted on young people's present lives as they attempted to manage the potential disruption.

The fear of becoming ill again or having a relapse associated with liver disease impacted on some young people's independence. For example, Kaylee was fearful of getting ill in future; she further described the loss of the independence she had built up by age fifteen or sixteen years.

Kaylee: So you've got all this independence. Well, mine kind of was snatched away 'cause I'd gone from being really independent, and having to rely on my mum and my dad, not wanting to be left on my own. I hated being left on my own at the beginning without family or a friend with me because I was scared something was going to happen. [Text omitted] it's taken like two or three years, two years, yeah, two years, to kind of get away and try and get that independence back but it's quite hard to get it back after losing it.

Kaylee experienced a disruption to the taken-for-granted behaviours she was used to as a teenager (Bury, 1982). Traditionally, adolescence is viewed as time of increased social autonomy, however, being suddenly diagnosed with liver disease reversed that (Harris, 2015). The biographical disruption Kaylee experienced impacted on her transition to adulthood as the independence she had built up was dramatically lost.

Another participant, Steven, at the time of the interview was undergoing some tests at hospital which were worrying him. He told me he had been “a bit nervous in the past few weeks” and was worried about the results. He had been hospitalised in the past on two separate occasions and had now realised his current symptoms were a cause for concern as he “knew it was coming this time”, and he knew what he would face. These experiences can be understood as recurrent biographical disruption (Saunders, 2017). Saunders (2017) argued biographical disruption can have a more profound effect during young adulthood due to the uniqueness of the pressures and expectations young people experience. Importantly, for young people like Steven, repeated periods of illnesses were as devastating as the ‘initial biographical disruption’ (Saunders, 2017, p. 735). Similar to the work of Saunders (2017), young people who had experienced periods of ill health in the past were presently concerned by the anticipated biographical disruption future ill health could cause. Furthermore, the experiences of young people with liver disease coincided with reports within the literature of the constant physical and psychological stress young people with chronic illnesses are exposed to (Northam, 1997).

An interesting finding from the interviews revealed that parents can observe behaviours which appeared to indicate their child was experiencing biographical disruption. Three parents, whose children were diagnosed with liver disease later on in childhood, discussed they noticed significant changes in their child following the diagnosis, supporting the idea that children can have a pre-established identity which may be disrupted by the onset of a chronic illness. Bianca’s daughter was diagnosed aged eight and she reported around adolescence she began to notice changes.

Bianca: [Daughter] had always been a very kind of (pause) bubbly, social kind of lovely character, (pause) and she didn’t really fear much ... you know she would always go and do things, not say she couldn’t or didn’t want to ... But I think as adolescence has kind of kicked in and then these other issues we’ve spoken about, erm (pause) she’s lost a little bit of that kind of you know carefreeness and er (pause) almost, well yeah I suppose a little bit of her self-confidence really. She was always kind of, she felt she knew who she was and knew, she had her own little, compared to our eldest daughter, she had her own little style and would just get herself dressed from a very early age. And she knew what she wanted. But now we’re not there at this point very much, maybe beginning to come back.

Bianca reported the changes in her daughter occurred as a result of the 'issues' she had discussed in the interview. The idea that as children reach adolescence their personality changes is not new (Hertz & Baker, 1941); Buchanan, Eccles, and Becker (1992, p. 62) reported that 'mood, attitudes, and behaviour' are believed to change during adolescence. However, what is important is Bianca perceived these changes were associated with her daughter's illness (Bianca's daughter was interviewed separately and also felt the impact liver disease had on her life became more profound as she grew older). The loss of carefreeness echoes the idea of the reckless teenager reported by young people and encapsulations of adolescence (Arnett, 1992).

6.3.3 Morphing into a different person

In seven accounts biographical disruption was clearly observable with participants reporting a loss of their former sense of self. I will now present accounts from young people which demonstrated how they felt they had changed as a person following their illness. These accounts reported a perceived loss of identity as seen in the adult chronic illness literature (Asbring, 2001).

Annie reported in the interview she did not feel human and in the example below we can see how she rejects her post-liver disease self as not being her.

Annie: I was just like this little ball of yellow, ball just on the bed, you know (laughs), lifeless and energyless and that's-that's not me like I was always fit and active and like I did my gymnastics and you know, I was- I did that like three times a week, three hours each session and it was like a dra-a dramatic change.

Annie mentioned changes in her physical appearance; the yellow referred to her jaundiced skin, which is a common indication of liver disease, that made her look physically different from other people (Roberts, 2009). From Annie's account, it was certain behaviours she attributed to herself pre-liver disease that formed her identity; she was fit, healthy and a capable gymnast. A loss of physical capacity to engage with sports activities was reported in other young people's interviews, for example, Shantaya could no longer play her favourite sport, despite being scouted to play competitively as her "body couldn't keep up". Another participant, Jessica, who reported being involved in a lot of sports before the onset of liver disease, gave up sports due to the exertion of energy. Previous research on adolescents' experiences of chronic fatigue syndrome also reported their mind and body did not always want the same thing; changes to their bodies

led to restrictions on activities and fun (Winger et al., 2014). Many young people with congenital liver disease also reported being unable to participate in sports, however, a key difference in the accounts was that some young people who had undergone liver transplantation were advised not to take part in sports; this is in contrast to those young people diagnosed later on in childhood who were physically unable to maintain their involvement. This may explain why those diagnosed later in childhood experienced this as a form of biographical disruption as an external source, such as a doctor, did not influence their decision to stop participating but instead, they physically could no longer manage. Therefore, their lack of energy was not normal for them (Williams et al., 2009).

Some parents also reported their child had experienced biographical disruption, for example, Martine described a decline in physical activity of her 'very active, lively, sporty child – most sporty child' at around age 9. She reported he became a child who was unable to walk down the stairs and was 'just lying on the sofa all day, very poorly'. For her son who was involved in sports prior to his diagnosis, being unable to partake in those sports was a disruption to a behaviour he had taken for granted. Martine described her son as 'resilient' and the rest of the interview suggested the disruption was short lived as her son's health improved for a few years. This demonstrates a parental perspective on the perceived biographical disruption their child is facing, ranging from initial disruptions to behaviour, to changed outlooks on life, and finally attempts to minimise disruption. Three parents described witnessing a loss of the attributes that defined their child, suggesting observing this disruption can be difficult from a parental perspective.

For some participants, living with liver disease changed the pace at which they anticipated they would transition into adults. For example, Raheema felt growing up with liver disease meant she was not 'a normal kid' and became 'an adult young'. Raheema felt defined by her liver condition, told me she could remember her life before her liver disease diagnosis and was indeed the most prominent example within those interviewed where biographical disruption was evident in relation to the original definition and stages put forward in Bury's (1982) work. Raheema was one year post-official diagnosis when interviewed and explained the enormity of her liver disease diagnosis on her life;

Raheema: I think little e-experiences can change you but like a big experience will just sort of morph you in a different way.

The 'morphing' described by Raheema can be understood in light of the term "biographical work"; Raheema's comments about 'morphing' can be seen as examples

of the biographical work she was undertaking to repair her identity (Alasuutari, 1997). She was healing her sense of self by embracing adulthood early, something which was not biographically congruent (expected for her) as she had previously not been exposed to illness or suffering in this way (Harris, 2009b).

Another way in which experiencing liver disease was not congruent with the expectations young people had of their lives were demonstrated in Julia's account. Julia was diagnosed aged sixteen and told me in the interview;

Julia: sometimes feels like the 'me' before the transplant was kind of a different entity. It triggered enough of a change in thought process that I think differently now.

The idea of Julia's former sense of self being so far removed from her current self echoed Raheema's comments about morphing into a different person. Julia reported things moved 'on a lot more quickly' following her transplant, for example, she grew apart from her friends at a faster rate which she felt without her liver disease she would not have done so. Julia had developed post-traumatic stress disorder following her frightening experience of undergoing a transplant and the pain she experienced when she became ill. She further explained; "there's more awareness of your own mortality (pause) I, how I'm going to die scares me because I'm not sure I can deal with being in that much pain again". From her account, it is clear her experience with liver disease had a profound effect on her and she told me she wished euthanasia was legal in the country she lived in so she could manage the pain of dying. Becoming ill and feeling pain was a 'disruption' to the lives of participants such as Raheema and Julia (Bury, 1982).

Following their liver disease diagnosis, young people without congenital liver disease had to come to terms with some lasting changes to their health, some which had outwardly depictions. In turn, these outwardly depictions affected some young people's identities negatively, particularly impacting how they felt about themselves. One such example is Naheed, who told me in the interview she was "just a freak". When I asked why she thought that, she pointed out two of the outwardly depictions associated with her condition; slurred speech and tremors. She explained,

Naheed: I have this [condition], I am a freak... Normal day to day life that I do, who shakes? Who shakes? And whose speech is slurry?

Here, Naheed was comparing herself to other people without these physical symptoms of her liver disease which highlighted her awareness of her visible differences. Naheed went on to tell me she "wasted away" following her initial liver disease diagnosis.

Naheed's use of freak was similar to another participant's (Shalima) use of the word "disgusting" when talking about how she perceived her friends would feel about her if they knew about her liver disease. Shalima talked about being "the odd one out" and how she feared she would lose her friends if they knew about her liver disease, suggesting she was experiencing felt stigma (Scambler, 2007). Shalima's fears can be understood in light of previous research which reported young people with a chronic illness or disability were more likely to experience bullying than young people without (Sentenac et al., 2011). Williams et al. (2009) reported young people's experiences of biographical disruption were more nuanced. In their study, as young people grew up they wanted to fit in with their peers, becoming more concerned about 'public definitions of normality and the views of others' (Williams et al., 2009, p. 1449). This highlights how young people can be concerned about the stigma associated with some aspects of their condition.

Both Naheed and Shalima used stark descriptions to portray their feelings towards their liver disease and this may stem from their experiences of living with a chronic illness in the context of their cultural background. For example, previous research exploring experiences of living with epilepsy in South Asian Muslims highlighted how crucial it was to understand their experiences within the intricacies of a cultural and religious backdrop (Rhodes, Small, Ismail, & Wright, 2008). In their article Rhodes et al. (2008) reported how within Muslim, South Asian communities misconceptions about the causes and communicability of illnesses can exist causing those with illnesses/disabilities to feel distressed; families can also be unsupportive or ashamed of the disabled person. The stigma associated with having a chronic illness can affect culturally important milestones for South Asians such as marriage. In an earlier reflection, I recalled how one of the first things a participant shared with me on the day I met her was her struggle in getting married. A parent participant in a study by Rhodes et al. (2008) contrasted the views of South Asian people with those from White communities, stating Asian communities held more prejudices against those with a disability, in particular around marriage where they were less open to marrying someone with a disability. Such negative connotations with an illness can fuel concealment as a way of managing the stigma; people can indirectly fear negative reactions and seek to avoid them by concealing their illness (Rhodes et al., 2008).

I would like to emphasise not all young people experienced a profound disruption as a result of their liver disease diagnosis. For another participant, Leo, who was diagnosed

with a major chronic illness as a child and had other comorbid conditions, being diagnosed with liver disease was not a disruptive event. The concept of biographical congruence was more appropriate to explain his experiences (Harris, 2009b). Leo told me his liver disease “was just like another thing which didn’t really bother me”. Leo’s experiences resembled similarities to literature on adults with chronic illnesses, in particular, the work of Harris (2009b) where participants had already experienced many hardships before their diagnosis. ‘Hardships’ in Leo’s case could be seen as his previous exposure to chronic illness as a child and developing another condition did not come as a shock.

6.3.4 Parental experiences as vicarious biographical disruption

It has already been established within the literature that a child’s chronic illness diagnosis can impact on parents’ working, personal and social lives (Alaee et al., 2015; Crettenden et al., 2014; Parish, 2006; Yuwen et al., 2017). Previous research has recognised that parents may attempt to construct new self-identities following on from their child’s illness, particularly in light of new roles associated with caring for a child with a chronic illness (Young et al., 2002). Motherhood in particular is intertwined with social constructions of childhood, and mothers can be expected to protect their children selflessly (Young et al., 2002). An exploration of parental interviews revealed although parents of young people with liver disease were not the ones experiencing the chronic illness, they were affected by their child’s illness, and eight parental accounts in particular demonstrated parents may experience forms of biographical disruption themselves. I have labelled this ‘vicarious biographical disruption’.

Five parents described the ongoing nature of a permanent disruption to their lives, for example, Cassandra described ‘living on alert’ and living in a ‘constant state of high anxiety’. This was echoed in interviews with other parents, such as Hayley, who described being unable to ‘switch off’ her mind and struggling to sleep at night, and parent Vicky, who reported she was constantly ‘looking for new signs’ to ensure her daughter’s health was not deteriorating. Parents were so concerned about their child’s health that this had an impact on their own health; Martine reported she felt ‘stressed, exhausted, depressed’. Elsewhere in the literature it has been documented that caregivers of children with other chronic illnesses, such as cystic fibrosis, also experienced disruptions to their sleep due to the stress of their child’s health (Meltzer & Mindell, 2006). A consequence of disrupted sleep is that parents may also report higher levels of fatigue and depression (Meltzer & Mindell, 2006). Parents responded differently to this new state of anxiety they were experiencing; Mary reported ‘pushing’ everyone

else out of her life in order to focus on her daughter during her difficult time and Hayley adopted the role of 'Muminator' to ensure her child received the care she felt he needed.

Mothers reported they faced various challenges associated with ensuring their child's healthcare needs were being met in a number of settings including hospital and school.

Hayley: They call me the Muminator [laughs] Like the Terminator but mum (pause) and all the teachers at school are scared of me [laughter] and you know what, I'd love to apologise for being like that but I love my kids, and I want my kids to be okay and if that means moaning at them [teachers] then that's what I'm going to have to do, you know.

Hayley's account can be understood as 'biographical work' as explained by Felde (2011) which encompassed how people may construct situationally-appropriate identities. Hayley began by explaining the impact her son's diagnosis at age twelve had on her life and how 'exhausting' it was. She felt she was 'always on call', which was a reference stemming from her job as a healthcare professional where she would need to be prepared for a medical emergency during the night whilst most people would sleep. The 'Muminator' label is interesting as in the 1984 film *The Terminator* directed by James Cameron, the Terminator is nonhuman and ultimately the 'bad guy' who is programmed to 'annihilate humanity' (Zacharias, 2015). This is a powerful image which reinforces the idea mothers are 'battling' against the world to fight for their children and reflects the negative perceptions others have of them as being machines. It would appear for Hayley, her new role was all-consuming but one which she was obliged to fulfil for the sake of her son. Given the sacralisation of children following the 19th century and the role of the family in ensuring children's wellbeing and upbringing, Hayley's account can be understood in light of societal expectations to manage the multiple areas of her child's life (Qvortrup, 1987).

Many parents reported their child's hospitalisation was disruptive to their lives; for example, Farooq told me about the financial and practical struggles associated with prolonged periods of overnight hospital stays, reflecting back, he told during those periods he was "struggling for everything". For other parents, the hospital environment appeared to be linked to experiences of biographical disruption. Two mothers, whose children were hospitalised for prolonged periods, described experiencing a form of biographical disruption for the duration they stayed in hospital. Eileen described herself as 'just existing' whilst she waited for a liver transplant for her daughter. She recalled being unable to leave the ward, losing weight, never eating out, experiencing poor sleep and her life being 'just totally on hold'. She reflected on her period of staying in hospital

as a 'waste of all those months'. Similarly, Mary reported 'after the first month or so, I felt quite institutionalized to be honest with you'; this was due to the 'same routine everyday' as she stayed with her child in hospital. Mary feared her daughter would not survive, she did not want to 'miss one minute of being with her' and described always rushing back to hospital after showering at home. Mary's experiences were similar to findings reported by Young et al. (2002), which emphasised the need for parents of children with cancer to be in close proximity to their hospitalised child.

Many behaviours that parents took for granted were disrupted when their child was hospitalised and as reported, had a negative impact on parents' own wellbeing, contributing towards a loss of their identity. Some parents reported they returned to work to reclaim their lost identities following the birth of their children; Mary described being 'relieved' when she returned to work. Erin reported a similar experience.

Erin: I also wanted to get my identity back. I wanted to be me again, because a little bit of me is work. I was a bit of an adrenaline junkie and I love my job.

In order to understand the experiences of these mothers, it is useful to contextualise the meaning of work in Western society; work can be seen as a strong component of people's personal identities, those who work are seen as valued members of society. As explained by Fryers (2006, p. 6), "ultimately personal identity and self-esteem are closely bound up together, and derive from a sense of personal value, of personal worth, of being needed". Previous research has reported for adults experiencing chronic illness themselves, the loss of a work-related identity was a form of biographical disruption (Asbring, 2001). This explains why returning to work was so important for parents like Erin and Mary to regain the 'lost' identity, as although they were not experiencing the chronic illness, they were experiencing the disruption stemming from the impact it had on their lives.

Whilst carer's responses may differ (some may feel relieved once they no longer work and others may feel the loss of these activities as sources of additional stress), one of the dangers of becoming immersed into the carer role is the gap which is left in the carer's lives once the caregiving has ended (Lewis & Meredith, 1988). In the context of having a child with liver disease, some parents reported experiencing difficulties when their caregiving relationship ended in different circumstances, for example, through the death of a child as experienced by Rosa; a child moving out of the family home to attend university as experienced by Erin; or, through the hospital transition to adult services as

experienced by Madison. Therefore, it is important parents are able to maintain their own identity whilst their children grow up.

6.4 Transitions denied and imposed when growing up with liver disease

The following quote from Jodie summarises the issues discussed in this thesis so far:

Jodie: I think some aspects are hard, and then some aspects are just like, I'll just get on with it, and like you're—my teenage life won't be the same as like my friends' teenage life. A lot would happen in my teenage years that they won't have to deal with, and I think growing up as a teenager with an illness is hard because we just—we never—when you're—I think when you're a teenager, all my friends they go out and plan stuff and meet up on the weekend, and they're really living their lives, whereas I sort of have to umm, plan stuff, and I can't always be that reckless teenager that my friends sometimes can be, I always have to think and state in the back of my mind all the time, and making sure that I don't do something bad that can hurt me.

Growing up with liver disease impacted different aspect of the lives of participants in this study as they made various transitions in their life during their journey from childhood to adulthood. Adolescence can be a difficult time in itself and previous research indicated young people with liver disease wanted to fit in with their peers (Wise, 2002). However, as explained by Jodie, their lives as teenagers were not the same as the lives of their friends due to the many things which they have to deal with in addition to growing up.

The meaning and impact of liver disease changes for young people throughout the life course and the importance of this was often weighted by young people in relation to differences between themselves and others, hence why this thesis has utilised the concept of stigma to explore these differences (Goffman, 1963). An obvious difference for young people with liver disease was the need to attend hospital appointments and for many, the treatment regimens associated with liver disease. Whilst for some young people liver disease only occasionally came to the surface, resembling biographical contingency (Monaghan & Gabe, 2015), for other young people it was always in the back of their mind, whether it was ensuring they had enough medication on them just in case their plans changed or avoiding engaging in activities which could be potentially harmful to their health. Whilst their peers made plans to have spontaneous fun, young people like Jodie had to plan to maintain their health. Having to be more responsible about their

health was experienced by some young people as a denial of the transition into a “reckless teenager” as they could not be carefree in the same way as their peers. As discussed in previous sections, other young people felt their exposure to the medical environment and the responsibilities associated with their condition had forced them to become more responsible at a younger age. This demonstrates the importance of the pace at which young people feel like they are growing up at and their experiences of adolescence, as the denial of the “reckless teenager” period invoked feelings of difference.

Feelings of difference were more profound for some young people and as discussed in other data chapters, alcohol was an important marker of difference for many of the participants in this study. A lack of alcohol consumption was experienced as not only stigmatising for some young people, but had a negative impact on their identity, hence this particular difference was experienced as a form of biographical disruption. Adolescence was a period where many young people began to be exposed to peer-drinking cultures and had to negotiate their own consumption in light of peer pressure, the expectations of others such as parents and healthcare professionals, and the stigma associated with liver disease stemming from alcohol misuse. In the context of growing up in the United Kingdom, their peers could engage in “reckless” alcohol consumption and reap social rewards, however, young people with liver disease were conscious of the stigmatising attributes of liver disease and actively sought to differentiate themselves from the stigmatised group. However, the transition to adult services within the hospital environment exposed young people to those with liver disease stemming from alcohol or drug misuse, which was reported as concerning by some.

Finally, as explained by Jodie, there are many aspects of living with liver disease that young people “just get on with”. On Jodie’s part, there appeared to be an acceptance of her life as a young person with liver disease and the differences she would have to manage. This differed from participants who were keen to maintain their former lives and rejected the consequences of liver disease which they had to assimilate into their lives, for example, they did not want to communicate with healthcare professionals during hospital visits. This highlights how young people choose to manage their liver disease will differ, particularly, following an onset later on in childhood.

6.5 Summary

In this chapter I have contributed towards the literature on young people's experiences of chronic illness by drawing connections between the work on stigma by Goffman (1963) and Bury's (1982) work on biographical disruption to help illuminate young people's experiences of living with liver disease. I have presented young people's experiences of the transplant scar and other visible markers to demonstrate how the transplant scar can be a source of stigma for young people undergoing various transitions in their life from school, growing up and forming relationships. Starting school can be a difficult time for young people who were born with congenital liver disease and transplanted at an early age as through physical education classes, young people become aware of their scar as a marker of difference. Whilst the liver transplant scar being a marker of difference has been established in previous research (Wise, 2002), in this chapter I have built on previous research by demonstrating how children's resources to limit unwanted attention are limited due to the openness of school changing rooms. I have also shown how scar stigma is not stagnant and is context-dependant across the various life transitions including primary to secondary school. Whilst for some young people the scar is a source of bullying and can disrupt their lives, particularly participants like Lydia who was transplanted whilst in secondary school, for others the scar serves as evidence of their liver disease, which can be invisible to others.

This chapter also demonstrates how gender influenced young people's experiences of their visible differences; the underlying feature aggravating negative experiences in relation to visible differences appeared to be the stigma of being different. Some female participants reported feeling restricted in their clothing choices, feared rejection of their bodies by future partners and were self-conscious about their scar. Whereas, male participants used the shark bite story to resist the stigma associated with being different and reinforce masculine identities through the use of humour.

Young people reported changes to their identity following their liver disease diagnosis and some of those changes can be associated with visible differences which can be understood as stigmatised attributes, for example shaking, slurred speech or medicine taking. This chapter demonstrates young people can have pre-established identities which are disrupted following the sudden onset of liver disease in similar ways to the literature on biographical disruption in adults. This can explain why young people may talk about being a "freak" or "disgusting". It is the stigma attached to consequential attributes of liver disease that has affected how they perceive themselves and contributed towards their experiences of biographical disruption. This stigma can be exacerbated for young people with liver disease from South Asian backgrounds where chronic illnesses more broadly are stigmatised within families and wider communities.

I have further demonstrated how biographical disruption can take place in the context of evolving identities, particularly, the loss young people feel of being unable to maintain what they feel is a developmentally appropriate lifestyle and the acceleration towards maturity following exposure to the hospital environment and illness.

My final contributions towards the literature on biographical disruption is in relation to parental experiences of having a child with liver disease. Parental accounts have supported the young people's accounts of experiencing biographical disruption. Furthermore, parents may experience 'vicarious biographical disruption' following the onset of their child's liver disease as they are faced with numerous changes to their identities in light of hospitalisation and the management of their child's liver condition.

7 Discussion

In this chapter I will summarise the whole thesis, focusing on the individual chapters and findings. I will demonstrate how my thesis has contributed towards the literature and discuss the implications of the findings. This thesis was produced as a response to the scarce literature on young people's experiences of living with liver disease. This was particularly important given the changing landscape of medical outcomes in relation to childhood liver disease; young people are now surviving into adulthood for the first time in the United Kingdom. At the start of the thesis, we knew from Wise's (2002) qualitative research young people strived to lead 'normal' lives, that having a best friend to share the 'secret' of liver disease was helpful, and from the quantitative research of Taylor et al. (2009) that young liver transplant recipients may struggle with the symptoms which follow a transplant, finding them distressing.

However, there were a number of issues that remained unaddressed within the literature, particularly in light of the what Kimbell et al. (2015) described as the stigmatising reputation of liver disease due to its associations with alcohol misuse. Within the United Kingdom ambivalent attitudes towards alcohol exist; on one hand alcohol is seen as an important part of social cohesion and on the other hand those who are deemed to be alcoholics are viewed as morally deviant. This led to an important question, how do these misconceptions regarding the cause of liver disease and negative associations of liver disease impact the lives of young people who are born with liver disease or acquire it at a young age? We knew very little about what young people's experiences of growing up amongst these ambivalent attitudes were. Furthermore, making the general transition from adolescence to adulthood can already be a difficult time for young people without a chronic illness, as young people seek their own independence and make the transition into employment, however, young people with liver disease also have to make the transition for paediatric to adult healthcare services.

In the first data chapter I discussed young people's experiences of communicating with healthcare professionals and their experiences of transitioning to adult services. The data resembled previous literature in that there were difficulties for young people when transitioning to adult health services more generally, which included the biological age of young people as not being a helpful marker, especially for young people who do not want to or feel they are not ready to transition between the ages of 16-18 years (Yassaee et al., 2016). This chapter has contributed to the literature by demonstrating how the transition to adult services can be viewed as a transition into stigma. Adult services exposed young people to the stereotypes associated with the adult liver disease patient population who are often deemed by others to have caused their liver disease through

personal shortcomings such as alcohol and drug misuse. When children and young people transition into stigma, this spoils their identity as 'innocent' liver disease patients.

In the second data chapter I explored young people's experiences of stigma in relation to alcohol consumption and liver disease. I demonstrated how the move towards individual responsibilities for one's health influenced young people's behaviour in relation to alcohol consumption. Some young people were keen to adopt the roles of good citizens by avoiding alcohol consumption. In adopting the role of a good citizen, young people were partaking in the othering of alcoholics. I drew on young people's experiences of feeling frustrated by those who they felt were causing their liver disease; this was because young people themselves were stigmatised by the negative associations with liver disease. I also demonstrated how parents, in particular mothers, were also subjected to stigma in relation to the liver disease label through the policing of pregnant women's bodies. This chapter has contributed towards the literature by demonstrating how alcohol can be a source of stigma across various transitions in the lives of young people with liver disease, including employment.

In the third data chapter I began by exploring some of the visible and invisible markers of liver disease. In particular I focused on liver transplant scars and the various ways in which the scar was experienced as stigmatising by young people. This chapter contributed towards the literature by demonstrating how stigma related to liver transplant scars was context dependant and complicated. Young people's feelings about their scar varied across different circumstances such as school and in their personal relationships. This chapter discussed the ways in which young people reported feelings of enacted stigma and felt stigma in relation to their scar (Scambler, 2007). Furthermore, whilst previous literature had acknowledged the "shark bite" narrative to explain the transplant scar (Wright et al., 2015b), in this chapter I demonstrated the role parents have in the production of this narrative and described how the narrative was used as a response to the stigma associated with looking visibly different.

I then discussed the ways in which stigma shapes experiences of biographical disruption. Some young people reported experiences of biographical disruption in similar ways to those featured in adult's experiences of chronic illness. This section of the thesis explored how young people's identities were disrupted and repaired in light of various aspects of liver disease. This chapter has contributed towards the literature by demonstrating parents can experience a form of biographical disruption vicariously; parents' lives can be greatly affected by their child's diagnosis. This includes parents whose babies are diagnosed with liver disease who have to stay in hospital and those

whose children are older who have to overcome many difficulties in ensuring their child receives the support they need.

I will now discuss young people's rejection of a stigmatised identity in more depth and the implications of this. This thesis drew on the concepts of biographical disruption (Bury, 1982) and stigma (Goffman, 1963) to explore the experiences of young people with liver disease across different transitions they made whilst growing up. Williams (2000, p. 50) questioned whether biographical disruption, a concept stemming from research with adults diagnosed with chronic illness, was relevant to the experiences of young people with chronic illnesses. The findings from this thesis have shown that biographical disruption served to be a useful tool for making sense of the experiences of young people with liver disease. Although the original concept was used to refer to the disruption to a person's identity following the sudden onset of chronic illness, which did reflect the experiences of some of the participants in this study who were diagnosed later on in childhood, the findings from this study have also shown biographical disruption occurred in nuanced forms in line with previous work on the concept, including recurrent biographical disruption (Saunders, 2017) and biographical contingency (Monaghan & Gabe, 2015).

For example, some young people's experiences resembled the work of Saunders (2017) on 'recurrent biographical disruption', who reported repeated periods of ill health were just as disruptive as the initial disruption. Furthermore, for other young people, it was the anticipation of potential disruption to their future lives as a result of their liver disease which worried them; for example, their identity as a future parent (one participant was worried about the intergenerational transmission of liver disease). Drawing on the sociology of childhood literature presented earlier, these findings support the ideas of Uprichard (2008), who suggested children should be viewed as both *being* and *becoming*, as participants' perspectives of their present and future selves demonstrated the daily realities of life as a young people with liver disease. Concerns about future disruption highlight potential areas where young people may need additional support and information, however, as shown in the first data chapter, young people may not always communicate their concerns to healthcare professionals despite reporting they were actively participating in their hospital appointments.

Given the variety in experiences and preferences in relation to communicating with healthcare professionals, the findings reflect the words of Brady et al. (2015, p. 2) who stated; 'there is no typical child'. Healthcare professionals need to be able to adapt to individual preferences to ensure consultations are fruitful for young people themselves,

not just their parents. Some young people benefited from being involved in their healthcare from an early stage and consistency in their involvement in consultations was important. Some of the challenges healthcare professionals may face include respecting the wishes of young people who do not wish to participate in their healthcare appointments. Whilst this may be a source of frustration for some parents, it is important to acknowledge how young people respond to their liver disease diagnosis, particularly if they were diagnosed later on in life, can be a way of managing the potential disruption to their identity. Young people's decision not to communicate with healthcare professionals can demonstrate their agency (Hartas, 2011; Tisdall & Punch, 2012). Young people may not wish to accept they are ill and elsewhere in the literature on other illnesses, 'bracketing off' the illness, or denial of certain aspects of a condition have been interpreted as a defence mechanism, which can be argued to contribute towards reconstructing one's identity, and the maintenance of a former identity (Bury, 1991; Locock et al., 2009; Salander et al., 1996; Williams, 2000).

Although several aspects of liver disease were reported as reasons for the disruption or anticipated disruption to young people's identities, in many instances the disruption was underpinned by the stigma associated with certain aspects of life with liver disease, for example, looking visibly different through medical scars or being unable to consume alcohol with peers. Addressing stigma held at a societal level, particularly around the unfavourable opinions associated with those who do not consume alcohol is not an area where I feel I can make recommendations. However, some participants reported concealing their lack of alcohol consumption as strategies to manage the stigma and avoid being labelled as different by others. Therefore, this may be an area where peer support could be developed, particularly as participants reported their friends who also had similar conditions were more understanding in other aspects of their lives, for example, when they had to cancel plans. It is important to note, not all young people experienced liver disease as a profound, disruptive event; their experiences reflected what Monaghan and Gabe (2015) described as *biographical contingency*, that is their liver disease only occasionally disrupted their lives. For example, young people may have pre-existing health conditions which they deem to be more disruptive to their lives than their liver disease. Therefore, they may not need peer support to manage aspects of their liver disease.

Many young people in this study were keen to reject the stigmatised identity associated with liver disease, distancing themselves from those with liver disease stemming from alcohol or drug misuse. The stigmatising associations with liver disease came to light for some young people in relation to moving to adult services, which was difficult for young

people who had been diagnosed with liver disease from a very young age. Young people who are diagnosed with liver disease later on in childhood and do not transition to adult services may need extra support as they have to contend with the unfamiliarity of being in hospital alongside going straight into adult services. With respect to addressing young people's concerns about the transition to adult services a number of key concerns may need to be addressed by transition programmes such as fears of sharing clinic space with "alcoholics", concerns of changes to service provision, young people's desires to remain in children's services and desire to move to adult services.

This is the first piece of research on living with childhood liver disease in the United Kingdom that has found the adult liver clinic to be constructed as a stigmatised space by some parents and young people with liver disease, thus, differing from previous research also exploring hospital transitions (Wright et al., 2016). There may be a number of reasons why the findings from this study differed from that of the research by Wright et al. (2016) which include; how I presented myself as a researcher to families, drawing on my identity as a university student rather than a medical professional; the rapport I was able to build with young people as another young person; and the location of the majority of interviews taking place in participants' homes and places that suited them, away from hospitals where power differentials between healthcare professionals and patients can occur. The implications of attending clinics in a 'stigmatised' space should be explored further in future research, particularly as research across other childhood chronic illnesses has shown around the period of transitioning to adult services many patients stop engaging with their healthcare (Harris, 2015).

Some mothers in this study reported experiencing courtesy stigma following their child's liver disease diagnosis. This occurred in two forms; accusations of being a 'bad' parent and allowing their child to misuse alcohol, or being accused of consuming alcohol during pregnancy which caused their child's liver disease. I explained earlier in the thesis how the policing of pregnant women's bodies left mothers exposed to stigmatising comments from others (Lupton, 2012). These accusations were not only reported as upsetting but also challenged their identities as mothers. The concept of biographical repair was useful to understand how some mothers attempted to contextualise their alcohol consumption during pregnancy (Felde, 2011; Kaufman, 1988). In light of changes to health promotion messages advocating abstinence of alcohol consumption during pregnancy and a lack of general knowledge about childhood liver disease, it is possible mothers of children with liver disease will face stigma as experienced by participants in the current study. Arguably, this is a matter which needs to be approached with a great deal of sensitivity, and future research is necessary to determine how support for managing stigma should

be provided and by whom. It may be peer support is useful in this context; Bray, Carter, Sanders, Blake, and Keegan (2017) reported peer-to-peer support for parents of children with disabilities was a good opportunity to share experiences with somebody non-judgemental and useful for the growth of those involved in the supportive relationship.

The findings from this study demonstrated young people with liver transplants can experience stigma related to their transplant scar. In particular, the school environment was cited by multiple participants as a site where stigma could be experienced. This included other children viewing the transplant scar through the arrangement of changing rooms for physical education/swimming classes and occasionally, partaking in teasing of the young person with a transplant scar, or young people feeling compelled to expose the scar to school teachers/pupils who did not believe that the transplant took place. Whilst dealing with teasing and bullying from peers can be difficult for young people within the school environment, particularly in primary school, it has been reported in other studies teachers may not believe adolescent pupils have a health condition (Winger et al., 2014). One recommendation would be to ensure school teachers are made aware of a young person's liver transplant and the status of their health, as young people may look "well" on the outside but still have to manage their liver disease and the side effects associated with their medications.

The findings in this study revealed that some young people felt unable to follow their desired career path due to their liver disease. Yeo and Sawyer (2005, p. 722) advocated health professionals should help young people with the transition from education to employment, chiefly through encouraging young people to develop their capacity for employment in the same way young people without a chronic illness would, and by "identifying strengths and abilities rather than disabilities". Suggestions for achieving this included sourcing appropriate work experience placements, and the timeliness for implementing these strategies was also emphasised as early adolescence. They further suggested assessments of young people's readiness for employment should be ongoing, paying attention to young people's "educational achievement, communication skills, self-esteem, expectations, and work experience" (Yeo & Sawyer, 2005, p. 722).

The findings revealed some young people in the current study had faced stigma in relation to securing employment, these young people felt they were at a disadvantage because they had liver disease. Whilst some participants reported concealing their liver disease from their employers, others felt concealing their liver disease would be beneficial to secure employment in future. Ideally, one would hope young people could disclose their illness to their employer without consequences and would receive support

to transition into their roles, to prevent situations where they would need to resign due to being overwhelmed with the workload. Some of the challenges young people anticipated facing included not feeling well enough to manage the work day; although it could be difficult to implement in reality, young people could benefit from flexible working arrangements. Particularly, as some participants were able to benefit from this due to their social capital, e.g. family businesses (Bourdieu, 1986).

Other challenges young people faced included managing their liver disease within institutional cultures centred on alcohol consumption. Within the context of celebratory rituals involving alcohol, young people with liver disease can feel excluded. Although some young people felt comfortable turning alcohol down, others may struggle to manage these situations within the workplace. Not consuming alcohol within the workplace can be experienced as a stigmatising attribute and can further prevent young people with liver disease from benefiting from the multiple social and economic rewards cited within the literature, such as, securing promotion (Allison, 2009; Ginsberg, 2000). However, it must be acknowledged that changing an institutional culture is not an easy task (Museus, 2007), and therefore, it is difficult to make recommendations for how this can be managed in the workplace. Workplaces may benefit from an information pack about childhood liver disease to address the stigmatising aspects of liver disease, for example, being wrongly labelled as a condition stemming from alcohol or drug misuse.

This thesis did not set out to explore the relationship between having a Muslim identity and experiencing alcohol-related stigma, however, given the ways alcohol was reported to be associated with stigma in the lives of non-Muslim participants with liver disease, this relationship with alcohol would have been fruitful to explore in more detail. Having a Muslim background tended to shelter young, South Asian Muslims with liver disease from the societal pressures to consume alcohol as it was already forbidden due to religious reasons, therefore, it was never a part of their lives in the first place nor anticipated to become part of their biography. Whereas non-Muslim participants were exposed to the ways alcohol was embedded into society and the drinking culture which they would not be able to partake in. Therefore, many non-Muslim participants experienced stigma, which manifested as a loss of the potential social benefits of consuming alcohol and the various identities associated with drinking, such as being a 'fun, young person'. The other side to experiences around alcohol consumption for non-Muslims with liver disease was the stigma and blame associated with alcoholism which exposed them to accusations and having their moral character questioned. This is the first study in the United Kingdom which has explored the viewpoints of young Muslims with liver disease around alcohol and therefore these differences in experiences are a

novel contribution to the literature on childhood liver disease. However, there were only seven young people participants who identified themselves as Muslim in the sample and future research which explicitly addresses this topic with a larger sample would be needed to draw any firm conclusions.

Another lens through understanding the experiences of the South Asian participants in this study would have been to contextualise their experiences within the caste system prevalent in Pakistan and India, however, participants were not asked to identify their caste. Gazdar (2007, p. 86) drew attention to how 'caste was class' in Pakistan; that is the caste system is similar to the social class classifications in the United Kingdom. Individuals are separated by kinship groups, also referred to as 'zaat', 'biraderi' and 'quom', which could be the crucial 'dimension of economic, social and political interaction' (Gazdar, 2007, p. 87). The hierarchy of the caste system would have influenced the upbringing of participants and is an important aspect of the Pakistani and more broadly South Asian identity. I know this not only through my own experiences as someone from a South Asian background but also because after an interview, a UK born, young adult participant of Pakistani descent asked me which caste I belonged to and within the interview was critical of the other castes they deemed to be inferior in their eyes. This is an example of how despite being born in the United Kingdom, kinship memberships are still an important aspect of the lives of those of Pakistani descent, and as Shaw (2014) discusses in her book, some people may talk about their caste with pride while others prefer not to discuss it. Another South Asian parent before the interview wanted to know about my background and upon discovering our shared cultural background introduced me to the rest of the family as "one of their own people". The reason why examining experiences of kinship groups is of relevance is because of the way it can dominate the social mobility of those from castes deemed inferior. In light of Imran's father discussing how misconceptions around his son's liver disease existed, what we do not yet know is whether these kinship ties can affect experiences of stigma around living with liver disease.

Despite the potential limitations in the ways the experiences of those from ethnic minority backgrounds could have been further explored had I set out to explicitly explore ethnicity and religion, this thesis has served an important purpose in giving voice to participants who would not have otherwise been able to participate. Previous research has acknowledged the difficulty in recruiting participants from minority ethnic backgrounds with long term conditions in health research particularly due to issues such as language barriers (Beadle-Brown et al., 2012). Through offering interviews in other languages, I was able to facilitate participation from two South Asian mothers who spoke very little

English. One of these women did not attend her son's hospital appointments so had never met me and it was her partner who had invited me into their family home for the interview. I am therefore aware of how the presence of a female, South Asian researcher was helpful in numerous ways, additionally as participants were able to draw on shared cultural references.

Given the exploratory nature of this study and the scarcity of research into experiences of childhood liver disease, this PhD has provided an insight into life as a young person with liver disease. Discussing this project with healthcare professionals who are involved in the medical care of young people with liver disease has been an interesting experience, particularly talking to those who were interested in the experiences of their patients' outside of, and within, the consultation room. A decision was made to utilise broad inclusion criteria rather than only include young people with specific types of liver disease. Reflecting on my conversations with those working within the field of hepatology outside of the United Kingdom, I acknowledge that the inclusion of young people with different liver diseases may have been limiting due to differences in disease severity, age of onset and health outcomes. Indeed, future research could focus on specific types of liver disease to understand condition-specific challenges faced by young people.

Future research is imperative to ensure young people with liver disease are able to overcome any practical or societal barriers to living the lives they want to live. In the words of a participant without a transplant;

“Most of the research is on transplants and there's hardly any research to do with people with other liver diseases... I feel I'm not as important as those with transplants... I think there's a stigma [if you haven't had a transplant]”.

There is a need for more research aimed at the different types of liver disease, not only focusing on transplant recipients. However, for childhood liver transplant recipients, there are many pressing issues which still need to be resolved that affect their lives such as having to pay for their medicines once they reach a certain age. Childhood liver disease affects more than physical health and in order to fully support young people it is imperative to look at the impact of liver disease on wider life. To conclude, support needs to be directed at the various transitions young people go through including starting school, transitioning to secondary school, entering employment and forming intimate relationships. I hope in future further research can help improve the lives of young people with liver disease.

8 References

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9 Appendices

9.1 Appendix 1: Sample Page Young Person Participant Information Sheet

What will happen to the interview recording?

The research team will keep the recording locked away to keep it safe. Afterwards, we will type up the interview.

Are you going to use my real name?

No. When we type the interview up you will be given a pretend name. All the files will be saved under your pretend name. This is to make sure nobody can find out what you said. Below is an example showing you how a young person called Sarah was given a pretend name "Anna" to protect her identity.

Sarah aged 14: "I was first diagnosed with liver disease when I was 10 years old".

When the researchers typed up the interview, this is how it looked.

Anna aged 14: "I was first diagnosed with liver disease when I was 10 years old"

What will happen to the information I give?

After the interview, we will put the information from everybody who took part in the study together. The information will be published so we can share what we have found. Remember, we will not use your real name.

9.2 Appendix 2: Sample consent form

Young People Living with Liver Disease: A qualitative study of experiences of transitions

Participant Consent Form

Name of lead researcher: Shahreen Bashir

Contact lead researcher: [REDACTED]

	Please Initial In The Box To Confirm 'YES'
I confirm I have read and understood the Participant Information Sheet for the above study. I have had the opportunity to think about the information provided, to ask any questions and have had these questions answered satisfactorily.	
I understand that participating in this study is completely voluntary and I have the right to withdraw at any time whilst participating without giving a reason. I understand if I choose to withdraw any information provided by me will be destroyed upon request.	
I understand that that the information I provide will be recorded and may be used and analysed for research purposes. The findings may be published in academic journals, in presentations and will form a part of a PhD thesis which will be published. I understand my real name will not be used in any publications.	
<p>I agree to take part in the study</p> <p>I consent to my child taking part in the study (if applicable)</p>	

	Parent/Carer Or Young Adult (aged 18 or over)	Young Person (if you are under 16 your parent/carer will need to sign on the left to consent)
PRINT NAME		
SIGN		
DATE		

If you would like the research team to retain your contact details for possible participation in future research studies please write your initials in the box	
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Young People Living with Liver Disease: A qualitative study of experiences of transitions

Please indicate your preference for an interview

Type of Interview	✓	My Home	Hospital
Face to Face			
Telephone			
Online			

Time	MON	TUE	WED	THUR	FRI	SAT	SUN
09.00							
10.00							
11.00							
12.00							
13.00							
14.00							
15.00							
16.00							
17.00							
18.00							
AFTER 18.00							

If you have any particular preferred dates/times, please list them below

Date/Time	
Date/Time	
Young Person (14 – 17 years old) phone number	
Young Adult (18 – 25 years old) phone number	
Phone number (parent if applicable)	
Email address	

Please hand this form to the researcher who will contact you for more information. If you choose to have the interview in your own home you will be asked for your address details prior to the interview. You may also email the researcher this form. Please send the completed form to: [REDACTED]