

HOW DO SIBLINGS MAKE SENSE OF THEIR EXPERIENCES WHEN ONE IS HIV
POSITIVE?

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The candidate confirms that the work submitted is his own and that appropriate credit
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ABSTRACT

Owing to advances in HIV treatment, adolescents are now living long and healthy lives into adulthood and beyond. Research has been conducted in order to investigate the psychological and emotional responses of those who are HIV positive. However, there is a paucity of empirical research that investigates those responses in the siblings of adolescents who are diagnosed with HIV but who are not HIV positive themselves. This is an important area for research as clinicians recognise that healthy siblings of chronically unwell young people experience significant difficulties. Therefore, this project aimed to explore the psychosocial impact HIV is having on HIV discordant siblings, as well as considering the impact of this on the sibling relationship.

Five sibling pairs (aged between 14 and 21), each consisting of one HIV positive and one HIV negative sibling, participated in face-to-face interviews with the author. This data was then subjected to Grounded Theory analysis which revealed 15 sub categories for the HIV positive group and 12 for the HIV negative group. Subcategories were subsequently arranged into a coherent framework before a group analysis was explored and a theoretical formulation describing the findings is offered. The theoretical formulation describes how the core categories that emerged from the research interact with one another whilst also detailing the systemic impact of HIV on the cognitive, affective and behavioural responses of participants. It emerged that both sibling groups struggle with the demands of secrecy in relation to HIV; both siblings manage disclosure anxiety and the threat of being exposed resulting from societal and cultural stigma associated with HIV. The sibling bond appears to be important to both. A family coping strategy of avoidance emerged for all families in that siblings offered a much needed source of support in discussing the taboo topic of HIV, often not openly discussed within the family. Participants discussed the influence HIV has had on their lives and the benefits of this were explored.

The theoretical formulations proposed by this project are considered within the context of the existing literature and implications for future research and clinical practice are discussed.

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ABBREVIATIONS

HIV:	Human Immunodeficiency Virus
AIDS:	Acquired Immune Deficiency Syndrome
PAH:	Perinatally Acquired HIV
PHIV+	Perinatally HIV positive individual (acquired HIV at birth).
PHIV exposed:	HIV negative individual with HIV positive loved ones.
HAART:	Highly Active Antiretroviral Therapy.
GLB:	Gay/Lesbian/Bisexual
QoL:	Quality of Life
GT:	Grounded Theory
IPA:	Interpretative Phenomenological Analysis
SCT:	Social Comparison Theory
MINI:	Mini International Neuropsychiatric Interview
COPE:	Carver Brief Coping Scale
REACH:	Reaching for Excellence in Adolescent Care and Health
CSM:	Common Sense Model
US:	United States
UK:	United Kingdom
WHO:	World Health Organisation
CET:	Coping Effectiveness Training
CF:	Cystic Fibrosis

1.0 INTRODUCTION

1.1 BACKGROUND TO HIV

The Human Immunodeficiency Virus (HIV) is a potentially fatal blood born condition that attacks a person's immune system, weakening its ability to fight infections and disease, and leaving the body vulnerable to opportunistic infections (Clark, Maupin, Hayes & Hammer, 2012). HIV was first identified in 1981 (De Cock, Jaffe & Curran, 2012) and in the three decades since its discovery the HIV epidemic has become one of the greatest challenges for global public health, with an estimated 36.9 million people currently living with HIV and over 34 million people losing their lives to HIV worldwide (The World Health Organisation, 2015). Currently it is thought that approximately 104,000 people are living with HIV in the UK, a prevalence rate of 1 in 615 people (Public Health England, 2015). Public Health England (2015) further states that over 6,000 new cases of HIV are diagnosed in the UK every year. Of those living with HIV in the UK, 44,000 are thought to be gay men and 54,000 heterosexual men and women; 2,160 men and women were infected through intravenous drug use.

HIV transmission can occur vertically (from mother to baby), or horizontally (acquired through direct contact with the virus via another person's blood or bodily fluid); horizontal transmission of HIV usually involves sexual transmission, (Janini *et al.* 1998). Vertical transmission of HIV is also referred to as perinatally acquired HIV (PAH) indicating that HIV infection passed from mother to baby during childbirth. Although there is no current cure for HIV, medical advances have seen this condition progress to become a chronic illness as opposed to a fatal acute diagnosis dependent upon the country a diagnosed individual lives in and local access to medications (Deeks, Lewin & Havlir; 2013). HIV medications known as Highly Active Antiretroviral Therapy (HAART) stop HIV from replicating within the body and allow the immune system to repair (Nosyk *et al.* 2013). If HAART is strictly adhered to, there is an extremely low risk of passing HIV onto another person and the individual living with HIV can live a healthy life, largely unaffected by the virus (Public Health England, 2015).

HIV is typically asymptomatic in that those living with HIV may appear and feel healthy or be unaware they are HIV positive. HIV will often not cause any signs

or symptoms for many years. During this time (between infection and the onset of physical symptoms), the virus remains active and causes progressive damage to the immune system. This process can take 10 years or longer. Marks, Crepaz and Janssen, (2006) highlight the difficulties for public health regarding this ‘hidden population’ as it is estimated that one in five people in the US are unaware that they are infected (Centre for Disease Control and Prevention, 2012a), a figure that is mirrored in the UK (Public Health England, 2015). This is particularly a concern given that 50-70% of new infections are spread by people unaware they are HIV positive.

It is fair to say that investment and research into HIV since it was first described in the 1980’s has been vast. However, funds and research have largely been geared towards developing an understanding of HIV from a biological view point, to the detriment of understanding more fully the psychological impact of the virus. Consequently, the need for psychological research regarding the human responses to HIV has been highlighted (American Psychological Association, 2002). This is an important area for research development as publications in HIV have dropped in the last 15 years (Higa *et al.* 2012). During this time HIV has become a chronic, manageable condition rather than the ‘death sentence’ this was once thought to be. Therefore, one might expect that human responses to this diagnosis have changed along with the illness and therefore the needs of people living with HIV have also changed. As such, a greater understanding is needed about how HIV impacts upon the person diagnosed, and their families.

1.2 THE CURRENT RESEARCH

This project is interested in the effect HIV is having on family members as well as those diagnosed. This research is particularly interested in the experiences of HIV from the perspective of adolescent siblings given that there is a strong evidence base to suggest that the demands on siblings of young people with a chronic health condition may be significant. Additionally, the experiences of young people living with HIV are less often researched, particularly the experiences of siblings affected by HIV but who are not HIV positive themselves.

1.3 LITERATURE REVIEW

This chapter will review current literature that explores the psychological impact that HIV has been found to have in both adult and youth populations in order to develop an understanding of some of the challenges that those who are HIV positive face. Given that this project is primarily interested in the psycho-social experience of HIV discordant siblings, this review will then consider research that focuses on the psychological consequences of being diagnosed with other chronic illnesses, both for the diagnosed adolescents and their healthy siblings. Exploring this area of research will help draw comparisons between HIV and other chronic health conditions in order to ascertain whether the psychological experience of HIV differs from that of other illnesses. Finally, this review will consider the current literature that specifically details the experiences of siblings affected by HIV.

1.3.1 Adult HIV research

This section will draw on the HIV literature conducted within Sub-Saharan Africa and the US in order to investigate the psychological responses observed in those who are HIV positive.

1.3.2 Investigating the psychological consequences of HIV for adults in Sub-Saharan Africa.

Research into the psychological effects of HIV has predominantly been conducted in Sub-Saharan Africa (Salomon, Gakidou & Murray, 1999) given this is where the HIV epidemic is most prevalent. However, understanding how HIV is impacting upon a Sub-Saharan population is a complex task given that Sub-Saharan Africa comprises of 44 countries that differ significantly in terms of wealth, education, and levels of healthcare. Therefore, a review of this research will be given in order to explore findings that are potentially applicable to a British population.

Olley, Seedat, Nei and Stein (2004) explored predictors of depression amongst a group of Sub-Saharan African patients who recently received a diagnosis of HIV. It has long been known that major depression impacts the course of HIV, yet little has been done to understand the demographic and clinical predictors of depression in people living with HIV. Olley *et al.* (2004) identified predictors of major depression as demographic and clinical variables, negative life events and

coping responses. Participants included 149 recently diagnosed patients (105 females, 44 males) who were assessed using the Mini International Neuropsychiatric Interview (MINI), the Sheehan Disability Scale and the Carver Brief Coping Scale (COPE). It was concluded that the variables: gender, impact of negative life events and disability predicted major current depression. Although it is known from research involving non-HIV samples that female gender and negative life events can have an impact upon depression, what is relevant here is that with a HIV positive client this may impact on the course of the HIV virus. For example, negative life events may speed up any deterioration or need for treatment in those living with HIV, which in turn may increase episodes of depression and anxiety.

Similar results have been noted by Freeman, Nkomo, Kafaar and Kelly (2007), who examined the association between mental disorder and HIV diagnoses in five Sub-Saharan African countries. This study recruited 900 HIV positive individuals who were all administered a composite International Diagnostic Interview to determine the presence of mental illness in terms of identifying any diagnosable mental health condition. In addition to this participants also took part in a structured interview which supported the assessment by highlighting other factors which may have contributed to mental illness. It was found that the overall prevalence of mental illness was 43.7%. However, it was also found that as HIV progressed so did the rates of mental disorder. For example, in what they describe as stage three of HIV, rates increased to 49.7% and by stage 4 they increased again to 68%. Only 18% of participants had access to anti-retroviral treatment at the time of study. Freeman *et al.* (2007) concluded that having pre-post-test counselling was not related to mental disorder, nor were the number of sessions or the professional status of the counsellor. It was found that being religious was helpful for the clients. However, being in a HIV support group was associated with mental disorder as was disclosing HIV status to others. Additionally, being isolated from the community and the experience of discrimination as a result of a HIV diagnosis were, unsurprisingly, associated with mental disorder. Finally the death of a significant other who also suffered from HIV/AIDS was also related to mental illness.

Findings like these suggest a strong need for the provision of psychological care for those individuals affected by HIV. A criticism of the Freeman *et al.* (2007) study, however, is that it fails to define what they refer to as 'stages of HIV' and it is

therefore difficult for the reader to interpret the meaning of stages three and four, as used in the paper. In contrast, The Terrence Higgins Trust, (2015) clearly describe three stages of HIV infection; stage 1, HIV infection without symptoms (shortly after the point of HIV infection). Stage 2, HIV infection with symptoms (a point where the individual experiences illness as a result of HIV weakening the immune system), and stage 3, later-stage HIV. At this later stage a person may become seriously ill with HIV related illness such as certain cancers.

Lawler *et al.* (2011) examined the incidence of depression among a group of 120 HIV positive individuals in Botswana, Sub-Saharan African. All participants were administered a measure of daily activities combined with two measures of depression. It was found that 38% were diagnosed with depression and as many as 12% displayed suicidal ideation. Depression was also correlated with a significant reduction in daily activities as well as a reduction in adherence to HIV medications. Findings like these support previous research suggesting the notion of a high prevalence rate of depression in HIV positive clients in comparison to the general population.

In an additional Sub-Saharan African study, Akena, Musisi and Kinyanda (2010) noted that depressive illness is the most common psychiatric difficulty associated with a HIV diagnosis, with its prevalence two to three times higher than in the general population. However, this study questioned whether HIV related depression is clinically different from depression in HIV negative populations, a fact that would have far reaching treatment implications. Akena *et al.* (2010) compared the clinical features of major depression between HIV positive and HIV negative patients with a view towards intervention strategies. A comparative, descriptive, cross-sectional study was carried out with 64 HIV positive depressed clients and 66 HIV negative depressed clients in Uganda. Participants in this study were compared along the parameters of the clinical features of depression. Pair-wise comparison, logistic regression and multivariate analysis were used for the two groups on several variables. Results indicated that HIV positive participants were more likely to be self-critical, had significantly more problems with decision making, suffered higher rates of fatigue and also experienced poorer sleep, as well as displaying more cognitive difficulties. As with previous research it was found that rates of depression increased with the progression of HIV, i.e. at stages 2 and 3.

In summary, these findings show that clinical and associated features of depression differ between HIV positive and HIV negative individuals. Therefore, it can be argued that those people living with HIV and depression require different management approaches. On the other hand, it is worth considering that the nature of stressors affecting a person with HIV are likely to be different and therefore this may offer, at least in part, an explanation for the difference in patterns of depressive symptoms between the two groups analysed.

1.3.3 Global research investigating the consequences of HIV for adults

Lesserman (2008) reviewed international articles to investigate the role of depression, trauma and stress in HIV progression. It was noted that, despite major advances in treatment, great variability remains in the progression of this illness. Evidence suggesting that depression, stressful life events and trauma account for some of this variation were reviewed including longitudinal studies both before and after the advent of Highly Active Antiretroviral Therapies (HAART). A complete review was conducted using PubMed, searching for all English language articles from 1990-2007. Lesserman (2008) found substantial and consistent evidence that chronic depression, stressful events and trauma may negatively affect HIV progression in terms of decreased CD4 cells and increased viral load, introducing a greater risk of clinical decline and mortality. It was recommended that more research is needed to understand the psycho-immune relationships. It is important to develop an understanding of the negative health impact of depression and healthcare providers should be working towards addressing these difficulties as part of a standardised package of care.

1.3.4 Investigating the psychological consequences of HIV for adults in the United States.

HIV research conducted outside of Sub-Saharan Africa is largely based in the US where government funding and resources are significant, due to the high numbers of HIV positive US citizens. Below a review of this research will be given in order to explore findings that are potentially applicable to a British population.

Chesney and Folkman (1994) used qualitative interviews to explore the psychological impact of HIV in 40 homosexual men in the US (20 HIV+ and 20 HIV-). They discuss the stress associated with HIV and the psychological

implications of this stress as well as the complex issues that HIV positive people encounter in managing their diagnosis. HIV positive participants described psychological consequences of their illness to include depression, anxiety, somatic complaints and suicidal ideation. This article also considered existing research on behavioural interventions such as coping effectiveness training (CET) designed to help HIV positive clients cope with their illness. CET is an approach which emphasises the development of existing coping skills. CET training seeks to facilitate an individual or group's ability to approach and manage stress in a more helpful manner, via a range of problem-focused coping strategies, by changing problematic aspects of stressful situations (Chesney, Folkman & Chambers, 1996). Chesney and Folkman (1994) found that CET is likely to improve coping, depression and morale in HIV positive individuals.

Heckman *et al.* (2002) focused on the mental health needs of adults 50 years of age and over who are living with HIV in two large U.S. cities. Eighty three participants (mean age 55.2) were asked to complete a self-report survey which elicited data on psychological symptomology, HIV related life-stressor burden, social support, barriers to healthcare, and social services. Using the Beck Depression Inventory (BDI), 25% of participants reported moderate to severe levels of depression as well as elevated symptoms characteristic of somatisation. This research also highlighted that participants with depression felt significantly higher HIV-related life-stressor burden, less support from family and friends and stress related to HIV stigma. These results suggest that adults are experiencing psychological difficulties related to their HIV diagnosis whilst also highlighting a lack of support felt from family members.

Linn, Monnig, Cain and Usuh (1992) investigated the psychological functioning of people diagnosed with HIV in community populations. Data was obtained from 156 HIV positive adults who sought support from counselling services from one of three HIV care and referral centres in the mid-south (US). The objective of this study was to test the hypothesis that levels of depression could be predicted by stage of HIV. Results indicated that symptoms of anxiety and depression were high in HIV positive individuals and moreover that these symptoms were exacerbated with the progression of HIV and a person's decrease in physical health. However, this study also emphasised the importance of the individual's perceptions

of their physical symptoms in relation to their depression and psychological functioning. This study does highlight that psychologically, people with HIV are vulnerable to psychological difficulties, although the sample used were those who sought help for these symptoms and this research does not represent the wider HIV population who may not suffer in this way.

In contrast to much of the above research, a U.S. study by Dunbar, Mueller, Medina and Wolf (1998) used qualitative interviews with HIV positive women. Thirty four women were recruited into this project on a voluntary, state wide basis in the US. This research focused on open ended questions looking at areas such as HIV as a source of stress, coping strategies, desire for further formal and informal support, and positive outcomes of living with HIV. Interestingly, this research highlighted positive outcomes associated with rebuilt relationships, newfound values, a sense of purpose and meaning in their lives and discoveries of a connection with nature and faith. This research highlights that there are positive outcomes associated with HIV. However, this research focuses on adult women and does not specify whether they were horizontally (transmission through contact with bodily fluids) or vertically (passed from mother to child) infected.

The research discussed seems to produce a consensus that HIV has far reaching consequences not only for those diagnosed, but also those close to them in terms of emotional, physical and social vulnerabilities. Moreover, this may, at times, have an effect on domains such as education and employment, further perpetuating the cycle of depression and anxiety, amongst other mental illnesses. Research has consistently shown that rates of mental illness are significantly greater in those people living with HIV than the general population. However, it is important to note that there are individual differences in the path from HIV diagnosis to mental illness as many individuals with HIV adjust well to their condition and live full and psychologically healthy lives.

1.3.5 A critique of Sub-Saharan African and US adult HIV research.

A criticism of the research above is that this focuses exclusively on Sub-Saharan African and US populations and therefore brings into question how far these findings can be generalised to a British group, given that cultural differences such as

access to medications, education, and higher quality healthcare are unaccounted for (Di Cesare *et al.* 2013). A UK population remain largely understudied in relation to HIV which is, in part, understandable given that Sub-Saharan Africa is significantly most affected by the HIV pandemic. However, despite apparent cultural differences, there are also cultural similarities that need to be considered in terms of access to HIV medications, in both the US and the UK particularly. In the US, citizens are also granted access to medication, although this is via financial support from health insurance companies as opposed to healthcare being free at the point of access in the UK. Those US citizens who are financially challenged are able to receive support from The Ryan White Comprehensive AIDS Resource Emergency Act (Ryan White Care Act). The Ryan White Act (2009) is to date the largest funded initiative in the US that ensures funding for HIV medication and treatment for low-income families, non-insured and under-insured people requiring treatment for HIV. The Ryan White Care Act (2009) now functions as a 'last resort' funding option for those families for which all other options have been explored and declined. It has been in operation for over 25 years and currently receives government funding of \$2.32billion annually. As of 2015 it provides care in terms of medical treatment for approximately 52% of all HIV positive people living in the US (US Department of Health and Human Service, 2015). Therefore, this act represents a vital part of the care offered to US citizens allowing all who require it much needed access to medications that allow those people to live long and healthy lives.

However, whilst considering the similarities and differences in a cultural context it remains that more research is needed to develop our understanding of how HIV is affecting young people in Britain. It is clear when conducting a literature review that youth culture, especially outside of the African continent, is often overlooked. This leaves a clear gap in the research that needs to be filled if we are to offer high quality psychological services to younger people living with HIV in Britain.

1.3.6 Adolescent HIV research

In this section the literature pertaining to adolescent HIV research will be discussed. Again, research conducted in Sub-Saharan Africa and the US is evaluated here.

1.3.7 Overview of perinatally acquired HIV in the UK.

In April 2000, The Collaborative HIV Paediatric Study (CHIPS) was established. CHIPS is an NHS funded longitudinal cohort study collating data regarding all HIV positive young people receiving care in the UK and Ireland. The objective of CHIPS is to obtain clinical data related to this population that describes treatment and use of services with a view towards enhancing the exchange of information between experts on a national level, in an attempt to increase clinical knowledge and promote expert care in a standardised form.

By June 2015, a total of 1,934 children were enrolled to CHIPS, of which 979 were actively being followed up. According to data reported by the National Study of HIV in Pregnancy and Childhood (NSHPC), 955 young people were receiving care from paediatric services in 2014. The median age of young people identified as having a HIV diagnosis and being seen in paediatric care at this time was 14. Year on year the median age of this cohort gradually increases owing to an increased number of young people transitioning to adult services and a reduction in new diagnoses following advances in prevention of mother-to-baby transmission during childbirth. For this reason, the number of young people in CHIPS also declines every year. The NSHPC and CHIPS (2015) describe demographical data regarding the 979 young people currently in follow up. CHIPS (2015) report that 53% of the cohort were female whilst 47% were male. Moreover, 50% of young people in active follow up with CHIPS were born in the UK. In terms of ethnicity, 78% of the cohort were of black African ethnicity, 6% were white, 10% were of mixed race, 1% were recorded as black other, 1% were Indian, and 4% were recorded as either 'other' or 'unknown'. CHIPS report that 48% of the cohort were receiving specialist HIV care in London and 52% are located throughout the rest of the UK and Ireland.

When considering clinically relevant data, CHIPS report that 5.1% (55 young people) were admitted to hospital between the years 2000-2013 for hospital based treatment. Furthermore, it is recorded that of the 979 young people in active follow up, 9% were not receiving any medication for HIV, 8% were receiving dual therapy, and 33% remained on their initial combination therapy, while 46% were receiving a subsequent combination therapy. A further 5% had discontinued drug therapy. Interestingly, in 2015 a large number of the CHIPS cohort (75%) had a suppressed

viral load (an undetectable amount of HIV virus in their bloodstream) in comparison to only 39% in 2004.

1.3.8 Global research investigating the effects of HIV on adolescents.

Mellins and Malee (2013) conducted a comprehensive literature review considering the mental health functioning of young people with perinatally infected HIV. This review pays particular attention to the risk factors for PHIV+ young people on their mental well-being. An extensive review of well sourced online databases such as PubMed, MEDLINE and Psychinfo was conducted. Only articles that included PHIV+ youth (age 10 or above); mental health outcomes; and mental health treatment were included in this review. A search of the databases revealed 93 papers in total although only 38 of those met the inclusion criteria for the review. Papers were not excluded based on country of origin. It was concluded that PHIV+ youths experience emotional and behavioural problems including psychiatric illness. This group were found to experience psychiatric disorders at higher rates than was hypothesised, often exceeding those observed in the general population and other high risk groups. The review indicates that factors such as child health status, cognitive function, parental physical and mental health and other stressful life events are associated with worse mental health outcomes for PHIV+ young people. Parental communication and social support were associated with greater functioning and outcome in terms of mental well-being. In conclusion, Mellins and Malee (2013) report a significantly high risk of mental health difficulties for PHIV+ young people. However, this review is unable to determine whether HIV as a condition was the cause of any psychiatric complaints or whether other factors such as stressful life events, poverty, and individual factors were more closely linked with poor mental health outcomes. Furthermore, the majority of articles reviewed were conducted in the US and Europe, therefore failing to account for the experiences of those PHIV+ young people outside of those areas. Nevertheless, this article clearly demonstrates a vulnerability to psychiatric disorder for PHIV+ young people.

1.3.9 Investigating the effects of HIV on adolescents in Sub-Saharan Africa.

Being HIV positive, particularly for young people with perinatally acquired HIV, presents a wide array of challenges for the HIV positive young person to

navigate. In addition to the difficulties of adolescence, which mark a challenge for most young people, the HIV positive young person must also cope with the demands of their illness.

Evangelini and Foster (2014) describe how the emergence of sexuality and an interest in developing sexual relationships are fundamental aspects of developing a sexual identity. However, for HIV positive young people this typical aspect of development is further complicated by the management of a sexually transmittable illness, one that is heavily stigmatised within society. Sohn and Hazra (2013) propose that it is not uncommon for HIV positive young people to have experienced long histories of treatment via medications and also experience the failure of such treatments. Mellins and Malee (2013) further argue that the HIV positive young person is exposed to additional stressors that are linked with having a chronic illness, for example; the experience of pain, hospitalisation, and lower school attendance which consequently may have an adverse effect upon social opportunities. These factors contribute to a picture of a struggling child, vulnerable to mental health difficulties. Mellins and Malee (2013) additionally highlight that many HIV positive young people will typically live in a household with one or more parents who are also HIV positive. Therefore it is reasonable to assume that those young people may then have experienced shifts in who provides care following parental illness or even death. This introduces additional complications in disclosing one's own HIV status for fear of inadvertently disclosing parents HIV status also (Hogwood, Campbell & Butler, 2013). In addition, for those young people who have lost parents or relatives to HIV, this can serve as a real reminder of their own mortality and can lead to predication or beliefs about one's life and death.

The World Health Organisation (2011) estimates that half of the global HIV population acquired the virus between the ages of 14-24. Despite this, adolescent populations have been the focus of relatively few studies. Similar to the research described regarding adult populations, much of the research regarding children and HIV is also primarily conducted in the US and Sub-Saharan Africa, and therefore relevant literature will be explored.

Foster and Williamson (2000) noted that little attention has been paid to children effected by HIV/AIDS and suggested that a greater understanding of the

impact of HIV/AIDS on children is vital in the design and evaluation of programmes to support children living with the difficult circumstances that HIV introduces into their lives. Foster and Williamson conducted a literature review investigating the psychosocial impact of children across Sub-Saharan Africa living with HIV. It was found that children experience a significant decrease in their quality of life following a diagnosis of HIV. The majority of HIV positive children in these communities have an increased sense of mortality and health anxiety through exposure to others with more advanced symptoms. In addition, those children may experience distress when parents provide care for relatives affected with HIV, or are orphaned if parents pass away themselves through HIV. Foster and Williamson hypothesise may ultimately see those children turn to the streets, removing a sense of stability from early life in the context of HIV.

Gachuhi (1999) furthers the notions of Foster and Williamson (2000), arguing that children are the most affected by the HIV/AIDS pandemic. For example, they may be left emotionally and physically vulnerable by the illness or death of one or both parents. Gachuhi (1999) focused on the effect HIV has on the educational system in eastern and southern regions of sub-Saharan Africa (Zimbabwe, Malawi, Namibia, Uganda, Lesotho, Botswana and Swaziland) finding that children living with HIV were less likely to be sent to school as family resources were focused on fighting the illness. At this time fewer children were being born, which means the numbers of children educated in Sub-Saharan Africa year on year decreases as HIV diagnoses increase. It was also noted that the quality of learning outcomes for children living with HIV who attend school with high levels of stress were also poor. Finally, it was also speculated that children living with HIV who were withdrawn from school or unable to attend, would not benefit from an education system which promotes positive behaviour and this may subsequently translate to inappropriate, higher risk behaviours later in life. When this information is considered alongside many HIV affected children's high stress levels, without an appropriate outlet or support for this stress, a picture emerges of a disadvantaged and vulnerable child.

1.3.10 Investigating the effects of HIV on adolescents.

Research appears to confirm the notion that young people living with perinatally acquired HIV exhibit high levels of psychological adjustment difficulties (Gaughan, Hughes, Oleske, Malee, Gore & Nachman, 2004; Gosling, Burns, & Hirst, 2004) and that this is higher than observed in healthy children (New, Lee, & Elliot, 2007).

Hein, Dell, Futterman, Rotheram-Borus and Shaffer (1995) investigated differences between HIV positive and HIV negative adolescents in New York City (U.S.) in terms of social and psychological status and detailed sexual and drug use practices. The aim of this research was to assess the ability of health belief and risk taking models to predict sexual behaviour and drug use in adolescents living with HIV. 72 HIV positive and 1142 HIV negative adolescents (ages 13-21) took part in a 207-item structured interview. However, only data from participants reporting sexual intercourse were analysed (71 HIV + and 722 HIV -) using logistic regression analysis over five domains. Hein *et al.* (1995) found significant differences in sexual risk acts based on HIV status and gender. This data also revealed that HIV positive adolescents were significantly more likely to have been sexually abused (33% vs. 21%), to engage in unprotected sex with casual partners (42% vs. 23%), have other sexually transmitted diseases (59% vs. 28%), use multiple drugs (43% vs. 9%) and engage in multiple problem behaviours (72% vs. 30%) than HIV negative adolescents. It was concluded that confidential HIV counselling and testing should be offered for adolescents practicing unprotected sex. It was also noted that care teams should consider adolescents histories of abuse, homelessness and other social and psychological factors when designing and implementing comprehensive care strategies that address the needs of a HIV positive youth cohort. Finally it was recommended that current health and risk models be reconsidered given their lack of association with HIV risk acts in an adolescent population. It must be noted that Hein *et al.* (1995) did not ascertain whether risk behaviour pre-dated the acquisition of HIV and therefore a causal relationship between HIV diagnosis and risk behaviour cannot be established. Furthermore, other potential factors such as extreme poverty were not accounted for.

Murphy, Moscicki, Vermund and Muenz (2000) conducted research with the aim of investigating the effects of life events, social support and coping on anxiety and depression among HIV positive adolescents living in the U.S. Murphy *et al.*

(2000) hypothesised that higher levels of stressful events would be associated with higher levels of both depression and anxiety. It was further hypothesised that this association would be mediated by satisfaction with social support and adaptive coping. 230 adolescents (median age = 16.09) from 13 U.S. cities were recruited into the Reaching for Excellence in Adolescent Care and Health (REACH) project. REACH was the first large scale disease progression study of HIV positive adolescents who had acquired HIV through sexual behaviour or drug use via injection. This study used an audio-computer assisted self-interview and least squares regression to test the above hypotheses. It was found that difficult life events were associated with depression and anxiety, some of these events that reoccurred for many participants included being prescribed medication for HIV (74%) as well as family financial problems (61%) and parental alcohol abuse (20%). Although significant life events were associated with psychological distress in a cohort of HIV positive adolescents, neither social support nor adaptive coping styles appeared to mediate this link. However, both adaptive coping and satisfaction with social support were correlated with lower levels of depression.

Lam, Naar-King and Wright (2007) aimed to describe the mental health symptoms of HIV positive adolescents in Detroit, Michigan (U.S.). 66 HIV positive young people took part in an interview and were administered the Brief Symptom Inventory (BSI) in order to evaluate social support, physical status and disclosure as predictors of symptoms of mental illness. Results indicated that 50% of the participant group scored above the cut-off for clinically significant mental health symptoms, highlighting a clear need for mental health services for this group of young people. This study also highlighted that lower social support, being gay/lesbian/bi-sexual (GLB), higher viral load and disclosure to acquaintances were all significantly correlated with more mental health symptoms. However, disclosure to family and friends and contact with services was not. Equally, these findings cannot account for cause and effect. It is understood that disclosure of one's HIV status for example is correlated with an increase in mental health symptoms. However, it is not understood whether disclosing one's status causes a decrease in psychological functioning or whether a struggle with mental health symptomatology led individuals to disclose their status and seek help. Nonetheless, this research suggests that mental health interventions for people living with HIV are vital, and it

was also suggested that further research on the role of stigma and homophobia are warranted.

Hosek, Harper, and Robinson (2002) conducted a study in Chicago (U.S.) with the purpose of qualitatively exploring how the formation of an adolescent's identity may be influenced by the presence of HIV. Eight HIV positive adolescents (3 male 5 female) aged 17-21 participated in a semi-structured interview that was combined with measures of identity development. Results indicated that all participants fell into diffusion or achievement identity statuses. Five of the sample (62.5%) fell into the diffusion identity status, a group marked by an apathetic response and almost purposeful avoidance of any reference to HIV. Clients were reported as having used euphemisms in its place such as 'my situation'. Participants in this group also portrayed a great deal of thought avoidance and reported actively avoiding thinking about their HIV diagnosis believing this would worsen their health and cause more distress. Conversely, for those in the "achievement identity" status, it would appear that receiving the diagnosis may have facilitated and expedited the identity formation process. It was hypothesised that perhaps the knowledge that their life might end may have pushed the adolescents to begin the exploration and commitment process earlier so that they might achieve their goals. On the other hand those who fear their life is limited may fear setting goals that may not be achieved which may inhibit the exploration of identity issues, promoting the avoidance of commitment. Hosek *et al.* recommended, given the lack of literature published regarding HIV positive adolescents, that there is a clear need to explore the developmental impact of this illness on youths in particular; it would be useful to understand what contextual factors influence whether an adolescent is encouraged towards identity achievement or diffusion.

Dorell, Earle, Katz and Reveley (2008) also conducted a qualitative research project investigating the experiences of young people who have acquired HIV perinatally with a view to developing an understanding of how HIV is affecting the lives of young people in the UK. Participants were PHIV+ young people ages between 13-24 years who had been aware of their HIV status for a period of more than one year. Qualitative analysis revealed many themes however only two "living with death" and "living with loss" are discussed in this paper. The theme of "living with death" encompassed a strong expectation on the part of many participants that

they would die or that death was inevitable. Those participants often had experiences of familial death due to HIV/AIDS and witnessing this trajectory had a profound effect on those young people. The “living with loss” theme described what participants felt HIV had taken away from them e.g. the loss of a parent or sibling, the loss of social relationships or connectedness due to the secrecy that is an important aspect of managing the stigma of HIV. Dorell *et al.* (2008) concluded that HIV is understandably difficult for young people to navigate and manage. Despite new treatment prolonging the lives of HIV positive young people, the social stigma of HIV remains and the difficulties associated with secrecy around HIV leave those young people feeling isolated and cut-off from others. This research marks an important step forward from the quantitative research already described. It is not enough that we understand HIV is having an impact upon the well-being and mental health of young people, we must seek to understand why and in what ways this is having an impact.

Van Nuil *et al.* (2014) conducted further qualitative research with PHIV+ adolescents in Rwanda. This project aimed to explore adolescents’ views on sex, love, marriage and their future. 42 adolescents who had received HAART for a minimum of 12 months were recruited into this study, along with a selection of their caregivers. Participants were asked to take part in three multiple day workshops that included role-play, eight in-depth interviews and focus groups for adolescents and one focus group for caregivers. Results showed that most adolescents typically experienced normative sexual desires and dilemmas in comparison to their non HIV affected peers. However, participants reported additional complexities resulting from HIV in terms of potential transmission and perceived rejection from romantic partners. Results also highlighted that although participants struggled with anxiety in relation to aspects of love, sex and marriage, almost all participants agreed that they would overcome those barriers, find love, get married and have children which suggests that a positive outlook on the future was held by participants. Therefore it was concluded that improving the skills of HIV positive adolescents around issues of disclosure may both reduce HIV transmission and also improve the quality of life and emotional well-being in terms of reducing the levels of anxiety experienced by those young people.

In similar research Busza, Besana, Mapunda and Oliveras (2013) explored how HIV positive adolescents in Tanzania experience their sexuality as part of an evaluation of a home based care programme. In this study 14 adolescents aged 15-19 who were PHIV+ were recruited, along with 10 of their primary care givers and 12 volunteer home-based care providers. Results revealed that adolescents experienced anxiety regarding their sexuality expressing that sex was hazardous and inappropriate for someone who is HIV positive. Worries emerged around disclosure to romantic partners as well as onward transmission to partners. Many PHIV+ adolescents expressed an expectation that they would abstain from sex indefinitely. It was also noted that caregivers and home-based care providers were reinforcing negative views towards any sexual activity for those who are HIV positive partly due to misconceptions around the harmful effects of sex when one is HIV positive. In conclusion it is suggested that care programmes would greatly benefit from facilitating open communication between HIV positive adolescents and their caregivers/providers regarding sexual activity to help bridge the gap between a lack of knowledge and appropriate guidance and care for PHIV+ adolescents.

The research described above by Van Nuil *et al.* (2014) and Busza *et al.* (2013) demonstrates an important contribution to the field in terms of qualitative research helping to develop a detailed understanding of how HIV is impacting on a youth population. However, this research is primarily focused on investigating the impact HIV is having on adolescents' perceptions of sex and love and is therefore limited in its ability to offer insight into the broader impact of having HIV on young people. Furthermore, this research is again conducted in Sub-Saharan Africa and highlights a lack of comprehensive sexual and reproductive health services. The same cannot be said for a British youth population with PHIV and therefore the experiences of this group in the UK may be different.

Greenhalgh, Evangeli, Frize, Foster and Fidler (2013) have conducted similar research within the UK. The authors highlight that there is little research attempting to understand the effects HIV has on intimate relationships for those young people in the UK who have grown up HIV positive. Greenhalgh *et al.* (2013) therefore conducted a qualitative study exploring in detail the experiences of PHIV+ young people regarding intimate relationships, and exploring participants' perceptions on how they experienced growing up with HIV and the effect this may have had on

those relationships. Seven participants (5 female, 2 male) aged 18-23 were recruited for interviews. Data were then analysed using the principals of IPA. Results highlighted three major themes of the research; HIV being viewed by partners as being linked to AIDS and HIV transmission, discrepancy between young peoples and their partners' views of HIV, and partners' views of risks of HIV transmission. The authors observed a connection between participants' experiences and personal challenges associated with HIV. It was concluded that support for young people around disclosing their HIV status to romantic partners is needed.

Evangeli, Greenhaul, Frize, Foster and Fidler (2014) further developed this work by exploring the effects HIV has specifically on PHIV+ young people's desire to become parents. The authors note that there remains a limited amount of empirical research regarding the intentions of PHIV+ young people to become parents. Evangeli *et al.* assert that during adolescence achieving intimate relationships and becoming parents are perhaps normative and important goals for young people. However, PHIV+ young people face additional challenges connected to parenting and relationships such as managing HIV transmission and HIV disclosure. Evangeli *et al.* (2014) conducted a qualitative study, recruiting seven participants aged between 18-23, two of whom were parents. All participants were recruited through a UK hospital clinic. Participants were asked to take part in a semi-structured interview and these data were then analysed using Interpretive Phenomenological Analysis. Four main themes emerged from the data; the perceived impact of having a child on intimate relationships, the effect of normative beliefs on parenting intentions and expectations, thoughts and feelings about disclosing HIV status to one's children in future, and the perceived impact of HIV on procreational intentions. It was concluded that PHIV+ young people do wish to become parents and are thinking about issues regarding parenting such as HIV disclosure. It is recommended that parenting intentions be assessed and that PHIV+ young people are supported to help explore parenting considerations via open communication either in individual or group sessions.

Rydström, Ygge, Tingberg, Navèr and Eriksson (2013) also conducted qualitative research in order to study the experiences of adolescents and young adults growing up with HIV in urban Sweden. Rydström *et al.* (2013) noted that there is a lack of empirical data that specifically details the experiences of living with HIV

since early childhood. As such they conducted a qualitative study relying on semi-structured interviews with 10 PHIV+ adolescents over an eight month period. Data was then transcribed verbatim and analysed using content analysis. The findings demonstrate five major themes; protect self from stigma, to be in control, losses in life but HIV is not a big deal, Healthcare and healthcare providers, and belief in the future. This study concluded that it is essential for those involved in the care of PHIV+ young people to offer safe, trustworthy, and professional healthcare throughout the childhood of the young person. The need for interventions that improve the care and support received, particularly focused on managing the stigma associated with HIV and social discrimination.

1.3.11 A critique of adolescent HIV research.

There is little research that particularly focuses on adolescents and the impact of a HIV diagnosis, and even less looking at adolescents and their siblings who may also be affected by this illness. The research available appears to highlight similar themes to those conducted with adults in that adolescents who are HIV positive may be more likely to engage in risky, challenging and problem behaviours (Hein *et al.* 1995; Gachuhi, 1999). However, we do not know why this is. Research has explored possible influences but there is no clear explanatory consensus. We need to know more regarding the challenges young people face when HIV affects the family from the perspective of the young person.

Interestingly, some research (Corona *et al.* 2008; Bettoli-Vaughan, Brown, Brown, & Baldwin, 1998) has identified that those affected by HIV but who are not HIV positive (e.g. family and friends of those diagnosed) appear to report significantly more challenges in terms of mental illness, something already known to be present in those adolescents with HIV. Thus far, the emphasis in research has mostly been on the HIV positive person. Whilst this is understandable, there are also significant others who do not have HIV themselves but who nevertheless may be affected by this illness and who may also place considerable demands on services (Campbell, Griffiths, Beer, Legemah & Saine, 2014). Therefore, more research is needed on how HIV impacts on healthy siblings and also how this differs from the impact on the young person living with HIV.

It should also be noted that similar to other areas of HIV research, the majority of the research on healthy siblings has been conducted in the U.S. and Sub-Saharan Africa. Although it provides some insight into how HIV is impacting on different countries and societies, there may well be important differences for those living in the UK.

1.3.12 Understanding the healthy siblings of children with a chronic illness

In addition to the impact a health condition has on the diagnosed child, research also asserts that healthy siblings of chronically unwell children also experience difficulties (Barlow & Ellard, 2006; Waite-Jones & Madill, 2008). When a child becomes ill it follows that this may lead to situational crises that bring about emotional distress throughout the family (Holmes & Deb, 2003). For the healthy siblings of ill children it can be understood that they may experience being treated differently by caregivers as the unwell child can often be perceived as the most vulnerable and ‘needy’ and therefore family resources are often prioritised disproportionately towards them (Vermaes, van Susante & van Bakel, 2012). Healthy siblings may also be required to take on additional roles and responsibilities that are inconsistent with their age and development, such as becoming a carer for their sibling (Coffey, 2006). As previously discussed, the available literature regarding the psychological effects of HIV on a youth population is sparse, with even fewer studies exploring the effects HIV has on healthy siblings. Therefore, a review of relevant literature pertinent to the psychological consequences other chronic health conditions has for healthy siblings will be discussed below in order to paint a picture of how chronic health issues impact on adolescents.

Sharpe and Rossiter (2002) reviewed literature pertaining to the siblings of children with chronic health conditions. 51 studies were identified and reviewed. This found that psychological functioning (depression and anxiety) as well as peer activity and cognitive functioning were all scored significantly lower statistically for siblings of children with chronic health conditions when compared with controls. Again this research promotes the idea that siblings of chronically ill children are at high-risk for negative psychological consequences. This review also calls for more methodologically sound research which investigates the psychological functioning of siblings of children with a chronic illness.

More recently, Alderfer *et al.* (2010) conducted a systematic literature review focussing on the impact of childhood cancer on siblings. 65 papers were found covering qualitative, quantitative and mixed methodologies. Results indicated that a significant portion of siblings experience post-traumatic stress symptoms, negative emotional reactions (such as fear, helplessness and guilt) and poor quality of life in emotional, family and social domains. Qualitative research reveals family level themes such as loss of attention and status as well as positive outcomes such as maturity in the healthy sibling and greater empathy. This review concluded that research regarding siblings remains methodologically limited but despite this siblings of children with cancer remain a psychosocially “at risk” group who should be provided with appropriate and supportive care.

We have known for some time that siblings of chronically ill children are vulnerable to psycho-social difficulties. For example, Cadman, Boyle & Offord, (1986) focused on the risk of psychiatric disorders and social maladjustment among the siblings of children with chronic health conditions in Ontario, Canada. 3,294 children aged 4-16 completed a general population survey and 1,869 children were randomly selected for the purposes of this study. It was found that the siblings of children with a chronic health condition presented a statistically significant, 2-fold increase in the risk of emotional disorders, including depression, anxiety, and obsessive compulsive disorder. A 1.6-fold increase in the risk of relationship difficulties was also observed as well as an increased risk of conduct disorder in 12-16 year olds. This research shows a clear need for clinicians to assess the mental health and adjustment of clients’ siblings. Although this study used a large cohort of participants, Cadman *et al.* (1986) focused on an overarching theme of chronic illness and did not break this down into specific illness sub-types. It is fair to suggest that each illness will present unique complications that intrude on the patient’s life in varying ways. Therefore, it may not be appropriate to group these unique experiences together to describe an equal reaction to those.

A study conducted in India, Rajajee, Ezhilarasi and Indumathi (2007) aimed to understand the psychosocial impact that childhood cancer can have on the family. 34 mothers of children diagnosed with cancer were included, of which 15 belonged to joint families (large extended families) and 19 to nuclear families (small families’ i.e. only parents and children). The results indicated that family support played an

important role in providing emotional sustenance as well as shared care of the ill child, the sibling and the home. Results indicated that the impact was most felt by the mothers of the ill child, however, it was also reported that the siblings were also affected both by way of school performance and behavioural difficulties. Mothers also reported that the child with the cancer diagnosis also showed signs of behavioural disturbances such as the physical and verbal abuse towards their mothers over time. Rajajee *et al.* (2007) concluded that the family structure was the foundation of psychological and emotional security and that professional psychological support would facilitate and enhance this for families affected by major chronic illness.

In a U.S. study, Ferrari (1984) focused on the adjustment of siblings in three groups of male children: children with pervasive developmental difficulties, children with diabetes and children with no known chronic illness. Interestingly this research did not find evidence to support the view that siblings of chronically ill children are uniformly at an increased risk of psychosocial impairment. Despite this, evidence was found in several domains to support the notion that both siblings and the mothers of chronically ill children were more susceptible to adjustment problems. It was noted that risk seemed to relate more closely to illness specific variables as opposed to the presence or absence of a specific illness. It was also noted that sex differences were found to suggest that same sex sibling pairs may be significantly more vulnerable to adjustment difficulties than opposite sex siblings.

Qualitative research conducted in the U.S. has been able to explore the experience of siblings of children with cancer. Cairns *et al.* (1979) and Spinetta *et al.* (1999) both conclude that in some domains siblings experience significantly more distress than the patients, frequently reporting feelings of loneliness, isolation, anxiety, rejection, fear, frustration, jealousy, guilt and anger. This research utilised psychometric measures such as the Piers-Harris Children's Self-Concept Scale and the Bene-Anthony Family Relations Test as well as a thematically analysed clinical interview which together highlighted that the emotional needs of healthy siblings are the least adequately met of all family members.

Gorodzinsky *et al.* (2013) aimed to explore the family dynamic when a sibling is suffering with chronic pain in a study based in the Midwest U.S. This

research used a qualitative interview with all immediate family members (parents and children) to explore the effect chronic pain had on the patient and their sibling as well as their perspectives on how chronic pain may have influenced the family dynamic. Most siblings reported dramatic changes to many aspects of their relationships, family processes and increased responsibilities which were attributed to the patient's experiences of chronic pain. On the other hand, the siblings living with chronic pain did not report significant changes to their relationships or family processes. Results appear to indicate that the sibling of the child with chronic pain is at increased risk of experiencing difficulties and stress and that the sibling is often an overlooked yet valuable source of information of family dynamics and illness influence upon family relationships.

Fleary and Heffer (2013) also explore the continuing impact on adolescents growing up with a sibling who suffers from a chronic health condition in Texas (U.S). The purpose of this study was to explore the impact of having a sibling with a chronic health condition in general and as such this is not health condition specific; participants merely identified themselves as having a sibling with a chronic health condition. 40 adolescents completed a demographic questionnaire, a semi-structured interview, Personality Assessment Screener (PAS) and 'My Feelings and Concerns Sibling Questionnaire'. Results found that participants reported clinically significant problems on some PAS scales. Gender differences were also noted for behaviours such as acting out and alienation. Male siblings were significantly more likely to report behavioural difficulties related to impulsivity, drug use or sensation seeking. Female siblings on the other hand reported failures of supported relationships and issues with distrust. This study, similar to others described in this chapter, also highlighted both positive and negative themes from the semi-structured interviews regarding the experience of having a sibling with a chronic health condition. Siblings identified a greater awareness of illnesses in general and family bonding and support as positive products of having an ill sibling. Conversely, siblings identified fears for unwell siblings' future, jealousy of time spent with family and concerns of their ability to help their sibling in a health crisis as negative experiences. This research, like many others in this field, provides evidence for some lingering effects of growing up with an ill sibling on late adolescent functioning. However, it should also be noted that such research also appears to give evidence of the development of

positive characteristics which may act as protective factors for siblings as they face the stressors of late adolescence.

Labay and Walco (2004) examined psychological adjustment among siblings of children with cancer in the U.S. 29 sibling pairs were recruited where one sibling was diagnosed with leukaemia or non-Hodgkin's lymphoma. Children and their parents completed self-report questionnaires during the active treatment of the 'sick' child. It was observed that the healthy sibling displayed increased empathy, social and academic abilities but did not demonstrate increased behavioural problems. These results suggest that empathy may play an important role in sibling adjustment but specific relationship and family variables may be helpful in identifying those siblings at greater need of psychosocial intervention.

Havermans *et al.* (2011) also looked at the effects chronic illness can have on the sibling relationship by comparing the quality of life (QoL) between the siblings of children with cystic fibrosis and the siblings of healthy children in Belgium. This research was primarily interested in assessing the self-reported quality of life and also the perceived impact of illness on siblings of children with cystic fibrosis (CF). Havermans *et al.* (2011) used The Child Health Questionnaire in order to assess quality of life and the Sibling Perception Questionnaire was used to assess the impact of the illness. Results indicated that the siblings of children with CF rated their QoL higher than those siblings of healthy children on most QoL domains such as mental health, behaviour, functioning and physical health. However, siblings who were older than the child who had CF reported a higher impact of the illness than siblings who were younger. The perceived impact of the illness increased when the child suffering from CF was hospitalised. In summary, siblings of children with CF reported a good QoL. It would appear that both QoL and illness impact are related to the severity of the condition and illness specific variables.

Much of the literature above has shown strengths and weaknesses of the research in identifying those siblings who are suffering the burden of psychological distress and developmental difficulties. However, these also show failings in providing a detailed reasoning or to capture the lived experience of these children. Furthermore, none of the research mentioned here details the experience of Siblings of children living with HIV and therefore we cannot assume that any of the findings

presented here are applicable to HIV which presents its own unique challenges in terms of disclosure difficulties and stigma. A major strength of much of the research presented here on the effects of healthy siblings is that this research has often utilised large scale literature reviews or included large numbers of participants. Therefore, this has been helpful in identifying a need and a population in need of support and further study. It can be argued that more is needed in terms of qualitative data to gain knowledge of the lived experience of participants and develop clinicians' understanding of what the damaging and protective factors are in the context of chronic illness, more specifically HIV. However, a major flaw in the above review is that research was conducted predominantly in the U.S. and therefore results may not generalise to a British population. Finally, it is important to consider that much of the research detailed in this chapter fails to identify how HIV positive participants acquired their illness (vertically or horizontally). It could be argued that there are potential differences in adjustment to HIV, understanding, and the experiences of HIV between those who are infected vertically and horizontally, therefore presenting a confounding factor in analysing these findings and making conclusions about this population. It would be reductionist to assume that all experiences of HIV are equal. However, the research described has provided much needed knowledge to aid our understanding but must be interpreted with caution.

1.3.13 Exploring the impact of HIV on the diagnosed and healthy siblings.

To date the psychological effects of HIV on the siblings of children who are HIV positive has been relatively less well researched than the experiences of those who have HIV. Therefore, the current project has drawn from the literature pertaining to the siblings of children with other chronic health conditions as well as the clinical experiences of people who work with HIV positive children and their siblings.

Early research focusing specifically on sibling pairs in which one was HIV positive and the other was HIV negative was conducted by Fanos and Wiener, (1994). Fanos and Wiener (1994) conducted a qualitative study which revealed themes including secrecy and communication within the family, sibling relationship, the parent-child relationship, school issues, the impact of parental mourning on siblings and the siblings mourning. This research aimed to alert researchers to a

clinical need which should be addressed and to inform the development of interventions for the siblings of children affected by HIV. To some extent this has been addressed in multiple papers detailing the effects of HIV both on PHIV+ young people and those young people who are exposed to HIV (including healthy siblings). These papers have explored the prevalence of mental health in a HIV exposed population (Malee *et al.* 2011; Mellins *et al.* 2012; Mutumba *et al.* 2016; Gadow *et al.* 2010). However, qualitative research focusing on healthy siblings of PHIV+ young people remains scarce. Highlighting the mental health needs of PHIV exposed samples, both vertically and horizontally exposed, marks an important start to developing empirical understanding. However, acquiring further knowledge regarding the mechanisms involved in increased mental health symptomatology within a HIV exposed sample is equally important. As such the field would benefit from more exploratory qualitative research investigating the experiences of this largely understudied group. Currently such research remains relatively scarce despite epidemiological data indicating that significantly more people are living with HIV today. This will likely be a continuing trend with numbers of HIV positive people increasing year on year due to increased survival rates and the infectious nature of the HIV virus (Martinez *et al.* 2007).

Malee *et al.* (2011) investigated the prevalence of mental health disorder among adolescents who were either PHIV+ or HIV- but exposed. The aim of this research was to identify the impact HIV has on mental health difficulties by drawing a comparison between PHIV+ and HIV exposed groups in order to understand possible risk factors associated with psychiatric disorder, and inform the development of appropriate intervention and prevention strategies. Young participants and their caregivers were interviewed using the Behaviour Assessment System for Children (BASC-2) in order to ascertain the rate of mental health disorder. The rate of mental health difficulties was calculated overall for both groups revealing a prevalence rate of 29%. This is higher than expected for the general population. Results also showed that rates of mental health difficulties were higher among the HIV negative but exposed group (38%) than among their HIV positive peers (25%). Therefore, it is concluded that HIV- but exposed young people are at a higher risk of developing mental health concerns. This suggests a need for treatment

programmes that may reduce the consequences of HIV for both the young people affected by the illness and their caregivers.

Gadow *et al.* (2010) also investigated the prevalence of psychiatric disorder amongst a PHIV+ youth sample in comparison to a sample of peers. The group of peers consisted of young people who were HIV exposed (had HIV+ family members or are currently living in households with HIV+ family members). In this study, participants were randomly recruited from 29 US and Puerto-Rican sites. All participants were asked to complete an extensive battery of DSM-IV standardised measures and rating scales. It was found that many HIV+ youths and peers were rated, by either self or family report, as meeting the criteria for psychiatric complaints such as conduct disorder, depressive disorder, anxiety disorders and ADHD. It was also noted that the HIV+ group did not indicate higher rates of mental illness than their peers. However, the results supported the findings of Mellins and Malee (2013) in suggesting that PHIV+ youths did exhibit higher rates of mental illness than the general population. Further to this, HIV exposed peers also demonstrated higher rates of psychiatric disorder than the general population potentially demonstrating a link between HIV and mental illness regardless of HIV status. However, this study is unable to shed further light onto the mechanisms involved.

Gadow *et al.* (2012) later further developed the above research and investigated the emergence of mental health concerns over time. Although it is understood from much research that HIV in young people does have a link with psychopathology, little research has investigated the emergence of this over time. Gadow and colleagues invited three groups (PHIV+ young people, HIV exposed young people and primary caregivers) to participate in a longitudinal study. Participants were compared for incidence of emerging mental illness and the use of psychotropic medication during a 2 year follow up period. This study found that a substantial number of PHIV+ young people (36%) and a significant number of the comparison group (42%) who did not meet the criteria for mental illness at the start of this project did so at follow up. Furthermore, participants who did meet the criteria for psychiatric complaints at study entry often also met the criteria at follow up (PHIV+ = 41% and comparison = 43%). In conclusion, it would appear that young people who live in families affected by HIV are at a higher risk of developing

psychological difficulties. A real strength of this study is the longitudinal design allowing for a detailed exploration of the role HIV may have on the development of mental illness. Despite this, this study also shows that not all young people affected by HIV develop psychological difficulties and more knowledge is needed about the resilience and protective factors for those individuals.

Mellins *et al.* (2012) also examined the role of perinatal HIV in influencing mental health symptomology and substance use over time. This was done by comparing changes in psychological difficulties within a PHIV+ and HIV exposed sample over an 18 month period. 166 PHIV+ and 114 HIV exposed youths were assessed using the caregiver and youth versions of the Diagnostic Interview Schedule for Children (DISC-IV). Results showed that over two thirds of all participants met the criteria for a minimum of one psychiatric disorder at study entry or follow up. It was also observed that within the PHIV+ group there was a decrease in psychiatric disorder over time and a particular decrease in anxiety disorders was noted. Conversely, within the HIV- but exposed group the prevalence of psychiatric disorder remained largely the same with the exception of an observable increase in terms of mood disorders. In conclusion, those who are HIV negative but exposed to HIV may struggle more than their HIV positive counterparts. Furthermore, it is clear that the prevalence of psychiatric disorder remains high for both groups in comparison to other vulnerable populations and the general public. Therefore, this would suggest that factors other than HIV illness are likely to have a more significant impact on the emergence of mental illness.

In similar research, Mutumba *et al.* (2016) explored changes in mental health symptomology among a cohort of PHIV+ and HIV exposed young people as they transition through adolescence. This research also aimed to identify associated psychosocial factors impacting upon mental illness over a five year period. 340 participants (206 PHIV+ and 134 HIV exposed) aged 9-16 were recruited in New York City. Participants and their caregivers were asked to take part in three interviews; one baseline interview on entry to the project, a second interview 18months later and a third interview which took place approximately three years after the second interview. Results indicated that the mental health symptoms of youths, irrespective of their HIV status, were positively associated with major life events and stressors. Therefore, it is concluded that major negative life events

increase mental health symptoms in young people affected by HIV and as such this highlights a need for interventions that reduce the impact of these stressors in an attempt to promote a positive effect on psychological well-being in those young people. These findings here are in support of Gadow *et al.* (2012) in highlighting an association between HIV and mental health symptoms in young people affected by HIV. A key finding here is the demonstration that HIV alone is not a sufficient trigger for mental health symptomology as both groups regardless of HIV status were struggling. Therefore this suggests that other factors may play a more influential role in the emergence of psychological distress over time. However, once more the specific role of HIV on the emergence of mental health symptoms remains unclear. It is widely accepted that negative major life events have a correlation with mental illness universally and not just in those who are affected by HIV. Therefore, one might reasonably expect that negative events would also impact those affected by HIV in a similar way. Consequently this research is open to criticism in terms of its original contribution to the field. Nonetheless, this strengthens the position that those youths affected by HIV are vulnerable to psychological difficulties.

Alperen *et al.* (2014) examined risk factors associated with recent substance use among PHIV+ and HIV exposed young people. The aim was to develop a comparison between the lifetime prevalence of substance use in a HIV affected cohort and substance in the general population. A longitudinal analysis was carried out across multiple US sites involving 511 participants aged between 7-16 who were either PHIV+ or HIV exposed. Data relating to substance use was collected by computer and assisted self-interview. Results revealed that HIV was not a statistically significant risk factor for either alcohol or marijuana use. However, it was observed that risk factors for alcohol use included emotional and behavioural difficulties and drug and alcohol use by caregivers in the home. Therefore it is concluded that substance use and lifetime prevalence amongst a HIV affected cohort of adolescents is similar to national norms. However, more is needed to be understood regarding any causal relationships around substance abuse and HIV. It is unclear whether emotional and behavioural difficulties influence young people towards substance use or whether substance use has a direct influence on emotional and behavioural difficulties. This further leaves a gap in our understanding of the specific role of HIV within this complex interaction. Perhaps HIV exacerbates or

potentially introduces emotional and behavioural concerns. As such further research is required to explore the role of HIV and its impact on young people affected by this illness.

Research has consistently demonstrated that the use of marijuana can have a significant impact on a developing adolescent brain. Marijuana use in adolescents has been shown to reduce neural connectivity as well as impacting the volume of specific brain structures (Volkow, Baler, Compton, & Weiss, 2014). Therefore, unsurprisingly, research investigating the use of marijuana in adolescents has demonstrated a strong connection between this illicit drug and mental illness (Armstrong & Costello, 2002).

Elkington, Cruz, Warne, Santamaria, Dolezal and Mellins (2016) highlight that PHIV+ young people are at an increased risk of marijuana use and therefore psychiatric disorders given an array of individual and contextual factors such as parental illness or death, exposure to trauma, parental substance use, and parental mental health concerns. Therefore, Elkington *et al.* (2016) examined the longitudinal reciprocal relationship between HIV and psychiatric disorder whilst paying attention to the role of HIV in a sample of PHIV+ and perinatally exposed but HIV- youths. Participants were recruited from four New York City medical centres and were tasked with completing two interviews that were conducted 18months apart. Interviews were designed to investigate associations between changes in marijuana use and changes in mood, anxiety and behavioural disorders irrespective of participant's HIV status. Results indicated that marijuana use predicted behavioural and mood disorders in youth with participant's HIV status having no effect on this. It was also noted that behavioural disorders predicted marijuana use for both PHIV+ and HIV exposed groups. Therefore, Elkington *et al.* (2016) concluded that interventions that specifically target early marijuana use may reduce later psychological difficulties for young people who are affected by HIV.

Bettoli-Vaughan, *et al.* (1998) conducted research which focused upon HIV status, family resources and maternal adjustment in 57 well siblings' adjustment. Three groups of children participated (HIV positive, HIV exposed and healthy controls) together with their HIV positive mothers. 37 siblings aged 5-17 and their mothers took part in this research. It was found that maternal adjustment difficulties

were positively associated with siblings' internalising symptoms of adjustment and negatively associated with mothers' perceptions of family resources. It was also shown that there was a relationship between maternal adjustment and sibling depression and anxiety. Therefore, findings were interpreted as supporting the role of family functioning with regards to children's management of stress.

Corona *et al.* (2008) detailed a qualitative analysis in the U.S. which explored family communication around HIV diagnosis, prevention, risk behaviours and transmission. 33 parents with HIV took part in this research along with 27 children aged 9-17 and 19 adult children older than 18. Results showed that the younger children felt uncomfortable discussing HIV within the family, worrying this would be upsetting and remind the parents of their illness. Adult children reported similar experiences and in addition few siblings reported talking with one another as they worried this may upset the other sibling as well as worrying the sibling may unintentionally disclose the parent's HIV status to others. In conclusion it would appear that HIV remains a taboo subject even within a family system leaving parents and children managing their distress privately and independently.

Betancourt *et al.* (2013) noted that young people in Sub-Saharan Africa living with HIV themselves or who are affected by HIV are at an increased risk of mental health problems. This is problematic in that this brings about complications for risk behaviour, educational achievement and the provision of care services. Betancourt *et al.* (2013) examined electronic medical records in order to identify all HIV positive children in Rwanda. Community health workers then assembled stratified lists of all HIV affected and non-affected children in the same villages, and one participant was randomly sampled from each of the stratified lists, matched at village level, to compare to each HIV positive child. A case-control design was utilised to assess the prevalence of mental health difficulties amongst 680 children aged 10-17 who fell into the following categories (i) HIV positive (ii) HIV affected but not infected (i.e. children who have a HIV positive relative) and (iii) non HIV affected. All children and their care-givers were assessed for mental health, functioning and resilience factors. Results indicated that HIV-affected children had significantly worse mental health difficulties than both other groups. When compared to HIV non-affected children, HIV affected children reported significantly higher levels of depression and impaired functioning. HIV positive children did not

report significantly higher levels of depression and impaired functioning compared with HIV non-affected children. In conclusion HIV-affected children and HIV positive children are at an increased risk of developing mental health problems and therefore require increased attention by care services.

Interestingly, the research above would appear to corroborate the notion that HIV is not only a taboo subject within society but also within the family affected by the illness. Despite HIV having an impact on both rates of anxiety and depression and also affecting the relationships and family dynamics, HIV positive children and their siblings often report feeling unable to express their experiences and seek care, nurture and support from appropriate resources (Fanos & Wiener, 1994; Betancourt *et al.* 2013). However, it must also be noted that the preceding research represents a small pool of evidence considering the effects of HIV on healthy siblings as well as the HIV positive client and therefore is unable to provide a full picture of the impact HIV has in a sibling environment. HIV in a sibling context is largely overlooked, especially in comparison to a range of other chronic health conditions. Noticeably, even the few studies mentioned above do not specifically detail the sibling relationship. The preceding research focuses on the family context, and inferences can be drawn on the sibling relationship and impact as a portion of that research. It is clear from the evidence detailed in other health conditions and studies looking at the psychological impact of HIV that more research is needed. The literature covered thus far is limited as this largely represents findings from studies conducted ten or more years ago and although an attempt has been made to cover recent literature, there is little, if any research that details the impact HIV is currently having in a sibling context, particularly within the UK. We know that for those privileged with greater access to healthcare, that HIV has transformed from an inevitably fatal infection to a chronic manageable condition (Palmisano & Vella, 2011). When we consider this alongside the little research into the psychological consequences of HIV, particularly involving adolescents and specifically in Britain, this leaves open clear gaps in current knowledge that this research could explore. The current project aims to fill this gap in the field and explore a more detailed, up to date and accurate image of how HIV in a modern, post anti-retroviral world is influencing HIV positive adolescents and their siblings.

1.4 Stigma and Disclosure

One of the key challenges for any individual living with HIV is the issue of disclosing one's HIV status to others (e.g. to a partner, friend, family member or colleague). When thinking about disclosure in paediatric HIV this can be thought of in two categories; full disclosure (when HIV is named for the child and they are made aware of their diagnosis, usually by clinician or caregiver), and self-disclosure (the patient sharing their HIV status with others).

Evangelini and Foster (2014) highlight some of the research investigating self-disclosure within a population of young people who acquired HIV perinatally. This paper further highlights that research into this field consistently finds that rates of self-disclosure remain low. As such, this section will review the research as cited by Evangelini and Foster (2014). For example, Birungi, Obare, Mugisha, Evelia, & Nyombi, (2009) conducted research in Uganda revealing that the rates of HIV self-disclosure amongst a sexually active HIV positive youth sample were low in terms of informing romantic partners. In addition, Tassiopoulos *et al.* (2013) investigated the rates of onward self-disclosure in young people and discovered that only one-third of young people engaged in sexual activity had disclosed their HIV status to their romantic partner. Furthermore, Lee and Oberdorfer (2009) were interested in HIV disclosure in Thailand and again found rates for disclosure to be low (48%).

Owing to advances in medical science young people with perinatally acquired HIV are now living into adolescence and later life. Adolescence is an important time for young people and establishing and maintaining romantic relationships is a key part of this developmental stage. Although disclosing one's HIV status to romantic partners may reduce the risk of HIV transmission, the decision to disclose is fraught with anxiety and the associated fear of rejection. Greenhalgh, Evangelini, Frize, Foster & Fidler, (2013) investigated how disclosure challenges are managed within intimate relationships by young adults with perinatally acquired HIV in the UK. Seven participants (5 female, 2 male) aged 18-23 who were currently or previously in a relationship took part. This was a qualitative study whereby participants took part in in-depth interviews which were analysed using interpretive phenomenological analysis. Four themes emerged from the data: (I) Decisions regarding starting, resuming or continuing relationships

shaped by disclosure, (II) disclosing early to avoid future rejection, (III) using condoms to avoid disclosure and (III) Testing likely partners reactions to disclosure. This study highlighted the extent to which HIV disclosure affected the experience of romantic relationships within this population.

Since the advent of HIV/AIDS in the early 1980's stigma has been synonymous with HIV, a stigma that despite significant medical advances, remains a significant part of the experience of having HIV today (Stackpool-Moore et al. 2013). Stigma is often attached to things people find difficult to understand and for many reasons people living with HIV remain stigmatised (Pachankis, 2007). Firstly people still do not understand how HIV is transmitted and may fear 'catching' HIV through social contact or sharing utensils (Stutterheim et al. 2012). Additionally many people hold strong views regarding sexual behaviour and hold views that sex in certain situations is wrong, and therefore cast judgment on a condition that can be transmitted sexually (Herek, Widaman & Capitanio, 2005). Therefore, the ways people think about HIV may also be linked to the ways people think about stereotyped groups seen to be most affected by HIV. Some people already hold negative views towards women, gay men, black people, immigrants and drug users. Therefore, HIV may serve to reinforce existing prejudice and stigma and itself become stigmatised (Garcia, Parker, Parker, Wilson, Philbin & Hirsch, 2015).

Stigma is one of the foremost challenges for HIV affecting those living with HIV in a multitude of ways. It effects HIV prevention in terms of individuals being afraid to seek HIV information or seek a HIV test, therefore increasing the likelihood of further infections (Knight, Small & Shoveller, 2015). Stigma has also been shown to have a link with low disclosure rates as people with HIV may perceive a threat of violence or social rejection and therefore are less likely to communicate their HIV status to partners, also increasing the risk of additional infections (Przybyla, Golin, Widman, Grodensky, Earp, & Suchindran, 2013).

For those living with HIV, research also appears to corroborate the notion that stigma attached to HIV is correlated with rates of depression and anxiety (Strodl, Stewart, Mullens & Deb, 2015; Costelloe et al. 2015; Wohl et al. 2013). Herek, Saha & Burack, (2013) investigated the effects of HIV related stigma in a sample of 197 people living with HIV. In particular societal stigma (felt stigma) and the negative

feelings participants held towards themselves (self-stigma) were focused upon in order to assess their connection to psychological well-being. It was concluded that both felt stigma and self-stigma were significantly correlated with symptoms of depression and anxiety.

Furthermore, many assume that individuals living with a concealable and invisible stigma escape the challenges faced by those living with more obvious and visible stigmas. However, research highlights that those living with a concealable stigma such as HIV are subject to considerable psychological challenges (Pachankis, 2007). Health conditions not understood by the public and which the individual living with the condition may be viewed as morally responsible for contracting, may lead to complex psychological difficulties (Herek, 1999). HIV not only presents these issues but also imposes personal, social and legal implications upon those diagnosed. As such, it follows that opting to disclose ones HIV status may leave people vulnerable to emotional distress resulting from possible rejection or violence (Parsons, VanOra, Missildine, Purcell, & Gómez, 2004). However, those opting to conceal their HIV status may also experience emotional distress. The costs of concealing their condition may include feelings of guilt, fraudulence, and betrayal in addition to suppressing aspects of one's identity and not feeling truly accepted (Lévy et al., 1999). Concealing a HIV diagnosis may also fuel anxiety associated with being 'found out' in addition to a desire to protect family members from shame associated with HIV (Murphy, Roberts & Hoffman, 2002).

1.5 Issues of informing a HIV positive child of their diagnosis

Informing a child of their HIV status is understandably a complex task for a large number of parents and caregivers. These complexities can arise from a range of concerns relating to stigma, issues within family relationships, difficulties around access to social support as well as the emotional and cognitive capacity of the young person to manage and understand their illness (World Health Organisation, 2011).

One of the fundamental challenges of concealing a HIV diagnosis from the young person affected is that this has a direct impact upon their ability to access specialist paediatric care, resulting in a lack of treatment for some young people who may require this sooner (Wiener, Mellins, Marhefka & Battles, 2007). This may lead to some young people requiring HIV treatment at the point of disclosure and having

to manage the potential emotional consequences of this illness with a stringent medication regime simultaneously. Understandably, those young people who are unaware of their diagnosis may later struggle with adherence to medications and safe sex practices which present a public health concern around the onward transmission of HIV and the potential transmission of medication resistant strains of HIV (Klitzman, Marhefka, Mellins and Wiener, 2008).

Perhaps the most significant barrier to the disclosure of one's HIV status remains the fact that HIV is a highly stigmatised and transmittable illness often associated with stigmatised 'risk' behaviour. Given that most HIV transmission in children and adolescents occurs vertically (from mother to baby), disclosure to young people is further complicated as this inadvertently reveals parental HIV status and may indicate parental 'risk' behaviours (Pinzón-Iregui, Beck-Saugé and Malow, 2013). Therefore, this presents a further barrier for parents and may offer a part explanation as to why some parents and caregivers delay disclosure of HIV to those young people affected in an attempt to protect both the young person and themselves from shame resulting from stigma.

The World Health Organisation (2011) recognises that health care workers charged with offering high quality care to families affected by HIV are also challenged by the complexities of the issues discussed prior. These barriers then also present similar obstacles for health care workers in supporting families around issues of disclosure. It is also acknowledged that healthcare workers are "*often without the support of definitive, evidence based policies and guidelines on when, how, and under what conditions children should be informed about their own or their caregivers HIV status*" (World Health Organisation, 2011). Therefore, guidance for health care professionals has been developed in order to ensure the physical, emotional, social and cognitive well-being of young people aged 12 and below diagnosed with HIV. This World Health organisation (2011) guidance recognises that the disclosure to the young person regarding their own HIV status is a crucial element in a developing child's comprehensive care. In summary, The World Health Organisation (2011) suggest the following key recommendations; (I) Children should be informed of their HIV status as soon as is possible holding in mind the best interests of the individual child, (II) children should be informed of their parents or caregivers HIV status, also bearing in mind the individual needs of the child

considering cognitive skills and emotional maturity, (III) The decision regarding who should disclose should be driven by the child's welfare and minimise risk to their well-being, and (III) Initiatives should be put in place to enforce privacy protection and institute policy.

Pinzón-Iregui, Beck-Saugé and Malow (2013) conducted a literature review regarding studies that specifically investigated the disclosure of HIV status to young people. This review also described parents and caregivers' views around disclosure and the potential consequences of this. 21 articles were identified as fitting the inclusion criteria for this review and 55% of all studies were conducted in low-middle income countries. It was found that in lower-middle income countries a smaller number children were aware of their HIV status (20.4%) in comparison to a much higher percentage in more industrialised countries (43%). Furthermore, in lower income countries participants tended to learn of their HIV status at an older age (median age = 9.6) than industrialised countries (median age = 8.3). Barriers to disclosing HIV status to young people remained remarkably similar across most studies with the most commonly reported barriers to disclosure being parental anticipation of emotional trauma to the child as a result of divulging status to others. In conjunction with the identified barriers this review also highlighted potential benefits of early disclosure to young people asserting that an increased likelihood of adherence to HARRT is described in those children who were aware of their HIV status at a younger age. It was concluded that disclosure to HIV positive young people is a vital aspect of their care and support should be offered alongside consideration of the individual's age and developmental stage. However, it is also noted here that despite such recommendations most children worldwide remain unaware of their HIV status.

In a similar review, Qiao, Li and Stanton (2013) conducted a global review of empirical literature that focused upon informing young people they are HIV positive. 38 articles that were published in English language journals worldwide prior to 2011 were considered, paying particular attention to reasons for disclosure or non-disclosure in addition to the impact of disclosure and non-disclosure. It was found that disclosure rates remained relatively low worldwide. Quio, Li and Stanton (2013) suggest that it would appear the decision to disclose or not is impacted by the young person's developmental level, parental practices, stigma, and the potential benefits to

the young person. The findings here suggest that early disclosure promotes long-term benefits to the young person in terms of their emotional well-being and adjustment to HIV as well as promoting well-being for the whole family. The results here are in support of the above review suggesting that there is a consensus amongst the research that early disclosure to young people has positive long-term benefits. This research shows particular strengths in that it appears these issues are not culturally specific and worldwide similar challenges face parents and caregivers. As such, a regular recommendation of such research is that evidence based interventions are developed in order to assist HIV positive parents to disclosure HIV to their children.

1.6 UK standards of care for HIV.

Parents and carers overcoming those barriers to disclosure remain a key aspect to the holistic care of young people who are HIV positive. However, once a diagnosis of HIV has been given to the young person it then becomes important for clinicians to bear in mind not only what provision of care can be made accessible to young people and their families, but also the standards required of such interventions. According to The British HIV Association (BHIVA; 2013) the standards of care in the UK for HIV positive service users across the lifespan are considered to be amongst the best in the world. However, BHIVA recognise that the modern NHS is currently under overwhelming financial pressures and therefore such high standards of HIV care must be maintained in the face of new structures emerging in an ever evolving NHS. As such, BHIVA (2013) have published documentation pertinent to the standards of care for HIV positive UK services users. These standards are thought to provide a guide in which clinicians are able to ‘benchmark’ the quality of care services they should be providing. BHIVA (2013) produced a document which broadly covers standards related to various aspects of a HIV patient’s care, including the provision of mental health support, effective medication management, supporting service users in establishing and maintaining a healthy sex life and reproductive health, and promoting high quality in-patient and out-patient equitable services. BHIVA (2013) in total outline 12 quality standards designed to promote a ‘minimum standard’ of care that people may reasonably expect to receive when attending an NHS, voluntary, third sector or associated organisation which aims to deliver effective HIV healthcare.

Prior to the aforementioned guidance BHIVA also published a document specifically regarding the standards psychological care provided for adults living with HIV in 2011. This document, similar to the BHIVA (2013) document, outlines standards of care that should be provided by services responsible for supporting HIV positive adults with their emotional and psychological support. This document takes into account the research evidence that mental health difficulties affect people living with HIV significantly more than the general population. BHIVA (2011) have produced standards that reflect the government's mental health strategy for England as set out in *No health without mental health*. BHIVA also highlight in this document that it is hoped that by promoting good psychological care in HIV positive adults that this will, in turn, reduce the likelihood of poor medication adherence and the onward transmission of HIV, as well as preventing avoidable poor health. Such concerns present additional costs to a resource limited NHS and financial restrictions in the health service pose a threat to the continued provision of high quality psychological care. In total, BHIVA (2011) outline eight quality standards that represent a 'minimum' standard of care that ought to be offered to HIV positive adults requiring psychological support. Standards include but are not limited to; support at the time of diagnosis, screening for psychological support needs, access to evidence based psychological interventions, and access to competent mental health practitioners. These standards are designed to enforce high quality standards for the psychological care of adults but fall short of offering guidance on the psychological support of children and adolescents affected by HIV.

In response to the BHIVA (2011) report, the Children's HIV Association (CHIVA; 2014) outlined a standards of care document relating to the psychological management of children and young people living with HIV. This document was developed by a group of psychologists who were all members of the Paediatric HIV Psychology group (PHP) and who work clinically with HIV positive young people. The PHP recognised that although there are many concerns that affect both adults and children alike there was a gap in the identification and management of youth specific concerns pertinent to HIV. For example, most of the youth HIV population contracted HIV perinatally which may present differing psychological concerns to those who acquire HIV horizontally (through sexual intercourse/contact with bodily fluid). As such the recommendations by the PHP are to be considered as

supplementary to the BHIVA (2011) report. The CHIVA (2014) report also considers the psychological support of young people regardless of their HIV status therefore considering the psychological support of young siblings and children living with people affected by HIV but who are not HIV positive themselves. The CHIVA (2014) report outlines six quality standards that represent a 'minimum' standard that should be met by services that offer psychological support for children. These standards include; engagement of young people and their families, support for understanding HIV and sharing information about HIV, access to psychological approaches to managing HIV treatment, and access to psychological support to manage the transition to adult services.

1.7 The nature of support offered for young people affected by HIV

Identifying support for young people affected by HIV is vital in promoting psychological care and well-being which, as discussed, may lead to greater long-term outcomes for those young people. Understanding the standards required of care, as mentioned previously, is vital in ensuring high quality interventions offered by the NHS and third sector organisations. CHIVA, for example, offer a range of support programmes aimed at promoting the well-being of young people affected by HIV. CHIVA run an annual summer camp for HIV positive young people named Freedom To Be (F2B). The objective of F2B is multi-layered; the camp aims to ensure that children diagnosed with HIV have a positive experience in addition to improving HIV related knowledge of the camp attendees. Furthermore the camp aims to reduce the social isolation that is felt by some of the young people as well as maintaining HIV peer contact. The camp runs annually and allows for 76 young people (aged 12-16) living with HIV from across the UK and Ireland to attend.

In 2011, Sigma Research were commissioned to evaluate outcomes in relation to F2B following CHIVA's pilot camp in 2010 in order to understand in more detail the impact of F2B on attendees. This project invited all camp attendees to voluntarily participate. Participation involved the completion of three questionnaires; one prior to camp, one the day before camp finished and a final follow up questionnaire administered three months after the camp had finished. Response rates were high with 55 young people consenting at phase one and 39 young people completing the follow up questionnaire. Results indicated that 35% of attendees had increased the number of their friends that were aware of their HIV

status therefore demonstrating a potential impact upon HIV disclosure. 97% of attendees had also remained in contact with other camp attendees via social media and mobile phone as well as face-to-face social activities. Furthermore, over two thirds of participants reported at follow-up that they felt they had a person to talk to about their HIV concerns. Finally, in terms of increasing knowledge about HIV this project reported that 44% of attendees were not more knowledgeable about HIV and the law, 39% felt they had a greater understanding of how to manage HIV stigma whilst a further 39% indicated a higher interest in sex and having children in the future. The results here indicate a success for F2B in terms of meeting the aims of camp. Attendees were reporting more knowledge and less social isolation which arguably had a direct impact upon their well-being. Despite this, the results here must be interpreted with some degree of caution. It is reported that many camp attendees already knew one another from CHIVA based support groups and therefore it cannot be said with any certainty that any social interaction or reduction in social isolation was due to F2B alone. Nevertheless, it is clear from qualitative responses that F2B provided a positive experience for those young people and therefore represents a valuable service for this population.

In addition to this, CHIVA also offer a range of other support programmes for young people affected by HIV. For example, CHIVA offer a range of peer support groups which provide a safe environment in order to learn more about HIV and how HIV medications work, paying particular attention to the importance of adherence. Groups may also explore psychosocial difficulties experienced by peers as well as considering the impact of stigma and promoting self-esteem for attendees. CHIVA may also offer additional individual home visits or one-to-one support for families that may benefit from this.

Nationwide there are a range of services similar to CHIVA who also offer packages of care and support similar to those described above. Examples include Body and Soul (London), Teesside Positive Action (north east), Positive Health (midlands), Skyline (Yorkshire). Some of these services are able to offer counselling for HIV positive young people as well as advocacy services and training and education relevant to HIV. Furthermore, some of these services will also offer care

and support to the families of those diagnosed with HIV providing a much needed service.

In addition to third sector and voluntary organisations named above, care and support are offered via the NHS. In terms of psychological support NHS services may assess the need for psychological assessment and/or intervention and make a referral where necessary, including access to a practitioner psychologist for those young people experiencing more complex mental health difficulties.

1.8 Models and theories of chronic illness.

1.8.1 Centrifugal and centripetal forces

Research has long supported the notion of interplay between family and illness on the psychosocial effects experienced by the family (Eisenberg, Sutkin & Jansen, 1984). Nichols (1985) proposed that HIV imposed a multitude of complex concerns that are unique to HIV that further burden families. These include fear of rejection, social isolation, physical and emotional devastation and sexual apprehensions.

Combrinck-Graham (1985) describes a developmental model for family systems that can provide a framework for understanding a family's response and adjustment to illness. This model incorporates the concepts of centripetal and centrifugal family styles. A centripetal force describes an emotional pull towards unity and which hold the family together whereas a centrifugal force describes emotional forces tending towards divergence and allows for differentness within a family. Rolland (1987) further discusses centripetal and centrifugal forces in relation to illness. It is proposed that chronic illness imposes a 'centripetal pull' on the family who may unexpectedly be required to nurture a sick member, which can exert demands on a family leading to an inward pull. If, at the onset of illness, a family is currently in a centripetal state, it may get stuck in this style. However, if the family, at the onset of illness, is currently in a centrifugal state it is proposed that a family will be forced into a centripetal pull towards unity and togetherness. This is at the expense of individuating which presents family members with a dilemma as familial caretaking competes with the individuals need for independence. This dilemma is more pertinent for families experiencing an "out-of-time" health condition (Rolland

1987). This suggests that illnesses that occur when not anticipated such as childhood cancer tend to cause greater disruption for families as opposed to caring for a sick elderly relative where one might argue illness is anticipated and somewhat prepared for.

Having a family member diagnosed with HIV may prove difficult in terms of the family finding a comfortable place to sit in terms of centripetal and centrifugal styles. Furthermore the possible episodic nature of HIV may provide confusion as the HIV positive person will likely be asymptomatic for great periods of time, allowing for families to begin shifting towards a centrifugal state only to be forced back towards a centripetal state when symptoms begin suddenly. Further difficulties for families accommodating a centripetal/centrifugal mode are focused around the stigma attached to HIV. An added burden unique for families with HIV is the prejudice and stigma associated with the illness which may view individuals living with HIV as responsible for their condition or highly infectious (Rivera, DeCuir, Crawford, Amesty, Harripersaud, & Lewis, 2015). Families often perceive rejection from those outside the family unit and therefore the boundary around the family is strengthened, which is consistent with the centripetal force, thus forming a heightened sense of family belonging. In summary, the interface between HIV, the individual's developmental issues in addition to those of the family are very important in our ability to develop an understanding of what is happening for both those diagnosed and affected by HIV.

1.8.2 A model of illness representation

Leventhal and colleagues developed the common-sense model (CSM) of illness representations (SRM) that aims to describe and predict how individuals represent and respond to health crises (Leventhal, Meyer and Nerenz, 1980; Leventhal, Nerenz and Steele, 1984). This model was subsequently built upon to consider how individuals cope with a chronic illness (Leventhal and Nerenz, 1983; Leventhal and Nerenz, 1986). The key construct of the CSM model is that individuals actively construct cognitive representations or beliefs about their illness and attempt to regulate health behaviour consistent with the representations formed. Leventhal et al. (1984) and Leventhal and Diefenbach (1991) suggest that there are four distinct categories on which an individual's illness representations are formed.

These include; identity, cause, time-line and consequences of the illness. Lau and Hartman (1983) added a fifth category which was control/curability. More recently, Hagger and Orbell, (2003) have conducted a meta-analysis that provide theoretical evidence for the stability and validity of the aforementioned categories.

Identity refers to the label or name given to the symptoms or the illness and a person's perceptions of the label. With many illnesses individuals may experience symptoms long before a diagnosis is offered and therefore are in some ways prepared for a diagnosis. Commonly this is the opposite for a HIV diagnosis. Individuals will be largely asymptomatic and a diagnosis may therefore provide a high shock and low predictability in addition to providing a label which carries great stigma within society (Chinouya, Hildreth, Godall, Aspinall and Hudson, 2014)

Cause refers to the individual's beliefs about how they came to have an illness and what caused this. Research has demonstrated that for individuals with HIV self-blame features highly as the cause is often internalised as the individuals 'fault'. Reynolds et al. (2009) found that individuals with HIV cited 'carelessness' as the most commonly perceived cause, other perceived causes included 'god's will' and 'punishment'. Given some routes to infection such as drug use via injection or sexual intercourse, HIV may also burden those diagnosed with a higher sense of responsibility and/or failure to protect one's self in a way that other conditions might not.

Time-line refers to the predictive belief about the duration and course of the illness and how long this will affect the individual. Expectations can lie in three camps; acute (symptomatic but curable and relatively short lived), Cyclical (symptomatic and removable but reoccurs over time), and chronic (enduring, long term and a stable part of the individual), (Leventhal and Nerenz, 1983). A perception of a timeline that is chronic understandably can be a significant stress for people and it is suggested that chronic illness introduces the highest severity of stress that is potentially on-going/reoccurring (Cousino and Hazen, 2013). HIV currently has no cure and therefore this is a life-long chronic condition.

Consequences refer to the individuals beliefs around how their diagnosis will impact upon them both physically and socially. HIV is a condition with dramatic consequences for many individuals. For example, a person may experience perceived

or actual stigma and discrimination, barriers to disclosure and support, barriers to forming romantic relationships or fear of infecting others in addition to serious concerns about one's physical health and well-being.

Controllability and curability refers to whether or not the illness can be cured or the degree to which it can be controlled as well as considering to what extent the individual plays a part in achieving this. As previously discussed HIV cannot be cured but it can be controlled with medications. Literature suggests that individuals with HIV who also have a higher sense of control tend to engage in more self-care behaviours and adhere to medication and therefore achieve better outcomes whereas those who perceive a loss of control are less likely to adhere (Reynolds et al. 2009).

In summary, the model views a person's adjustment to chronic illness and health related behaviour as consequential of the individual's integration between internal and external illness information with existing cognitive structures in order to build an illness representation. The illness representation then directs the individuals coping and appraisals of coping are then made to form representations of future coping. This model provides a framework from which illness adjustment and coping can be better understood.

1.9 Overall summary

Over that past few decades mortality rates in those living with HIV have significantly improved and HIV has progressed from a fatal diagnosis to a chronic, manageable illness. Nonetheless, research consistently indicates that HIV has far reaching consequences for those diagnosed in terms of higher rates of mental illness and emotional, physical and social difficulties. Such difficulties may present further complication in causing a 'knock on' effect in areas such as employment, relationships, and education, further perpetuating stigma and mental illness within this population. When considering the impact of HIV on a youth population, the literature highlights similar findings to those investigating adults diagnosed with HIV. Young people living with HIV are also more likely to face emotional and behavioural difficulties and are more likely to engage in risky behaviour. The difficulty with these findings again is that knowing young people face these challenges is only half the story. In terms of siblings of those young people living with HIV the research becomes even sparser. Instead we must draw on literature

pertinent to siblings of children with other chronic health condition. This consistently reports that siblings of ill children are at an increased risk of suffering emotional and mental health difficulties. When focusing particularly on literature relevant to family's managing a HIV diagnosis we understand that young people are at risk of being significantly affected by HIV and are shrouded in secrecy due to the stigma of the illness. This prevents care seeking behaviour outside the family unit and may also affect the young person's ability to garner much needed emotional support.

1.10 Rationale for current research

There is a paucity of data specifically relating to the experiences of those living with HIV and their siblings and research continues to overlook this, particularly in Britain. It could be argued that Sub-Saharan African populations are detailed in a great deal in research and whilst this is important in furthering our understanding of how people respond psychologically to HIV, more is required to understand the British experience of this condition. Cultural differences are unaccounted for within a British sample such as access to medications and treatment and greater access to education. Therefore we cannot make assumptions regarding how young people in Britain respond to HIV based on research conducted in other countries and an exploration of young people affected by HIV is needed. Additionally it must also be considered that the cultural makeup of young people in Britain is ethnically diverse and therefore a portion of those living with HIV may have also lived in other countries prior to living in the UK.

Further to this, there is very little research into the psychological experience of paediatric HIV in comparison to other chronic health conditions that perhaps are better funded, such as paediatric oncology or cardiology. HIV presents its own unique and complex difficulties for families in terms of social stigma, issues of disclosure, potential transmission etc. Once more we cannot make assumptions regarding young people's experiences of HIV based on other health conditions. The unique nature of HIV requires further research.

Moreover, we know that HIV is now a manageable chronic condition and as such it is feasible that the human experience of HIV has changed also, this further highlights a need to update empirical research. In addition, year-on-year more and

more people are diagnosed with HIV and as such more people are accessing services. It is vital that we are in a position to offer the best support possible and so research into the unique experiences of both HIV positive young people and their siblings is important.

Finally, research has largely focussed on identifying the challenges related to HIV and has as yet been less successful in exploring why this is the case and what can be done to improve the well-being of the population studied. As such, more research is required to shed some light onto what the experiences of young people are but also to offer an explanation as to why this might be the case. In summary there remains a distinct lack of empirical evidence focusing on the subjective experiences of young people affected by HIV in addition to any form of explanation. This further limits the capacity of services such as the NHS to offer meaningful interventions specifically targeted to this population. This is something the current research aims to address.

1.11 Introducing the current study

The current study explored the subjective experiences of young people who are HIV positive as well as their HIV negative siblings. The study used a qualitative research methodology (Grounded Theory) in order to carefully analyse the experiences of the young people who participated.

1.11.1 Research question

How do siblings make sense of their experiences when one is HIV positive?

1.11.2 Research aims

To explore young people's experiences of both the positive and negative consequences of HIV from the view point of both the diagnosed and healthy sibling. The research will investigate the psychological impact of HIV and how it is adjusted to in adolescence, focusing particularly on the emotional and social aspects of the condition and how HIV affects the sibling relationship.

2.0 METHOD

2.1 Design

This research project investigated siblings' experiences of HIV from the perspective of both the HIV positive and HIV negative sibling. For the purposes of this study a qualitative research design employing semi-structured, face-to-face interviews was used. Interviews were conducted with ten participants consisting of five sibling pairs. Within each pair, one was HIV positive and one HIV negative. Participants were interviewed on their own in an attempt to elicit their own unique and individual experiences. All interviews were transcribed and then analysed using Grounded Theory (GT).

2.2 Methodological Considerations

This research project utilised Grounded Theory as the overall approach to data collection and analysis. This chapter will describe Grounded Theory methodology, the purpose of qualitative research, and provide a rationale for the use of this.

2.2.1 Qualitative research

Within the field of psychological research qualitative methodologies are often employed in order to explore a phenomenon of interest. Qualitative methods are principally focused on eliciting rich descriptions of complex data pertinent to the phenomena under analysis (Geertz, 1973; Smith, 2015; Richards, 2014). In psychology, qualitative research is relied upon to explore a participant's unique understanding of their own, personal experiences (Green & Thorogood, 2013). In contrast to quantitative methodology, which is primarily focused on establishing a cause and effect relationship, qualitative research seeks to explore participants' lived experience and the meaning that is attributed to this (Willig, 2008). Qualitative methods are open to criticism owing to the labour intensive nature of those methodologies which can be time consuming for the qualitative researcher. However, a real strength of qualitative methods is that it has high ecological validity in addition to being able to tolerate contradictions and extremities within the data. This is in opposition to quantitative analysis which would seek to view extremities as outliers of the data and subsequently remove this from the data set. Qualitative

research is particularly interested in these outliers, understanding that each individual comes with their own unique experiences that are not necessarily similar to others accounts of the same phenomena (Willig, 2008). There is little qualitative research within the HIV literature, particularly pertaining to the experiences of siblings, yet this field of research has the potential to highlight the rich experiences of these young people. Therefore, qualitative methods were considered to be the most appropriate for this research.

There are a range of qualitative methodologies that a researcher may choose to adopt including Grounded Theory (Glaser & Strauss, 1967), Interpretative Phenomenological Analysis (IPA; Smith, 1996), Discourse analysis (Potter & Wetherall, 1987) and Thematic Analysis (Braun & Clarke, 2006). Whilst each of these research methods varies in their application each also has its own strengths and limitations. Despite a range of research methods to choose from it will be argued that Grounded Theory is the most suitable approach for this project.

2.2.2 Description of Grounded Theory

GT is a widely used qualitative method that allows the researcher to construct theory from the data obtained (Glaser & Strauss, 1967). GT provides an overarching framework for the development and formulation of theory that has been distinctly generated and therefore 'grounded' within the data (Turner, 1981). GT is considered an inductive method given that the theory is rooted within and emerging from the data (Glaser, 1978). GT operates in the reverse fashion of the majority of social science research which strongly follow principles of positivism. Quantitative methodologies remain the dominant form of research and are rooted in positivism i.e. from the outset quantitative methods assume an absolute truth, one which is based in logic and scientific objectivity (Charmaz, 2008). However, research using Grounded Theory is likely to begin with a question or sets of data and through the systematic review of data and coding, constant comparisons can be made in order to refine data into concepts and increasingly higher order categories. As such, the researcher is constructing theory from the data as opposed to selecting an existing theoretical framework and gathering data to in order to ascertain whether the theory does or does not apply to the phenomena under investigation.

GT was developed by two sociologists (Barney Glaser and Anselm Strauss)

during collaboration in research focusing on hospital patients receiving end of life treatment. Both researchers remained dissatisfied with research measuring human experience in a quantitative manner, but also recognised that during the 1960's qualitative methodologies were not scientifically robust. Therefore, an attempt was made to join the richness of qualitative analysis with the scientific rigour of quantitative analysis (Walker & Myrick, 2006). However, following their original 1967 publication both authors have had conflicting ideas regarding how GT should be applied causing a divide between Glaserian and Straussian paradigms. The divide, in terms of the Glaserian paradigm, asserts that the researcher remain objective and unbiased in their view and interpretation of the data, allowing theory to emerge solely from the data set free from interpreter bias. Conversely, the Straussian paradigm advocates that the researcher take more of an active role during interpretation suggesting this is necessary in managing the data and recognising that eradicating interpreter bias fully, on all levels, is perhaps an impossible task (Charmaz, 2006). In light of this it is imperative that the researcher be aware of his own potential biases with regards to the current project and consider how these may impact upon data analysis.

As the debate for Glaserian and Straussian paradigms is on-going in terms of the relative merits and limitations of each approach, it has also been suggested that dividing GT into strict opposing categories is unhelpful for the GT researcher (Birks & Mills, 2011). Birks and Mills (2011) have argued that "there are no right or wrong approaches to using Grounded Theory" (pg. 8). Furthermore, as an alternative, Bryant and Charmaz, (2007) argue that potential researchers should instead view GT guidelines and to select an approach that suits the style of the researcher, enabling them to make the most use of GT and therefore do justice to the phenomena studied.

2.2.3 Rationale for using Grounded Theory

A qualitative research method was selected for this project as there is currently little research that explores the experiences of siblings within the context of HIV. When considering the context of both HIV positive and negative siblings research becomes sparser still. This research is chiefly focused on understanding the participants' perspective of the impact of HIV and a qualitative approach is better

able to capture and make sense of the rich information provided by participants.

Although there are a range of qualitative methods to choose from (IPA, thematic analysis, discourse analysis etc) GT enables the researcher to interpret participant data and formulate a model of their shared experiences. Birks and Mills (2011), suggest that GT is appropriate when little is known about the field of study and when the researcher aims to develop a model with descriptive power. Given that this has not been done prior to the current study, from a psychological perspective, and little is known about the sibling relationship or experience of HIV in a discordant sibling context, it was appropriate to select GT as the research method for this project.

Other qualitative methodologies were considered during the planning phase of this project – particularly IPA (Smith, 1996) however, this would not have provided the researcher the opportunity to construct a theoretical formulation which may enhance current understanding of the needs of adolescents with HIV and their HIV negative siblings. Other research methods such as discourse analysis were also not used for a number of reasons. Although discourse analysis would have provided insight into complex models of human thought it would have been reductive when dealing with complex text. Furthermore, discourse analysis is often criticised for disregarding the context of the data analysed, something that the author felt would be imperative to explore when developing an understanding of participants' experiences.

2.3 Ethical Considerations

2.3.1 Ethical Approval

This project was initially reviewed for ethical approval by the School of Medicine Research Ethics Committee at The University of Leeds in June 2015. Non-NHS recruitment was planned from the outset of this project given that ethical approval would need to be sought from multiple NHS trusts. As such, a nationwide approach to recruitment through a charitable organisation improved access to a relatively niche sample that would have been hard to reach within one NHS trust. Following amendments to the recruitment procedure in terms of recruiting through a

different organisation, the panel was asked to review an amended ethical application in October 2015. Following minor amendments regarding the consent procedure for young people the project received ethical clearance from Leeds University (see Appendix 1).

2.3.2 Informed Consent

It was important that participants of this research were able to give their informed consent to participate. Participants were not recruited via the NHS, instead each individual was approached by an Adolescents and Adults Living with Perinatal HIV (AALPHI) research nurse (Marthe Le Prevost) who was involved in other research projects with all participants. AALPHI is a nationwide cohort study of young people who are born with HIV, and a HIV negative comparison group including parents, siblings and friends of the HIV positive individual. AALPHI is affiliated with University College London. The nurses identified sibling pairs on behalf of the author based on the inclusion criteria for this project. Those HIV positive siblings who gave an expression of interest were invited to select a negative sibling to take part. Once consent was achieved from both parties the research nurse would arrange a date for interview independent of the author. The protocol outlined that it was necessary for both siblings to consent for either to take part. Participants were able to ask questions about the project via the research nurse prior to interview and again a protocol was provided immediately before interview with encouragement to ask further questions if needed. Once verbal consent was obtained, a written consent form was completed (See appendix 3). In line with AALPHI protocol parental consent was not required for those participants under 18. The nationwide study conducted by the AALPHI research group sought consent from the young people themselves by measuring their competence to consent in association with their responsible clinician at their HIV clinic. Therefore, age was not a measure of consent but the young persons' competence to make decisions was. As such this study was guided by the AALPHI team in this instance as those young people attend clinics and make medical decisions as individuals and so parental consent was not required for this project. The author relied upon the AALPHI team to consent participants in the first instance and then gained written consent himself at interviews. The consent procedure is illustrated in the figure below.

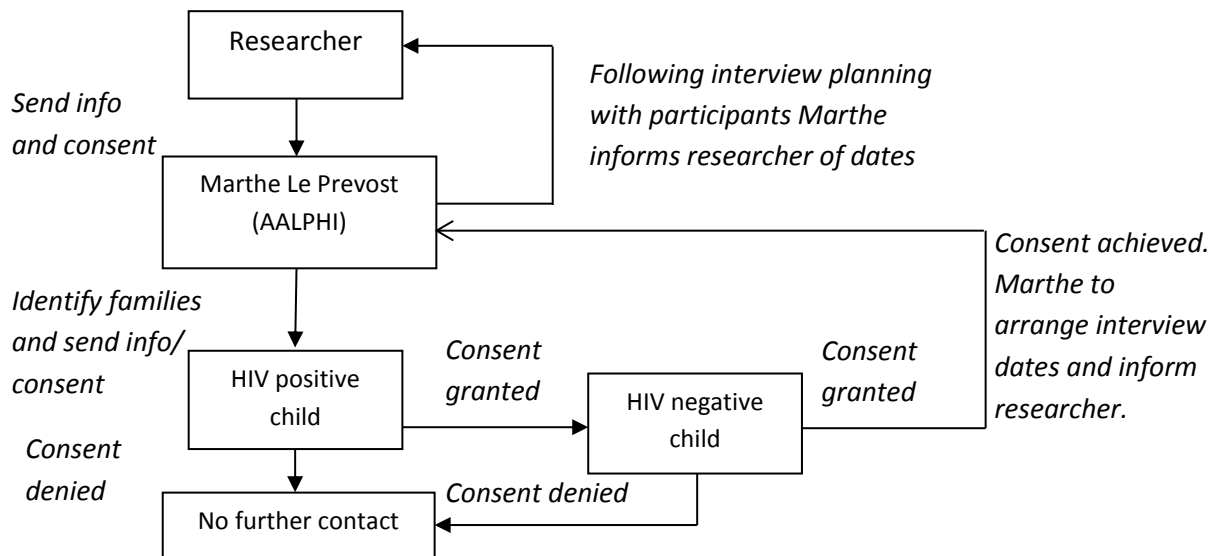


Figure 1 - Diagram illustrating the consent procedure

2.3.3 Anonymity

Given the sensitive nature of the material discussed, the dignity and well-being of all participants was paramount throughout interviews. Understanding that qualitative data contains rich, detailed and possibly identifiable information all participants were assured anonymity. With this in mind, all participants were offered the opportunity to create their own pseudonym by which they would be known for the purposes of this research. Given that all ten participants declined the opportunity to create a pseudonym, an ID code for example ‘SibPair1a’ was used during transcription and write up in order to protect participant confidentiality. The author also explained to participants the clinical guidance relating to confidentiality prior to interviews beginning, specifically, that confidentiality can be breached should a disclosure be made concerning a risk either to self or others during interviews. This was not necessary for any participant. In addition to anonymising participants’ identifiable information further information such as names of relatives and friends as well as names of locations was also removed. In addition, quotes selected for the results section were sensitively chosen, in a further attempt to limit identifiable information that could be linked to participants.

2.3.4 Storage of data

Participants' signed and confidential consent forms were stored in a locked cabinet at the home of the author. Electronic files such as audio transcripts were stored on an encrypted Dictaphone and deleted at the earliest possible convenience, i.e. at the point of transcription. Furthermore, all electronic files were stored on the authors personal M: Drive of the University of Leeds computer system as well as the author's personal home computer which is also password protected. The transfer of information from university computer to the author's personal computer occurred using 'Desktop Anywhere' meaning that whilst the data is actually stored on the university M drive this can be accessed via the home computer of the author ensuring the safe transfer of anonymised information. On completion of this research project all materials will be returned to the Doctorate in Clinical Psychology office at The University of Leeds where they will be stored in a locked cabinet. Any remaining electronic files will then be stored on the university N: Drive for a period of up to three years maximum.

2.4 Sampling

A 'purposeful sampling' method (i.e. whereby the researcher actively pursues information rich cases who are likely to help meet the overall research objective) was essential to this research study's design. As HIV discordant sibling pairs were needed it was necessary for AALPHI research nurses to select potential participants from families open to them in which those families had siblings who were HIV discordant. Without purposeful sampling recruitment would have been an extremely difficult task.

2.4.1 Participants

Ten participants were interviewed, six were male and four female. Participants were adolescents and young adults aged between 14 and 21. Participants consisted of five sibling pairs in which one sibling was HIV positive from birth and the other HIV negative. All participants were UK residents living in the UK for over 7 years; 4 participants moved to the UK from Sub-Saharan Africa and 6 were born in the UK. Participants were recruited nationally through the AALPHI research database. Inclusion criteria included; participants must all be siblings one HIV positive the other HIV negative, participants also needed to speak English to a level

that they were easily able to understand the information sheet, and finally participants were required to have been aware of their own or their siblings HIV diagnosis for a period of more than one year. Exclusion criteria would have prohibited participation in this project if either sibling was physically not well enough to participate or if either sibling was diagnosed with another chronic health condition; this was not applicable to any participant who opted in.

2.5 Recruitment of participants

After ethical approval was granted, AALPHI research nurses compiled a list of potential sibling pairs who would meet the inclusion criteria for this research. Following this, the HIV positive sibling was approached regarding the study in the first instance during a regular appointment with the AALPHI research team. Once consent was obtained from the HIV positive sibling this individual was then invited to nominate a sibling of their choosing who was HIV negative. Recruitment was conducted by asking many people to participate and once the desired sample size was achieved (five sibling pairs) additional interested participants were informed that spaces were no longer available. Once consent was achieved from both siblings then the AALPHI research nurse would contact the author and arrange a time for interview based on the preferences of the participants. The author had no contact with participants until interview. At interview the study was explained in greater detail and participants were provided again with information sheets to ascertain their knowledge regarding their involvement with this project and all were offered a further opportunity to ask additional questions they might have. If participants were still willing to proceed with interview they were asked to sign a written consent form.

2.6 Data Collection and Interview Schedule

Interviews were structured around two interview schedules; one for HIV positive siblings and one for HIV negative siblings (see Appendices 4 & 5). Although both schedules shared similarities, each was designed with the two groups in mind i.e. the affected and non-affected sibling, with questions relating to individual experiences from the perspective of those two groups. Semi structured interviews were used that comprised of 23 items including questions and follow up prompts that remained brief, clear and jargon free. Questions were designed to

capture the unique and subjective experiences of participants to garner an understanding of what day-to-day life is like for families affected by HIV.

Initially, items 1 to 5 are designed to elicit information regarding the family context and to gain a sense of the participant as an individual helping the author form an understanding of their family structure etc. Items 6 to 19 are principally focused on eliciting the experience of living with HIV (either directly or indirectly) and what meaning the participant attributes to this. Finally, items 20 to 23 aim to explore participants beliefs about their future with an emphasis on eliciting to what extent participants believe HIV plays a role in their future. Broadly, it can be said that the interview is based on a structure that seeks to understand the experience of HIV in terms of the participants' past, present and future in order to capture as much of the participants' experience as possible within the remit of this research. Central to all questions was a focus on examining the role and influence of HIV as well as considering the sibling relationship in the context of HIV. Although there were 23 questions in total, the schedule allowed for prompts and ad-hoc questioning in order to elicit full and detailed accounts from participants. The interview schedules were developed over a period of weeks. The author considered relevant literature pertaining to affected and non-affected siblings in chronic health literature outside the field of HIV, as well as discussing with supervisors the gaps within the HIV specific literature. The draft questions designed by the author were then discussed with research supervisors during supervision meetings. This resulted in a draft interview schedule for both groups (HIV positive & HIV negative) which was subsequently trialled with a fellow clinical psychology trainee as well as two adolescent family members of the author. Following this trial and further research supervision amendments were suggested and reflected upon relating to the phrasing of certain questions. Furthermore, interviews were adapted, where appropriate, following each interview. In some cases participants of this study provided feedback on the phrasing of questions and this was subsequently changed between interviews. In most circumstances interviews lasted approximately one hour and were conducted in a private room within AALPHI research space or within voluntary sector organisations.

2.7 Data Analysis

The analysis phase of this project was largely directed by Charmaz (2006) and Strauss and Corbin (1990) in terms of open, axial and theoretical coding. The coding process started with the transcription of all interviews which were then analysed by the author using increasingly higher order categories and relying on constant comparison of the data set to establish emerging themes within the data. The structure and method of analysis will be illustrated more fully in the next chapter. Alongside coding the data at differing levels, the author also employed additional techniques typically associated with GT research such as memo writing, diagramming and maintaining a reflective diary in order to maintain a record of the authors' thoughts and impressions of the data set and interviews as a whole following each interview. This section will review each of the techniques utilised within this project describing these more fully.

2.7.1 Transcribing

It is recommended by Strauss and Corbin (1990), that all interviews be transcribed by the researcher. However, within the time scale of this project it was not feasible for the author to transcribe all interviews. Therefore, two interviews were transcribed by the author and eight were transcribed by a trained third party. Those interviews that were transcribed by a third party were transferred via a password protected and secure network. Upon receiving transcripts from the third party the author also listened to audio recordings of interviews alongside the transcript in order to check the accuracy of transcription. This also provided the author with additional opportunity to become familiar with the participants' accounts.

2.7.2 Coding

Each interview was analysed separately using a system of 'coding'. Charmaz (2006) defined coding as the analytical bones from which the research may shape and build the theoretical skeleton. During the initial coding phase described as open coding, the researcher seeks to make sense of the data by attending to transcripts line-by-line and providing each line with a code which symbolise a shift from the concrete statements made within the data to an analytical interpretation on the part of the researcher.

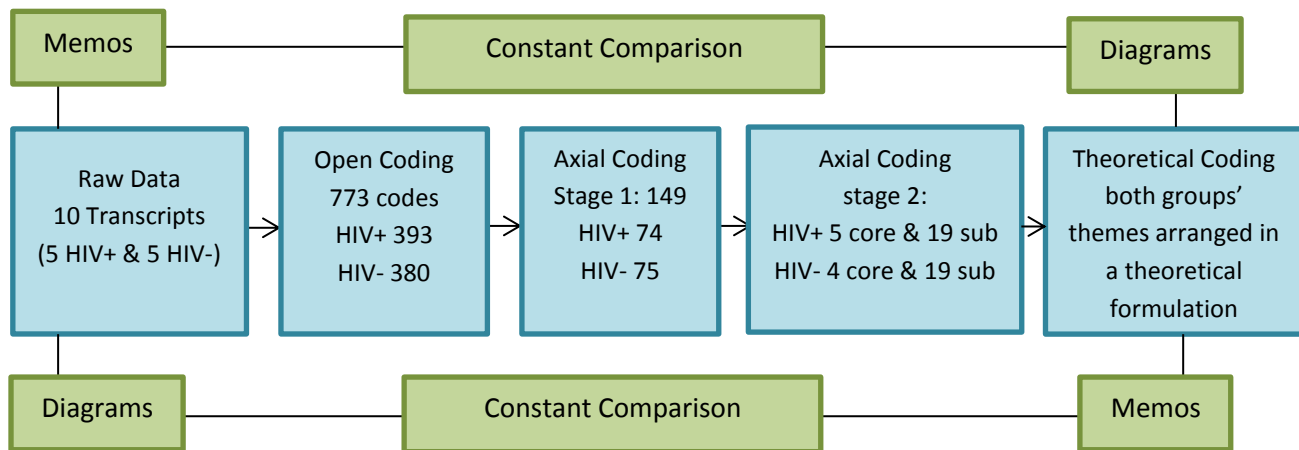


Figure 2 - GT coding process.

2.7.3 Open Coding

As described previously, the first stage of analysis is open coding. During this stage the researcher is tasked with breaking the data set down into manageable units of meaning (Schreiber & Stern, 2001). In this project the author worked through transcripts, line-by-line, paying attention to particular words or phrases with a single unit of meaning. These single units of meaning were labelled using an ‘open code’. Open codes were not necessarily descriptive summaries of participants’ accounts but also abstract accounts or implicit meanings derived from the interaction between participants and the author.

During this stage of analysis the author would continually ask himself “what does this mean?” and “How can this be defined?”. It was also imperative that the author remain close to the data and remain open to conflicting accounts within and across transcripts or different theoretical direction in which the data might lead. At the initial open coding stage of analysis 773 open codes were produced across both the HIV positive and HIV negative sibling groups. This consisted of 393 open codes for the HIV positive sibling group and 380 open codes for the HIV negative sibling group. Again, constant comparison was used in order to cleanse the data of repeating codes in addition to continually referring back to the data in order to check the meaning of established codes and that those which were more unclear were correct. An example of the process of open coding is demonstrated in Table 1 below.

Table 1: Example of open coding

Participant quote	Example of open coding
Participant SibPair5+: <i>"I didn't really understand because the way they usually portray it in movies and everything they say you're going to die, you've only got a few years to live so I thought, wow, maybe I would hit 25 and die. I would just die young. But then I realised the pills will help me to control it, it'll be fine. But then that's the bit that worries me the most I have to depend on something rather than myself. At the time I didn't feel like I could talk to anyone about it and that meant I was very lonely so yeah I just shut off and closed myself off from everyone and that's how I deal with it I suppose. I just keep myself to myself and keep my secret because people in school yeah, they would like mock AIDS so it's better to stay quiet I think. Safer then."</i>	Confusion Media as source of information HIV = death Mortality worries / vulnerability I will die young Sense of control Anxiety Dependency / no control Don't talk about HIV Isolated and lonely Shuts off from others Withdraw as coping strategy Secrecy HIV Stigma Secrecy provides safety

2.7.4 Axial Coding

The second stage of the analysis process involved axial coding. During this stage the large number of open codes are broken down and gradually brought together to represent smaller categories of meaning that capture the participants' experiences.

Within GT axial coding typically occurs in two stages (Charmaz, 2006; Strauss & Corbin, 1990). During the first stage the researcher is tasked with revisiting the open codes, checking for similarities between codes in terms of their meaning. This results in initial subcategories forming from the data, forming the basis of axial coding and the overarching themes of the analysis. In this study, the author organised 773 open codes into 149 subcategories across both groups. As individual groups, these were organised as 75 subcategories for the HIV negative sibling group and 74 subcategories for the HIV positive sibling group.

During the second stage of axial coding the 149 subcategories were revisited in order to explore conceptual links between the individual subcategories. Following this, the author organised the 149 subcategories in a hierarchical fashion resulting in 9 core themes and 24 sub-themes. In terms of the two groups studied, the HIV positive sibling groups' data was organised into 5 core themes and 12 sub-themes

whilst the HIV negative sibling group was organised into 4 core themes and 12 sub-categories. At this stage of analysis supervision was received from both research supervisors to consider the conceptual organisation of all open and axial codes in order to form a consensus as to whether this captures participants' experiences and makes adequate sense of the data obtained. This served to reduce subjectivity and any researcher/interpreter bias on the part of the author. The process of axial coding is demonstrated in Table 2 below.

Table 2: Example of open and axial coding from participants SibPair5+

Open Code	Conceptual Categories	Sub-category	Core Theme
Conceal HIV	Disclosure worry	Secrecy burden	Stigma
Sexual risk fears	My risk to others	Transmission anxiety	HIV burden
Talking = upset	Avoid HIV	Protect self from pain	Distance from HIV
Only family aware	Disclosure worry	Secrecy burden	Stigma
HIV is no different	Normal experience of HIV	I am normal	Desire to fit in
HIV motivates me	HIV positives	HIV as motivator	Self-growth
Family ignore HIV	Family avoidance of HIV	Family avoidance strategy	Distance from HIV
Bad for relationships	Future worries	Relationship concerns	HIV burden
HIV keeps me healthy	HIV positives	HIV = excellent health	Self-growth
I'm strong for family	Responsibility to protect	Protect others from pain	Distance from HIV

2.7.5 Theoretical Coding

At this stage the data was arranged into 12 sub-categories for each group and 5 core categories for the HIV positive sibling group and 4 core categories for the HIV negative sibling group. However, this formation of categories emerging from the data was without an overall theoretical structure. Theoretical coding offers this structure. Theoretical coding is the uppermost level of coding in which the GT researcher seeks to develop a theory that describes how the core categories relate to one another (Charmaz, 2006).

Theoretical coding was achieved via the use of post-it notes and diagrams as well as revisiting the memos made by the author in order to bring together a coherent

picture that is reflective of the stories shared by participants. A theoretical formulation is offered for each of the sibling groups in chapter III. Following this a theoretical formulation is also proposed that attempts to capture and describe the experience of both sibling groups. Theoretical coding within this project was discussed and refined in research supervision and the data was revisited in order to ensure the data supports the theory developed and reduce subjectivity. The process of theoretical coding is demonstrated in Table 3 below.

Table 3: Example of theoretical coding process

Open Code	Sub-category	Core Theme	Process Described
Conceal HIV	Secrecy burden	Stigma	HIV stigmatises me
Sexual risk fears	Transmission anxiety	HIV burden	HIV isolates me
Talking = upset	Protect self from pain	Distance from HIV	HIV isolates me
Only family aware	Secrecy burden	Stigma	HIV stigmatises me
HIV is no different	I am normal	Desire to fit in	HIV can't change me
HIV motivates me	HIV as motivator	Self-growth	HIV adds to my life
Family ignore HIV	Family avoidance strategy	Distance from HIV	HIV isolates me
Bad for relationships	Relationship concerns	HIV burden	HIV stigmatises me
HIV keeps me healthy	HIV = excellent health	Self-growth	HIV adds to my life
I'm strong for family	Protect others from pain	Distance from HIV	HIV isolates me

2.8 Other procedures in the methodology

2.8.1 Constant comparison

As previously discussed, constant comparison is an integral component of GT and therefore was utilised throughout the analysis stage of this study. Constant comparison dictates that the researcher constantly revisit the data in order to check for comparisons of experiences, interpretations and actions within and across transcripts with the aim of confirming or discounting theory as this emerges from the data through the progression of the analysis (Charmaz, 2006). It was also pertinent to bear in mind the family context and individuals' presentations during interview when considering such comparisons. At the open coding level this was carried out by

repeatedly coding the transcripts and remaining mindful of repeated codes that either appeared earlier in the transcript or earlier within other transcripts. This was done by making comparisons within individual transcripts but also across the group to which that transcript was organised i.e. HIV positive siblings and HIV negative siblings. At the axial coding level, this was carried out by constantly comparing codes in order to gain a sense of whether or not they represented the same phenomena. Again this was achieved both within individual transcripts and across the group to which the transcript was organised. At the theoretical coding level, this was carried out by revisiting the raw data and making comparisons between this and the emerging theoretical formulation in order to ensure that the resulting grounded theory was able to reflect the stories shared by participants as accurately as possible.

2.8.2 Memo Writing

Memo writing is another integral component of GT research (Clarke, 2005). Throughout the analysis process the author maintained a reflective diary capturing his initial impressions of the data set, his impressions of interviews as a whole as well as impressions of what sense he made of participants' experiences. This enabled the author to record initial ideas regarding subcategories and also allowed the author to hold onto ambiguous data or emerging theories that he could then take to research supervision. This proved useful in terms of highlighting emerging themes given that the author was able to maintain a record following each interview of the more prominent issues that arose during this time with participants. Memo writing proved to be a crucial aid, serving the memory of the author in addition to helping with the constant comparison of the data. An example of the author's memos is shown in Figure 3.

Memo date: 30/01/2016

Participant SibPair4+ *"If I present myself that it's affecting me yeah then it will affect him as well. In a way, if I present myself like I don't care and they don't see how I feel and think, well he doesn't care about it so why should we, and they will just leave it there.*

Participant is communicating that he puts on this 'brave face' in an attempt to protect his family and his sibling in particular. This is done by not expressing own emotional difficulties. I wonder if part of him prefers this style of not outwardly exploring HIV with others close to him?

Link with participant SibPair5-: Feeling responsibility for containing emotions. So this is not specific to HIV + group. Could this have something to do with older sibling feeling responsible for care of younger?

Figure 3 - Example of memo writing

2.8.3 Diagramming

Diagramming is a further aid when utilising GT as a research methodology. In this study, diagramming served as a crucial aid in helping the author make sense of how emerging themes and sub-themes were interrelated and helped illustrate for the author how these might be further categorised and brought together in a coherent whole. Birks and Mills (2011) have argued that diagramming alongside the analysis of data provides the researcher with an increased sense of the organisation of emerging interpretations of the data. Diagramming was used throughout all phases of the analysis process in-line with memo writing to capture as fully as possible the author's interpretations of the data as this progressed and developed. Initially, at the open coding stage, this resulted in intricate and 'messy' post-it diagrams that were difficult to comprehend. However, as the analysis of the data progressed the diagrams progressed in parallel and became more coherent and clear, drawing together smaller units of meaning. This proved particularly useful in terms of organising the data for the author and provided an aid for research supervision in which both research supervisors were able to review later diagrams and discuss the understanding of these for the population studied. Examples of completed diagrams are referred to in the results chapter.

2.8.4 Managing mismatched data

During the analysis and indeed following interviews it was apparent that some participants' experiences were in contrast with one another. For example, some

spoke of the overwhelming burden of being HIV positive in terms of emotional difficulties and perceived stigma, whilst one individual recounted an enlightening experience, describing being HIV positive as a greatly positive factor. This was deliberated upon during the analysis stage as these codes are clearly in opposition with one another and therefore become more difficult to structure together. This dichotomy of conflicting data was discussed at length during supervision and it was decided that it was important that this dichotomy was added to the evidence that HIV as an illness has changed and developed over time and as such the experience of HIV may have changed too.

2.9 Quality Control

During this section the author will outline the steps taken throughout this project, in particular the analysis stage, in an attempt to ensure the credibility of GT analysis.

2.9.1 Credibility Checks

Assessing the credibility of qualitative inquiry is recommended in order to establish rigour (Creswell & Miller, 2000). Three credibility checks were carried out in order to assess credibility of coding and to establish whether or not there was a high percentage of agreement with the author's coding. In order to achieve this, the author relied upon two trainee clinical psychology colleagues, one of whom was utilising GT for their research project, and a non-psychology post-graduate known to the author. These independent coders were each given 30 anonymised quotes from the transcripts with 30 separate sub-categories. Each independent coder was asked to match the quote with its relevant subcategory to establish whether or not the independent coder coded quotes similarly to the author. The non-psychology acquaintance correctly matched 22/25 quotes, the non GT clinical psychology trainee matched 23/25 and the clinical psychology trainee using GT correctly matched 23/25. Quotes and subcategories were picked at random across both the HIV positive and negative sibling groups to assess credibility for both groups and reduce any potential biases as far as possible.

2.9.2 Supervision

For the duration of this project the author received regular supervision from both research supervisors in the form of monthly (and more regular) formal face-to-face supervision and regular informal supervision via email. Supervision became particularly helpful throughout the analysis stage of this project. The author adopted a systematic and visual approach to analysis via the use of an excel spread sheet detailing quotations and subsequent codes in addition to diagrams that illustrated the emerging ideas of the author. These were utilised during supervision and ensured that adequate quality controls were in place. This provided an easily accessible format for supervisors to check the line-by-line coding and offer comments from open coding up to the categorisation of the core themes and sub-themes. Minutes from all supervision sessions were noted and electronically saved on The University of Leeds PDR, providing a record of supervision. In addition to this, the excel spread sheet and accompanying diagrams provided the author with an audit trail which according to Meadows and Vollman (2016) constitutes a significant aspect of ensuring methodological rigour. The use of both the excel spread sheet and diagrams in supervision was invaluable to the analysis stage of this research.

The author also regularly met up with and maintained telephone contact with a fellow psychologist in clinical training also using GT methodology. This provided a useful support mechanism and a further opportunity to reflect on the process and receive feedback from an independent party not involved with this project. This also served the author in checking the process of GT analysis and clarifying ideas.

Whilst it is hoped that these steps reduced the subjectivity of the author it is important to recognise that the complete removal of interpreter bias is unlikely (Strauss and Corbin, 1990) and therefore some of the authors own biases are likely to have impacted upon his understanding and interpretation of the data and its findings.

2.9.3 Potential researcher bias

According to GT, and arguably most, if not all forms of scientific research, it is essential that the researcher have an awareness of their own biases. Researcher bias has the potential to influence the interpretation of the data obtained as well as the potential to influence any other processes involved in this research. As previously discussed, Birks and Mills (2011) advocate that writing memos,

maintaining an audit trail and keeping an account of the researcher's reflections on the process and data are all conducive of limiting the subjectivity and influence of the researcher's biases. All these additional components were employed throughout this project and have been described in detail. In order to shed further light onto any potential researcher bias in this study a brief description of the author will be given.

2.9.4 Introducing the Author

The author is a 27 year old, British, male from the North East of England, training to be a clinical psychologist in Leeds. Prior to gaining a place on clinical training he experienced acute and chronic illness in his personal life and whilst training to be a clinical psychologist, he worked in a clinical setting with children and young people experiencing acute and chronic illnesses. Following personal and professional experiences of the challenges faced by young people and their families within the context of chronic illness, the topic became of interest to the author.

Currently there is little qualitative research that focuses specifically on the experiences of young people living with HIV. The literature pertaining to the experience of non-affected families and siblings affected by HIV remains almost non-existent, particularly within a UK setting. This inspired the researcher to bring his passion for the area into his academic study and conduct a research project he could be proud of.

In considering the authors experience in research methods, throughout his academic career and professional training he has had many opportunities to become involved in small scale research projects utilising both qualitative and quantitative research methodologies. Qualitative methods were used throughout his MSc thesis as well as smaller scale research project during his doctoral training. Despite this, prior to the current project, he had no experience of using GT.

It is important to highlight that throughout this project, the author experienced strong personal reactions to the literature, data collection and analysis. Having the rare privilege to hear the participants' accounts in detail left him feeling a great sadness for those individuals. However, this also left him with a sense of admiration for those young people who showed great resilience in the face of quite significant social and psychological pressures. These emotional reactions further reinforced the author's passion for the area and his drive to conduct a useful research

project that effectively relays the experiences of the participants ensuring their voice is heard, given that this has sadly been widely overlooked in psychological literature.

3.0 RESULTS

This chapter will outline the findings from the ten interviews conducted with five adolescent sibling pairs who were HIV discordant. Firstly, a description of the overall sample is provided followed by a more detailed pen portrait of individual participants, including an account of the author's reflections on each interview. Following this a description of the core categories is offered in addition to describing the subcategories, with supporting quotations from participant interviews.

3.1 Description of the sample

Ten adolescents participated in this research. Participants consisted of five sibling pairs in which one sibling was HIV positive and the other HIV negative. All participants were interviewed between November 2015 and January 2016. Participants were aged between 14 and 21, six participants were male and four participants were female. All participants were British; six were born and raised in various parts of the UK and four had moved to the UK as young children (ages between 5-10) from differing parts of Sub-Saharan Africa (Zimbabwe and Sierra Leon). A breakdown of this information is represented in Table 4 below, illustrating this information as relevant to each participant.

Table 4: Summary of participant information

ID Code	Gender	Age	HIV Status
SibPair1+	Female	15	Positive
SibPair1-	Female	17	Negative
SibPair2+	Female	19	Positive
SibPair2-	Male	14	Negative
SibPair3+	Male	16	Positive
SibPair3-	Male	21	Negative
SibPair4+	Male	15	Positive
SibPair4-	Male	15	Negative
SibPair5+	Male	17	Positive
SibPair5-	Female	21	Negative

3.1.1 Pen Portraits

Pen portraits of each individual participant are provided here in an attempt to introduce the reader to the participants of this research and to deliver background information as to the circumstances of each young person and to consider the context in which each of the interviews occurred. It is hoped that by offering a more detailed overview of the ten young people who participated, the reader may appreciate their unique experiences, how this informed the interviews that took place, and subsequently the author's impressions and findings following this. This section will also aim to detail the author's impressions captured in memos and a reflective diary immediately upon completion of each interview. In this section the participants' non-verbal interactions are reflected upon providing further relevant information. Participants will not be discussed in order of interview but rather in sibling pairs.

Participant one: SibPair1+

Participant one was a 15 year old HIV positive young girl who had originally relocated to England from Sub-Saharan Africa as a young child. She and her sibling moved to the UK following the death of their parents, who had died due to AIDS related illnesses. Therefore, this participant and her sibling came to England to live with their grandmother and uncle. Shortly after arrival this participant reports that she became very unwell and was subsequently admitted to hospital where it was discovered that she too was HIV positive. At the time of interview this young woman was attending full-time education and reported enjoying school and had plans to attend university. She also reported having a healthy social life although her friends remained unaware of her HIV status.

Participant one appeared highly anxious both before and during interview. She requested that her sibling be interviewed first, which was granted. Initially during the first part of the interview many of her responses were one word replies e.g. 'yes' or 'no' and it seemed that she struggled to offer eye contact. It was reported to me by the team who work with her that she is typically an anxious individual and that it should be anticipated that opening up, for her, during interview would be difficult. As a result, for a significant portion of the interview there was limited conversational flow and I became reliant upon the structure of the interview questions to keep conversation going. I had also become acutely aware of my own

need to reassure this participant and make the interview experience as comfortable as possible, bearing in mind that I was asking this young person to open up about a potentially stigmatising condition in which she has learned to avoid discussing outside of her family. I wondered whether my anxieties about causing upset to the participants impacted upon the quality of the interview. Nonetheless, this participant became increasingly more comfortable and began to elaborate on her responses as the interview progressed and I felt confident that she was able to share her experiences to a level that was comfortable for her.

Participant two: SibPair1-

Participant two was a 17 year old HIV negative young girl who along with her sibling relocated to the UK as a young child from Sub-Saharan Africa following the death of her parents, who died due to AIDS related illnesses. At the time of interview this participant was under the care of her grandmother and uncle who she lived with along with her sibling. This participant, being older than her sibling, reports a much clearer memory of her parents' death and the sense she made of this. Upon her sister receiving her diagnosis she remembers being convinced that this was a terminal illness owing to her experiences of death through HIV in Africa and remembers being fearful of losing her sister, who was the only immediate family member she had remaining. This caused significant emotional turmoil for this participant who reflected on this a great deal during interview. Interestingly, she also recounted a shift in cultural ideas around HIV that were shocking to her. She remembered a time in Sub-Saharan Africa in which HIV was openly spoken about and people were supportive. This was starkly at odds with the UK experience of HIV in which she and her sibling were informed of the importance of secrecy regarding HIV by both their family and the hospital staff. This participant reported a strong bond with her sister and sense of gratitude that she survived and can be with her. Participant two was also highly sociable and academically focused.

The interview with participant two lasted much longer than with her sibling. She was very confident in answering all questions and expanded on these in great detail. This was my first interview for this project and I became anxious that conversation was flowing 'too well' in terms of not sticking to the interview schedule clearly, regularly going off on a tangent that felt pertinent to the participant. During this interview I found myself feeling saddened by this young girl's

experiences and the emotional difficulties that have occurred as a result. Following interviews with this young woman and her sibling I also felt shock given that my expectation, despite the literature to the contrary, was that those diagnosed with HIV would experience more difficulties and in this sibling pair that did not appear to be the case. This made me realise that I had not fully acknowledged the challenges faced by those affected by HIV but who are not living with HIV themselves.

Participant three: SibPair2+

Participant three was a 19 year old HIV positive young girl who was born and raised in the UK. At the time of interview she was an A-level student at college with strong career ambitions. Participant three comes from a large family and lives at home with both parents. She has two younger siblings and two older siblings. She is the only sibling of five to have a HIV diagnosis but is also aware of her mother's positive HIV status, reflecting that she and her mother 'go through HIV together' and therefore she does not feel 'lonely' in her condition. This participant does not recall a time that she became physically unwell due to HIV and has been stable medically all her life in terms of HIV.

This participant was very confident and appeared relaxed throughout interview. She seemed comfortable and happy to share her experiences and have her voice heard. This meant that conversation flowed well and that the interview lasted somewhat longer than expected, but this facilitated participant three conveying her experiences in a manner that she felt comfortable with. Throughout this interview I spoke very little and occasionally prompted the participant but she was readily able to offer detailed and rich responses. My reflection on this interview was one of admiration for this participant who described a great deal of emotional burden as a consequence of HIV, yet she conveyed herself as a strong young lady who was determined to rise above the challenges she faced.

Participant four: SibPair2-

Participant four was a 14 year old HIV negative young boy who was born and raised in the UK. At the time of interview this participant was in full-time education and reported to enjoy school. He lived at home with both parents, a younger sibling and two older siblings. Only his older sibling and mother were HIV positive within the family. Participant four had many hobbies including a keen

interest in sports and interest in being a musician which came across during his interview. This participant described a limited understanding of HIV and felt that this was something to be avoided both cognitively and emotionally where possible.

The interview with participant four was approximately 30 minutes shorter than all other interviews. He openly discussed that his view was that HIV should not be spoken about or even thought about and therefore the interview which was designed to elicit this information was extremely difficult for him. Initially, I became aware of his anxieties and facilitated a conversation around his hobbies and interests in the hope of easing his anxieties and engaging him, however this proved ineffective. Throughout the interview any question focused on his experience of HIV was met with single word responses or a general "I don't know". Any attempt that was made to gain clarification or elaboration on responses appeared to upset the participant and so the decision was taken to allow him to complete the interview comfortably, answering in whatever manner he felt able. I wondered upon completion of this interview if this reflected my anxieties that mirrored the participants. I was aware I did not want to give any participant of this research a negative experience of discussing something that typically is not discussed for them and felt it important to provide a positive experience for all participants.

Participant five: SibPair3+

Participant five was a 16 year old HIV positive young man who was born in Sub-Saharan Africa and moved to the UK over ten years ago. His parents were separated and he lived with his mother and three of his siblings. In total, participant five has five siblings; three older and two younger and some do not live in the family home. Within this family only participant five and one of his siblings is HIV positive; he reported being unaware of his parents HIV status explaining this was not openly discussed within the family. This participant was confident and relaxed throughout the interview and reports having great ambitions and a good group of friends. His HIV status remains hidden from his friends.

Participant five can be described as a rather placid and polite young man who was immediately comfortable with the interview. Interestingly, participant five explained his experience of being HIV positive in a very different light to all other participants. He described being happy with his diagnosis, recognising the ways in which HIV has contributed to his life, in terms of being a motivator and keeping him

healthy. He informed me that HIV was something he valued as a unique experience he was fortunate to go through and something others cannot relate to. In terms of my reflections I struggled with my own thoughts regarding participant five. On the one hand, he explained this overwhelmingly positive scenario but also discussed the difficulties he faced in terms of stigma and his desire for a cure. This left me wondering if participant five felt truly able to share his honest reflections or whether what was observed in interviews was an internal conflict that was unspoken in interviews, leaving me to question whether he was defending against his emotions. This would be unsurprising given that participant five and his sibling shared a perception that their family appear emotionally guarded also.

Participant six: SibPair3-

Participant six was a 21 year old HIV negative young man who was born in Sub-Saharan Africa and moved to the UK over ten years ago. His parents had separated and he lived at home with his mother and three of his siblings. In total, participant six has five siblings some of whom are older and no longer live in the family home. Within the family only two of his siblings are HIV positive and this participant was unaware of his parents HIV status, explaining this was not openly discussed within the family. At the time of interview he was in full-time education and was particularly career focused.

The interview with participant six was the longest of all the interviews. This participant presented as a highly anxious and restless young man. He was confident in interview and answered questions in vivid detail, but described great sadness and anxiety in his personal life which he attributes to HIV. Participant six struggled with the lack of communication regarding HIV in his family and felt pressure to not express the many worries he had. His principal concern was that he was at risk of 'catching' HIV himself and was regularly seeking HIV screens to ease his worries. Participant six was hyper-vigilant to the perceived threat of HIV which he experienced as a significant stressor in his life. He perceived others outside the family as an additional threat: given that HIV was kept secret within his family, he anticipated others would also conceal their HIV status and place him at risk. Participant six also did not discover HIV affected his family until his adulthood and consequently felt mistrusted by his family who he experienced as keeping the secret from him.

My reaction to participant six was very strong on an emotional level, and this interview left me feeling overwhelmingly sad for this young man. This interview in particular highlighted for me the impact of stigma on those families affected by HIV and the damaging effects that intense secrecy is having for some young people both inside and outside their families. This interview also allowed me to make comparisons with previous interviews in which the HIV negative sibling appeared to be significantly more burdened than the HIV positive sibling and left me wondering why this was. After a debrief with this participant we both decided that I would speak to the AALPHI research nurses on his behalf to identify some methods of support for him as he was keen to vocalise his anxieties with others following this interview.

Participant seven: SibPair4+

Participant seven was a 15 year old HIV positive young man who was born and raised in the UK. His parents were separated and he lived at home with his mother. Participant seven had three siblings and he was the only sibling who was HIV positive. Participant seven is a twin and selected his twin brother to also be interviewed for this project. Although this participant was in full-time education at the time of interview he expressed very little interest in his studies and was unsure whether he would attend college. Within the family, only the participant's mother was HIV positive. He also expressed that HIV is not spoken about within his family and that typically he was not used to talking about his condition.

The interview with participant seven was difficult to initiate and his anxiety was apparent. He began by offering one word responses yet despite this he began to ease into the process and became much more reflective as the interview continued. This participant reflected on a sense of responsibility he felt as the HIV positive individual to contain the emotions of his family. He expressed that he felt a need to contain his own emotions and portray himself as well adjusted to HIV in an attempt to limit the upset of his family, holding the view that should he display his upset that this would in turn upset others. According to the participant this left him feeling powerless in response to HIV and this gave him a 'just get on with it' attitude to his condition. However, he was fully able to share his experiences of his struggles behind the 'front' that he puts on for his family and those close to him. The

resilience of participant seven was impressive and left a lasting impression with me. It struck me just how much this young person, and others interviewed, were managing from a psychological perspective, and yet he maintained this air of maturity and consideration for others whilst facing his own significant but hidden challenges which I found inspiring.

Participant eight: SibPair4-

Participant eight was a 15 year old HIV negative young man who was born and raised in the UK. His parents were separated and he lived at home with his mother. Participant eight had three siblings, only one of which was HIV positive. Participant eight was a twin and interviewed with his twin sibling. This participant described his understanding of HIV to be limited and explained that HIV is not spoken about within his family. He is aware of his mother's positive HIV status and that of his brother. Despite not discussing HIV much with his mother he described that both twin brothers will regularly discuss this topic and support one another.

Throughout the interview this participant did not describe many difficulties for himself and appeared to be well adjusted to HIV within the family. He did however, describe a strong sense of guilt that stems from his knowledge they are both twins and that he was not born with HIV. He described a struggle to understand why he was not HIV positive or whether he 'deserved' to be HIV negative instead of his brother. In addition to this he reported a strong desire to 'take' HIV on behalf of his brother, if he could. I got the sense that this left him feeling a need to support his brother at all times despite his own admission that, at times, this can be 'too much' and that he has found himself unmotivated to support his brother, although he continues to do so. He used this interview as an example, his brother had asked him to participate and his inclination was that he did not want to but could not let his brother down. I therefore clarified the consent procedure and asked participant eight if he would like to withdraw, although he expressed a desire to continue with the interview. I wondered whether this could in part be explained by this guilt that dominated parts of the interview conversation. I particularly warmed to this participant's caring nature and the way in which he described his love for his brother and the many ways in which he supports him.

Participant nine: SibPair5+

Participant nine was a 17 year old HIV positive young man who was born and raised in the UK. His parents are separated and he lives at home with his mother and three siblings. This participant was the only HIV positive sibling and both parents were HIV positive. Academia was a real focus for this participant who had strong ambitions for his future. Participant nine described a real effort on his part to withdraw from others around him and isolate himself as a way of managing his emotional responses to HIV. He discussed how HIV was not typically spoken about within his household although he was aware that he could access support from parents, although he opted not to. His sister, with whom he interviewed, was described as a strong source of support for him and a person who he felt most comfortable discussing HIV with.

Although participant nine informed me that he usually tries hard to avoid HIV, this was not observed during interviews and he appeared very comfortable discussing his experiences. This interview was longer than most other interviews and it seemed that participant nine was not only comfortable, but was benefiting in some way from having open and reflective discussions about his experiences with HIV. As such, the interview flowed well and his conversational style facilitated a deep and rich discussion that the data set benefited from. My personal reflection on this interview was that this seemed to flow much more naturally and calmly than others. I wondered whether the natural calmness of the participant elicited calmness in me, given that I was less occupied by my need to ease participants into interviews. This allowed for a free-flowing interview that often went off topic to follow the participants lead but also utilised the semi-structure of the interview.

Participant ten: SibPair5-

Participant ten was a 21 year old HIV negative young woman who was born and raised in the UK. Her parents are separated and she lives at home with her mother and three siblings. Both parents are HIV positive and only one of her siblings is HIV positive. Participant ten maintains little contact with her father. Participant ten had a keen interest in a career in mental health and prior to the interview asked if we might have some time to discuss my career in clinical psychology as this was an interest of hers. As such, I provided time at the end of the interview to discuss a

career in clinical psychology, answering all the questions participant ten had. Participant ten is currently completing a degree at university. She explained that HIV is not spoken about at home and until her brother disclosed his diagnosis the family had kept their 'secret' from her. She expressed that she and her brother regularly talk about their experiences of HIV together but she also has a best friend who is aware of HIV within the family and who supports her.

The interview with participant ten was considerably longer than many interviews. She appeared completely at ease with the interview process and reported to have enjoyed taking part. Throughout the interview she elaborated as fully as possible on all questions asked. In terms of her calmness and conversational style this appeared to mirror her brothers and therefore this interview flowed well allowing the participant to express a detailed account of her experiences comfortably and as fully as possible. I had reflected on this interview upon completion and questioned the interaction I had with this participant. We shared similar interests in terms of our academic studies and career options in addition to interests in similar programmes on television. Therefore, this interview from the outset appeared to take more of an informal tone. I am confident that this facilitated a comfortable and successful interview in terms of data collection but was left wondering about what it was that initiated this informal style as this did not occur in any other interview. I also found the care and compassion this participant had for her brother very endearing as well as her determination in protecting and supporting him.

3.2 HIV positive group analysis

This section will begin by outlining a theoretical formulation of the data obtained during interviews with the HIV positive sibling group. The data pertaining to this group produced 5 core categories and 15 subcategories. The HIV positive sibling group is discussed first as this will help provide the reader with some context regarding the subthemes described in the HIV negative siblings, where accounts are predominantly focused around concerns participants had regarding their HIV positive siblings. Each core category will be discussed and detail regarding each subcategory will also be expanded upon using participants' direct quotes to illustrate the formation of each subcategory.

3.2.1 Theoretical formulation

The Grounded Theory coding method produced 393 open codes and 74 axial codes for the HIV positive sibling group. These were then reduced to 5 core categories and 15 subcategories. The theoretical formulation embraces the interacting processes described by participants during interviews and is illustrated in the diagram shown in Figure 4. The formulation demonstrates the process of managing cognitive, affective and behavioural responses to HIV as experienced by the HIV positive siblings interviewed for this project. The 5 core categories have been arranged into four process areas as demonstrated in Table 5.

Table 5: Arrangement of core categories into a theoretical formulation

Core Category	Process Areas
Category 2: Stigma	Society/Others
Category 5: Desire to fit in	Individual desires
Category 4: HIV Burden	Individual responses
Category 1: Distance from HIV	
Category 3: Self-growth through HIV	Individual benefits

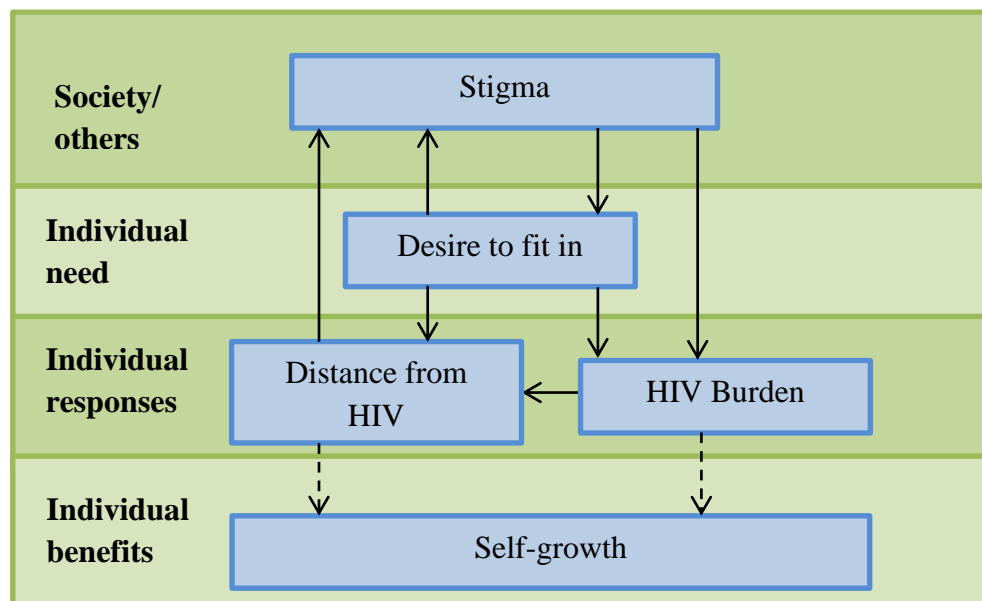


Figure 4 - Theoretical formulation for the HIV positive siblings group.

3.2.2 Description of theoretical formulation

Society and others

Participants reported overwhelming external pressure regarding HIV. Participants discussed their understanding and perceptions of the negative societal and media perceptions of HIV and how these impact upon their cognitive, affective and behavioural responses to their condition. External stigma appeared to affect multiple areas of the participants life e.g. school/college, family, sibling relationships as well as affecting the individual. Participants explored living with stigma and ways of challenging this in order to take care of themselves.

Individual need

Participants reflected upon their wants and desires in the context of HIV and how the condition can either act as a barrier or a facilitator in achieving these. In particular the desire to fit in appeared prominent as participants considered feelings of being an outsider or their perceptions that others might reject them because of HIV. Feeling 'normal' was significantly important to participants.

Individual responses

Participants explored the many strategies they utilised to manage the emotional load introduced to them by HIV. This includes the ways in which participants perceive HIV to be burdensome to them in addition to the active effort to place distance between themselves and HIV. This was discussed in terms of behavioural and cognitive strategies that offer emotional distance from HIV for the individual in order to help participants cope with the illness. This appears effective as a short-term strategy to manage emotional conflict in the here and now. However, as a longer-term strategy this appears ineffective and serves to reinforce difficulties experienced by participants. Unfortunately, participants feel powerless to effect change in this cycle given that societal stigma continues to present an ever present perceived threat to the family again reinforcing this cycle.

Individual benefit

Individual's benefit refers to the ways in which participants feel HIV has contributed to their lives. It was reported that through the challenges HIV introduced for participants, their siblings and their families, that those experiences added strength of character and developed participants as people as well as strengthening

relationships within the families in some cases. This also served the function of increasing participants' resilience to the external stigma as well as allowing those young people to function within the strict secrecy around their condition and provide increased emotional well-being.

3.2.3 Summary

Overall, participants report a complex series of cognitive, affective and behavioural processes which serve, initially, to reinforce difficulties experienced by participants but that ultimately facilitate growth and adjustment to HIV in a manageable way for participants.

3.2.4 Core categories

This section will expand on the each of the five core categories and the fifteen subcategories that arose from the data analysis. The number of participants that contributed to each category is also shown in order to reflect the strength of any corroboration between participants' experiences. As previously described, each core category was constructed using lower level subcategories and this section will illustrate the formation of those subcategories using participants' quotes. Space prohibits the illustration of complete coding hierarchies depicting all open and axial codes that contributed to every core category. Therefore, a diagram highlighting the complete coding hierarchy used to construct core category one will be provided. In addition to this the remaining core categories and each of their contributing subcategories will be represented diagrammatically.

Category 1 – Distance from HIV

Number of sources: 5

Description: All participants in the HIV positive group discussed managing their emotional reactions to HIV by actively trying to distance themselves from the condition. This was discussed in terms of participants purposefully not talking about HIV with others and by not thinking about HIV themselves where possible. The full coding category used to construct core category one is shown in Figure 5

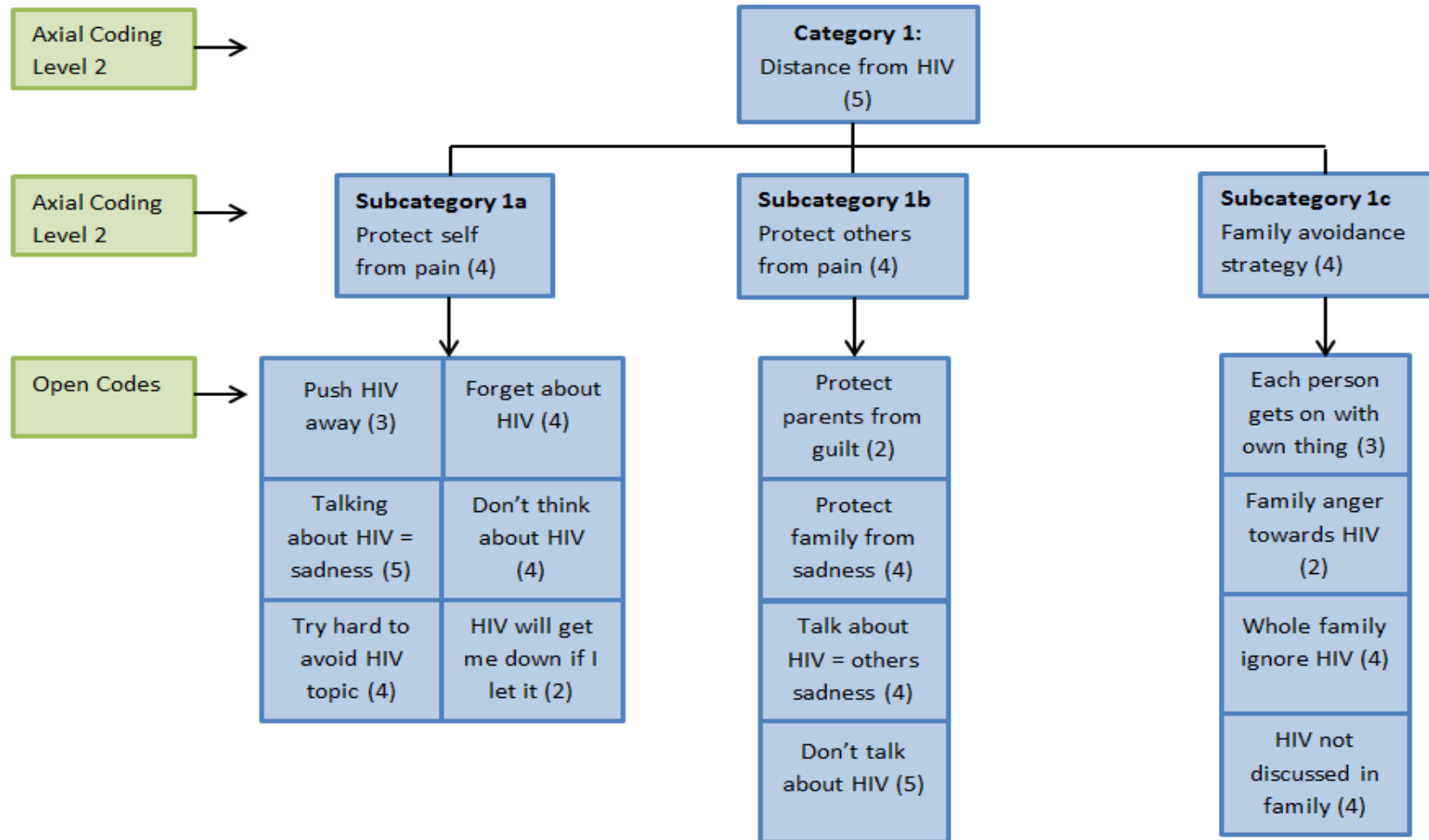


Figure 5 - Coding hierarchy for Category 1: 'Distance from HIV'

*Subcategory 1a: Protect self from pain***Number of sources:** 4**Description:** Most participants from this group reported a belief that discussing HIV would cause emotional pain for themselves and reflected on a number of strategies utilised in which they would seek to avoid the perceived emotional fall out.**Examples:**

Participant 1: It just makes me so sad, when I think about it I get very sad actually I don't know why. I just try to forget about it, that I have HIV and get on with my life. I just try to not think about it and do whatever I can to make myself happy I mean I'm not the only person in the world with HIV and people have bigger problems than me I just try to remember the good things about my life and keep happy not the bad things like HIV."

Participant 7: "If you keep talking about it it's going to get to you eventually, it's a negative thing and that can only get you down so obviously I don't want to talk about it usually, why would I? I don't want to make myself sad and upset on purpose so no I just try to not think about HIV and all that stuff."

Participant 9: "I used to just go and talk to someone, friends and that, if I was told something big but I don't think I can go to my friends and talk to them about this because it'll just upset me and make me too uncomfortable. I just close myself off from that and I tried to like not think about it like not thinking about it, not talking about it I feel like kind of closed off to everyone else I just kept myself to myself."

*Subcategory 1b: Protect others from pain***Number of sources:** 4**Description:** In addition to trying to protect themselves from emotional distress most participants in this group also reflected on the belief that they would elicit similar distress in others close to them if they spoke about HIV. Participants reported a need to protect others from this.**Examples:**

Participant 1: "I don't really remember it coming up a lot actually but they get all emotional and cry and stuff when it has come up so it's just not worth it at all and it makes me even more sad when I see my family upset. So yeah, I wouldn't bring it up I'd feel bad for making them feel bad."

Participant 3: "I think people would wait for me to bring it up but I couldn't do that it wouldn't be fair because it would upset everyone and that would be all my fault."

Participant 7: "If I present myself that it's affecting me yeah then it will affect him as well. In a way, if I present myself like I don't care and they don't see how I feel and think, well he doesn't care about it so why should we, and they will just leave it there. I just think don't let them go down with me"

Subcategory 1c: Family avoidance strategy

Number of sources: 4

Description: In addition to participants considering their own methods of placing distance between them and HIV most also elaborated on the families style of avoiding HIV discussing how, for most participants, their families were closed to openly talking about the condition.

Examples:

Participant 3: Just my mum has HIV but we don't talk about it the most we talk about is doctor's appointments but we won't sit down and talk about the actual thing. The whole family doesn't really want to talk about it I suppose.

Participant 5: "I don't know if they ever think about it but nobody ever talks about it, in my family it just isn't something we ever talk about.

Participant 9: "My mum has it but we don't really talk about it together. I do remember that she is going through it as well but we would never sit down and talk about it."

Category 2 – Stigma

Number of sources: 5

Description: All participants within this group discussed the issue of HIV related stigma and the impact this has had for them in different areas of their life in addition to the effect stigma has on how those participants manage their condition and their well-being.

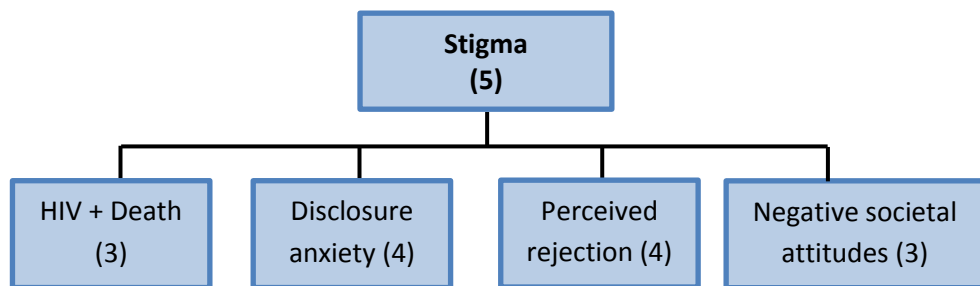


Figure 6 - Subcategories contributing to the HIV positive group data – Category 2.

Subcategory 2a: HIV and death

Number of sources: 3

Description: Many participants discussed initial beliefs upon diagnosis that HIV was a ‘death sentence’ and that they were ultimately going to die and the profound effect that feeling had for those individuals. Furthermore, the view that society largely sees HIV as a fatal diagnosis was discussed.

Examples:

Participant 5: “I know people die of this but those people get to die knowing they had this experience that not many people have”

Participant 9: “If you have HIV you’re going to die that’s what I thought so I thought like I’m going to die, I knew I was going to die at some point I’ve never been more scared in my whole life”

Subcategory 2b: Disclosure anxiety

Number of sources: 4

Description: For the majority of participants disclosing their HIV status to others, in particular romantic partners, was extremely anxiety provoking. Those participants reflected upon the role of stigma in their anxieties around disclosure.

Examples:

Participant 1: “When I get a boyfriend I’ll need to tell him and when I tell him I have HIV then what will happen? People don’t understand HIV like I do who knows what they’ll think.”

Participant 3: "I can't just go around telling people I have HIV, people wouldn't want to talk to me they will just look at me like oh you're sick! I already feel dirty I couldn't handle that."

Participant 7: "People don't know I have HIV it's none of their business to be honest and people make jokes about it you know like all the time and I get to hear what people really think about it so I could never tell them about me never."

Subcategory 2c: Perceived rejection

Number of sources: 4

Description: Many participants focused on their potential to enter into romantic relationships and discussed their concerns that possible partners would reject them based on their HIV status.

Examples:

Participant 3: "In the future I imagine HIV will stop me getting into some relationships I bet most people would run a mile when they found out about me."

Participant 9: "Having this will make it harder to get into relationships who's going to want to go out with somebody that has HIV? I perceive it to be like mutants and humans and I'm the mutant 'cause of HIV."

Subcategory 2d: Negative societal attitudes

Number of sources: 3

Description: Many participants in this group spoke about their understanding of societal views of HIV, the impact knowing this view has had for them in terms of how they relate to others and also how they relate to themselves.

Examples:

Participant 5: "People just don't want to know the truth about HIV my friends say you can catch it just from touching someone people think it's something you deserve because you done drugs and stuff, it's quite ignorant really."

Participant 9: "It really affects my mood it affects the way I think because like I said society sees it as this massively negative thing it makes me feel like I'm not really a part of society but I'm just in society"

Category 3 – Self-growth through HIV

Number of sources: 5

Description: All of participants in the HIV positive sibling group highlighted the many ways in which HIV has added to their lives or benefited them in some way. Participants described how, for them, HIV has facilitated personal growth and played a role in shaping them into the young people they are.

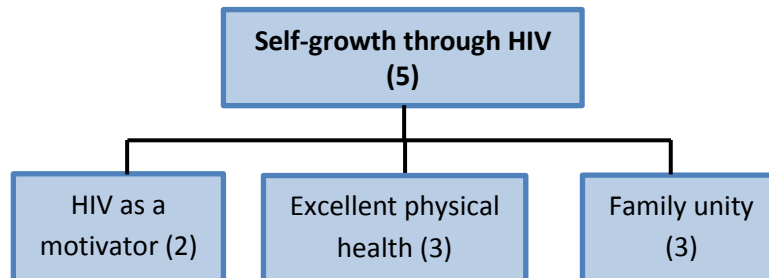


Figure 7 - Subcategories contributing to the HIV positive group data – Category 3.

Subcategory 3a: HIV as a motivator

Number of sources: 2

Description: During interviews some HIV positive participants described how HIV motivates them to strive for more in their lives and equally how they themselves are motivated to not allow HIV to take away from their lives.

Examples:

Participant 5: “When you think about it HIV motivates people to do new things. I know I use it to motivate myself, to push myself to do things that are worth doing. I just use it as a motivator.”

Participant 9: “It just makes me more determined to achieve whatever I want to achieve and that’s what’s helped me through, it makes me want to aim higher.”

Subcategory 3b: Excellent physical health

Number of sources: 3

Description: During interviews some participants explained how HIV has preserved their health and given a sense of security, due to on-going and regular health checks, providing reassurance that outside of the controlled HIV virus they are perfectly fit and healthy.

Examples:

Participant 1: "No, I'm quite healthy. I don't worry about my health too much I know that if something was wrong the doctors would spot it and help so that's a good thing I guess."

Participant 7: "I hardly ever get ill. These pills yeah they keep you healthy my immune system is working perfectly my friends are always ill and I never am and I'm the one with this big illness but the meds make my count very very low."

Participant 9: "I never get anything, well other than the occasional flu but that's it."

Subcategory 3c: Family unity

Number of sources: 3

Description: Many participants reported that they had experience their families becoming more unified given their shared experience of going through HIV and the family cohesion of keeping a secret that is designed primarily to protect the HIV positive sibling. Those participants in this group reported being closer to their siblings in particular who were viewed as more open to discussing HIV related issues.

Examples:

Participant 1 "My sister takes care of me a lot she's the only person in the world who I can share this with she just gets me and what I'm going through. We were always close but I'd definitely say this made us even closer."

Participant 3: "Bringing me closer to my family I would say is a positive like my siblings we're like the best of friends not siblings they look after me and protect me and care."

Category 4 – HIV Burden

Number of sources: 4

Description: Most participants reported the ways in which HIV presents a burden to them, thinking in detail about the ways HIV presents challenges that they otherwise believe they would not face in the absence of HIV.

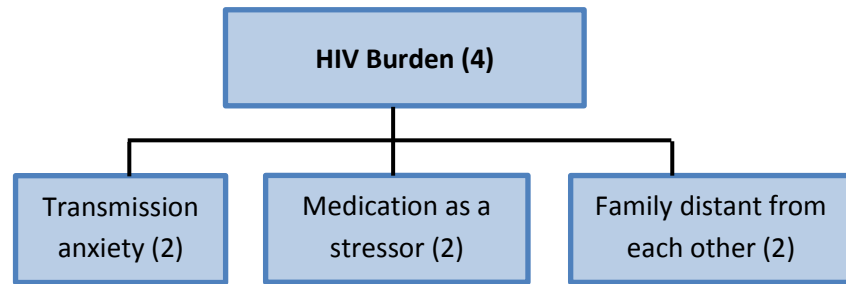


Figure 8 - Subcategories contributing to the HIV positive group data – Category 4.

Subcategory 4a: Transmission anxiety

Number of sources: 2

Description: Two participants reported that a significant challenge was anxiety relating to the potential for transmitting HIV to another person, speaking in detail of the stress this can cause.

Examples:

Participant 3: “Since like I’ve turned 19 and come into contact with boys I have to be like cautious especially with the relationship side of things I always think what if I gave it to someone and how bad would I feel.”

Participant 7: “I can’t do anything about me having HIV but I can protect myself from catching anything else or from passing it on. Because I have HIV I am always like thinking about condoms.”

Subcategory 4b: Medication as a stressor

Number of sources: 2

Description: Two participants reported that the rigid routine imposed by taking daily medications at a strict time introduces a particular stressor. In addition those participants found adherence to medication difficult and worried about the consequences of forgetting this leading to a resentment of the treatment.

Examples:

Participant 3: “So now the meds have started and I don’t like it, it reminds me every day that I have this and I worry a lot like can I drink when I’m on these. I went to the dentist the other day and I had to fill out a form and it asked do you take medication and I just froze with the pen I didn’t want to tell them that.”

Participant 9: “I have a routine before I go to sleep now I’ve had to get into the habit of taking my pills with a glass of water before bed that’s how I remember. It makes it hard to do normal things like sleep over at a friend’s. I have to remember to take them with me but then people can’t see them or they’ll ask questions.”

Subcategory 4c: Family distant from one another

Number of sources: 2

Description: Two participants reported feeling that HIV had played a role in family members withdrawing from one another and that this was evident in the lack of communication regarding HIV within the family that has been previously discussed in this section.

Example:

Participant 9: “It did seriously affect relationships in the family especially when I was first diagnosed nobody wanted to talk about it nobody wanted to upset anybody and for me it was kind of like a blame thing. I’m the only one of four siblings to have it and I’m not even the first born. So yeah, we kind of all ignored each other.”

Category 5 – Desire to fit in

Number of sources: 5

Description: All participants in this group discussed being HIV positive in terms of this having a minimal impact and that HIV was normal. It was acknowledged that for others this can be viewed as abnormal and the struggle between wanting to fit in and feeling as though they can and should, and the anxiety of others not accepting them was explored.

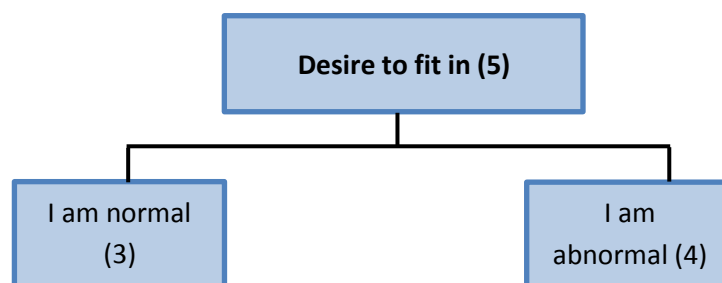


Figure 9 - Subcategories contributing to the HIV positive group data – Category 5.

*Subcategory 5a: I am normal***Number of sources:** 3

Description: Some participants reported a sense of normality within the context of HIV. For those three participants who reported a sense of normality, being HIV positive today has little impact on their physical health and functioning and is concealable, allowing them to function as well as a person who is HIV negative. Those participants continually reassured themselves during interviews that they are normal.

Examples:

Participant 5: "It's just like living a normal life there's nothing different, it's not really much of a big deal. I feel the same as any other person."

Participant 7: "There's no difference really. I'm normal, nothing's changed I'm still the same person only now I have HIV."

*Subcategory 5b: I am abnormal***Number of sources:** 4

Description: Most participants reported a sense of feeling abnormal themselves or a sense that others view HIV positive people as abnormal. During interviews participants appeared to unpick this struggle between their view of themselves and the view they perceived others might have of them.

Examples:

Participant 3: "I just feel so dirty like I'm just scruffy and dirty."

Participant 5: "Other people will see it as a disadvantage but it's not about what they think since they don't have this condition."

Participant 9: "I perceive it to be like mutants and humans and I'm the mutant 'cause of HIV."

3.3 HIV Negative group analysis

The analysis of the HIV negative sibling group produced four core categories. Each core category will be expanded upon in this section in addition to a detailed description of the associated subcategories utilising participants' quotes from interviews to further demonstrate this. The core categories established in the HIV negative sibling group are similar to the HIV positive sibling group. This is unsurprising given that siblings are discussing the same phenomena within the context of their family and as such one might expect that particular experiences are similar in nature. However, despite the broad category being the same, siblings in the HIV negative category describe their experiences from a different perspective, thus contributing to the complex view of the impact HIV is having for different family members.

3.3.1 Theoretical formulation

Grounded Theory analysis produced 380 open codes and 75 axial codes for the HIV negative siblings. These were then reduced to 4 core categories and 12 subcategories. The theoretical formulation embraces the interacting processes described by participants and are illustrated in the diagram shown in figure 10. The formulation demonstrates the process of managing cognitive, affective and behavioural responses to HIV as described by the HIV negative siblings. The 4 core categories have been arranged into three process areas as demonstrated in Table 6.

Table 6: Arrangement of core categories into a theoretical formulation

Core Category	Process Areas
Category 2: Stigma	Society/Others
Category 1: Distance from HIV	Individual responses
Category 4: HIV Burden	
Category 3: Self-growth through HIV	Individual benefits

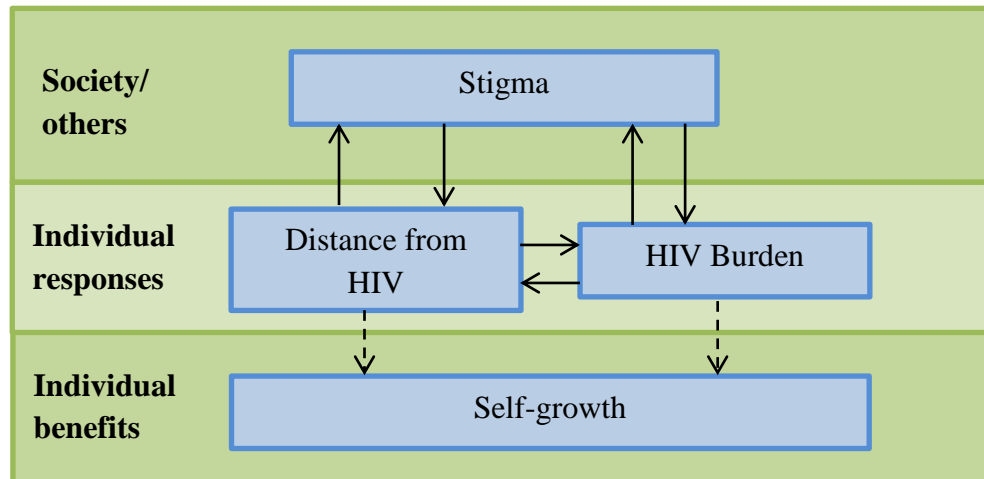


Figure 10 - Theoretical formulation for the HIV negative siblings group.

3.3.2 Description of theoretical formulation

Society and others

Participants reported an overwhelming external pressure placed on them and the family which was attributed to HIV related stigma experienced within society and by the participants. Participants reflected upon stigma and the impact it had on their views of HIV and the development of their understanding of this illness, as well as their ability to seek support or disclose their difficulties outside the strict family boundary of secrecy reported by many participants. Some participants were also able to offer differing accounts of multicultural experiences of stigma, shedding further light on to the impact HIV is having for some people in the UK and how this might differ to other cultures.

Individual responses

Participants explored the many strategies they employed to manage the emotional burden introduced by HIV, from the perspective of young people who view themselves, and feel viewed by their families, as a lesser priority in terms of need and resources. Participants in this group explored strategies to manage supporting their siblings and protecting them at all costs but also discussed the difficulty in attending to their own care needs or feeling powerless to seek this support. Participants described a continuing active effort to distance themselves from HIV both cognitively and emotionally in an attempt to cope. This strategy, although effective in the short-term management of emotional dysregulation, unfortunately

appears to exacerbate the difficulties experienced by those participants as this appeared to reinforce the problem. However, participants experienced feeling powerless to effect change in this area given that the societal stigma presents an ever present perceived threat to their family again reinforcing this cycle.

Individual benefit

Individual benefit refers to the ways in which participants feel HIV has contributed to their lives. It was reported, particularly for this sibling group, that fulfilling a caring and supportive role for their siblings and other relatives provided them with an increased empathic response to others which was highly valued by those participants. This also appeared to allow participants an increased resilience to the external stigma of HIV and allow them to function within the boundary of secrecy and increase emotional well-being.

3.3.3 Summary

Overall, participants appear to report a complex series of cognitive, affective and behavioural processes which can serve to reinforce some difficulties associated with HIV. Participants also experienced some benefits and personal growth resulting from HIV.

3.3.4 Core categories

This section will expand on each of the four core categories and the twelve subcategories that arose from the data analysis. Once more, due to limitations in space only the full coding hierarchy for core category one will be represented diagrammatically. To supplement this, the additional core categories and associated subcategories will be illustrated in a diagrammatical format.

Category 1 – Distance from HIV

Number of sources: 5

Description: All participants in the HIV negative group discussed managing their emotional reactions to HIV by actively trying to distance themselves from the condition both cognitively and emotionally. This was discussed in terms of participants purposefully not talking about HIV with others and by not thinking about HIV themselves where possible. The full coding category used to construct core category one is shown in Figure 11.

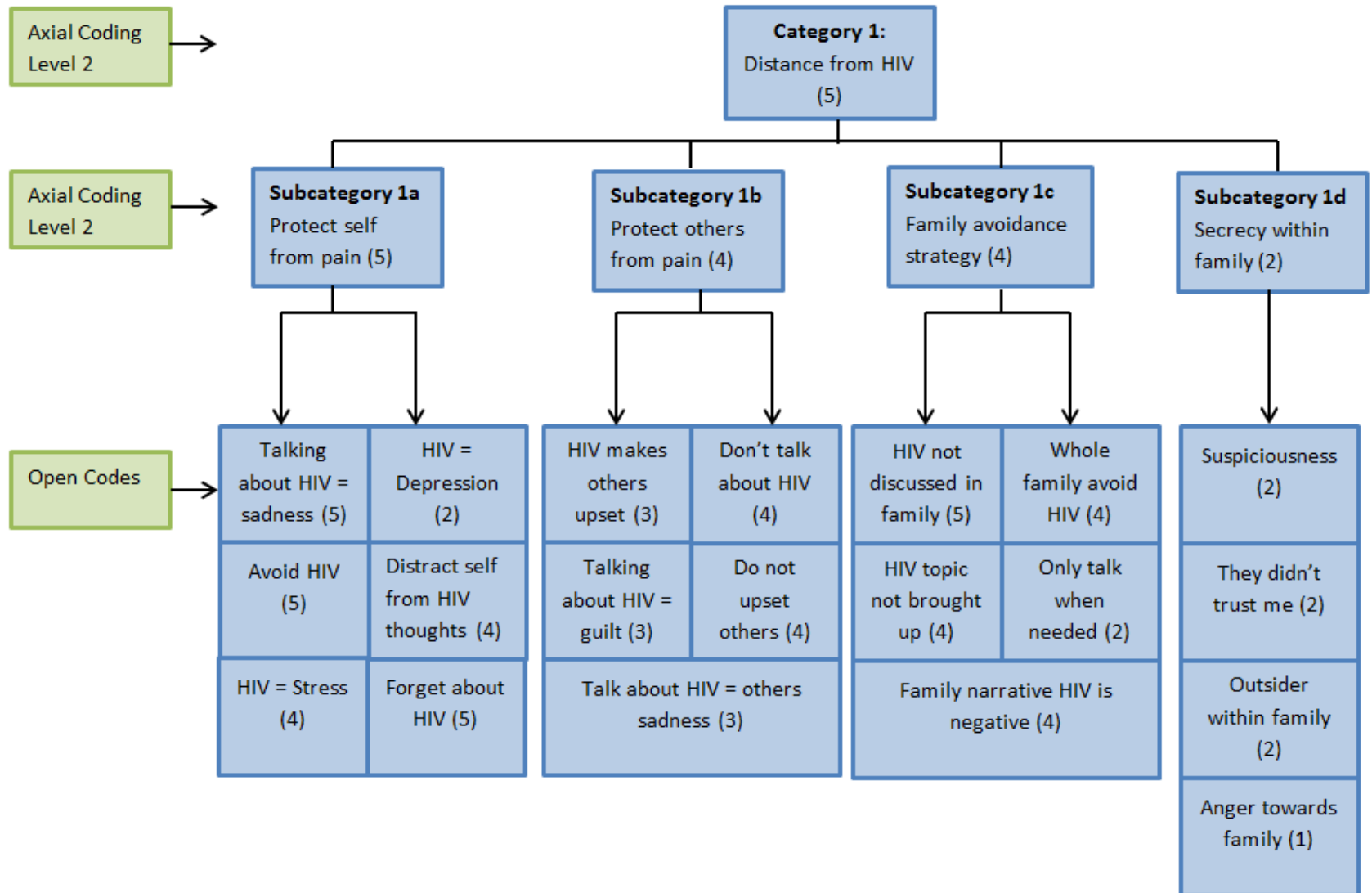


Figure 11 - Coding hierarchy for Category 1: 'Distance from HIV'

Subcategory 1a: Protect self from pain

Number of sources: 5

Description: All participants in this group discussed the overwhelming emotional impact of their sibling's diagnosis for themselves, their sibling and other family members and the difficulties they experienced in managing this. Participants explored a number of strategies utilised in order to avoid the perceived emotional impact of HIV.

Examples:

Participant 2: "If I think about it I will start crying and get emotional because it makes me feel sad sometimes. I mean, when it does come to my mind I get emotional and sad. I just don't think about it I just don't put that negative thing in my mind... I just get so stressed when talking about HIV I don't like to think about those things."

Participant 6: "nobody talks about it, no it would just bring tension and that would bring sadness so I just keep it on the low low. If I think about that I just keep myself depressed or stress myself out it saddens me when I think about it. I try not to think about it anyway."

Participant 8 "I'm easily able to just not think about it yeah I just forget that he has it or that my mum has it and if we don't want to talk about it then that's ok, well I don't personally. It just makes me more sensitive so you just get on with it you know?"

Subcategory 1b: Protect others from pain

Number of sources: 4

Description: Most participants reported a strong belief that initiating conversations around HIV would elicit an adverse emotional response in HIV positive siblings (and other diagnosed family members), often viewing their diagnosed sibling as 'emotionally fragile'. A responsibility to protect family members from this was discussed. Participants often reported that given it was not them diagnosed they felt unable to initiate such conversations or that this was inappropriate.

Examples:

Participant 2: "She was a mess she would get all emotional and start crying and it makes me feel sad sometimes especially when I see the others upset. If we don't think about HIV we will be happier so it's just better if I don't ask about it really."

Participant 6: “No way, if we did bring it up yeah and told, well, if they knew how bad it was what if my parents thought we was blaming them ‘cause obviously they didn’t ask to be born with this, none of us asked for this but they might think we blame them or something.”

Participant 10 “He’s my little brother I am always going to protect him, I feel responsible because I’m the oldest and I want to support him but I worry if he can’t deal with this illness he might end up doing something he regrets. He might think there is no point in living so I worry about his safety like any sister would. So I want to keep his thought processes like you know, positive not negative so I just treat him normally and don’t really talk about it. He unloads when he needs to and then we talk about it but I can’t talk I don’t really want to talk about it either”.

Subcategory 1c: Family avoidance strategy

Number of sources: 4

Description: Most participants reported a family based strategy of avoiding HIV based conversations owing to concerns that this would incite upset amongst the family.

Examples:

Participant 4: “My family don’t really talk about it I think my sister would just start crying and I don’t understand what’s going on so no we don’t talk about it.”

Participant 6: “Nobody talks about it nobody even thinks about it I think we all just know that if we did then there would just be no point, all it would do is upset everyone yeah”

Participant 10: “We probably should talk about it as a family. Maybe we handle it in a way that’s a bit abnormal. It’s kind of highlighted a communication breakdown in my family where we just don’t speak about it. But then again it would just upset everyone I think.”

Subcategory 1d: Secrecy within the family

Number of sources: 2

Description: Two participants reported that within the families’ continual efforts to place distance between the family, its individual members and HIV that in some cases the HIV negative sibling is not informed of their sibling’s illness. Given the

concealable nature of HIV this secret can be hidden for many years. Those participants reported how this left them feeling angry, betrayed and untrusted by their families and how they had to navigate the raw emotions of the diagnosis at a time the family were more adjusted to this, leaving HIV negative siblings to feel out of sync or an outsider within their family.

Examples:

Participant 6: “I shouldn’t get angry over things like this but I do, to be honest it was a shock and I might have reacted differently to it than I did when I was 18/19. They knew for years and didn’t tell me I don’t know if they thought I’d tell people or not but I would never do that it worries me that it might get out.”

Participant 10: “I wasn’t told to be honest, I can’t remember exactly how I found out I had a feeling and I guess they just expected me to figure it out, I saw him take his medication every day and thought that’s a bit weird but nobody would tell me. Then I found out on a piece of paper and was shocked but I didn’t say anything they obviously didn’t want me to know.”

Category 2 – Stigma

Number of sources: 4

Description: Most participants within this group discussed the power of stigma they felt from outside of the family in terms of societal and media perceptions of HIV and the many ways in which this impacted on various areas of their lives.

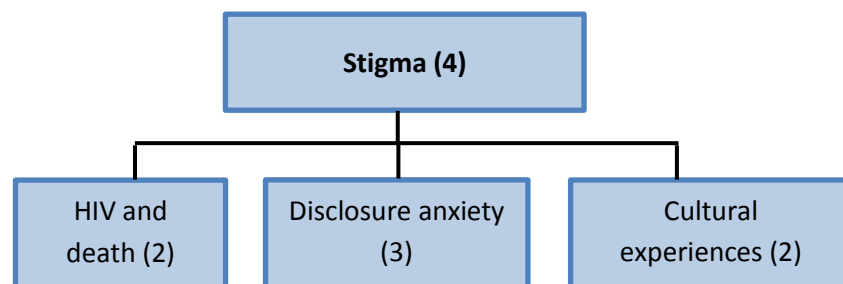


Figure 12 - Subcategories contributing to the HIV negative group data – Category 2.

Subcategory 2a: HIV and death**Number of sources:** 2

Description: Two participants reported beliefs, once aware of their siblings' diagnosis, that the sibling would die. One had previous experience of death in the context of HIV. Therefore this along with the media perception of HIV produced a real sense of threat to their sibling and a sense of impending loss for the participants.

Examples:

Participant 2: "She was in hospital getting worse and worse and obviously my parents died of HIV. I tried really hard not to be negative but I was worried she might die too. Like people in Africa used to die of things like HIV so sometimes I'll just be like well my sister is not dead she is alive and remember how lucky we are. She's all I have left I don't know what I would have done if I lost her too."

Participant 4: "I don't know, I remember thinking is she going to die because you hear things people say about it or you see it on the tele and they say you die from this so I thought she is going to die from this too."

Subcategory 2b: Disclosure anxiety**Number of sources:** 3

Description: Many participants reported a strong anxiety around the disclosure of their siblings' diagnosis. This was discussed in terms of potential risks to the safety of their siblings as well as a threat to the emotional well-being of siblings if their HIV status was exposed. Those participants in this group were also concerned that exposure would also place parents and other family members at risk and some predicted that a poor reflection on the family name would be asserted by others who would seek to reject the family as a whole. Therefore maintaining secrecy was protective for the entire family not just those who are HIV positive. Secrecy also served to manage fears HIV negative siblings had for their own well-being.

Examples:

Participant 2: "If other people knew they might start talking about us badly and that would be stressful we would probably get emotional and upset. I think it's obviously better if it stays in the family because if it didn't stay in the family I would get upset, I would get really upset, I actually would. It's safer that way."

Participant 6: "It worries me that it could get out, if people knew things would never be the same. I don't want other people outside the family to know this it would be damaging to the family name and give us a bad reputation, they will say it's your mum's fault she should have known. My family runs a business people might use it to blackmail us or people might not want to do business with us if our reputation is ruined. I know it won't get out the family though and that relaxes me."

Participant 10: "He might have to tell a partner one day and stuff like that and I worry in terms of his emotions you don't know who you can trust and it's a risk but I worry about what that would do to him. He's a really good guy and anybody who would reject him based on that would be pretty stupid I worry because of the person he is, if people hurt him he won't be able to look past it."

Subcategory 2c: Cultural Experiences

Number of sources: 2

Description: Some participants reported markedly different cultural experiences regarding societal attitudes towards HIV in terms of peoples understanding, acceptance and the stigma associated with the condition.

Examples:

Participant 2: "I remember being shocked when we first came to England and my grandma and uncle were like telling us you cannot tell anybody about the HIV people do not understand this here. In Africa loads of people have HIV and people talk about this and help each other's families but here we had to be quiet. Then you slowly get to hear what people say and it shocked me it really did. It's such a different attitude it was hard to get used to at first."

Participant 6: "It's very different here my brother yeah he still lives in Africa and he will tell you people here are nasty when it comes to HIV you have to be careful here. I mean HIV still isn't a good thing out there but it's just so much worse to people here and those people don't care, they don't want to understand HIV either they just make jokes on tele about it and stuff. This is people's lives its upsetting do you know what I mean?"

Category 3 – Self-growth through HIV

Number of sources: 5

Description: All participants discussed how HIV has contributed something valuable to their lives and the lives of their families. Participants in this group discussed how this has facilitated personal growth and helped shape their personalities and the young people they are today.

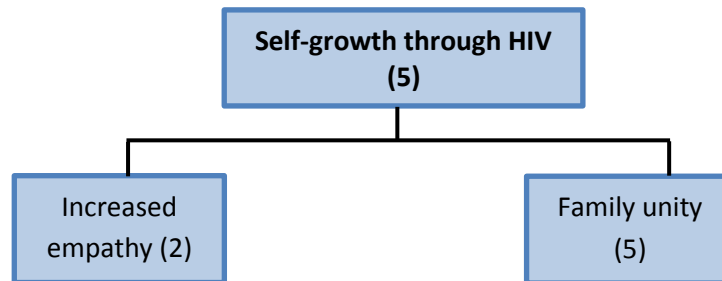


Figure 13 - Subcategories contributing to the HIV negative group data – Category 3.

Subcategory 3a: Increased empathy

Number of sources: 2

Description: Some participants in the HIV negative sibling group reflected on their increased compassion for others having been through a process of supporting and offering care to other family members including siblings. This was reported as a characteristic participants valued within themselves and attributed this to their experience of HIV.

Examples:

Participant 8: “I’d say it’s made me more caring, not that I didn’t care before I really did but I know now when something is important to someone. You can’t always be 100% bothered or want to do your own thing but I have to support my brother and at the same time I want to. Sometimes it’s not about what you want is it you have to think of the other person and help them in any way you can.

Participant 10: “I think this whole experience has helped me understand people’s emotions more which is something I think is important to be able to be there and care for the people you love but to also understand where they are coming from I guess. It’s good for the career I want to go into too.”

Subcategory 3b: Family unity

Number of sources: 5

Description: All participants reported that they had experienced their families becoming more unified given their shared experience of going through HIV. The family cohesion of keeping a secret that is designed primarily to protect the HIV positive sibling is also something the HIV negative siblings appear preoccupied with doing. This suggests that in some ways families display a united approach to managing HIV. Participants in this group reported being closer to their siblings in particular who they valued for sharing their experiences with them.

Examples:

Participant 2: “Well we are really close now we’re closer than close actually. I just treat it like oh she’s got HIV so what and just keep positive. We’ve been through so much together she’s not just my sister she’s my best friend we are the only ones that really know each other and get each other and that’s important.”

Participant 4: “We like all take care of each other and support each other so yeah we are pretty much a lot closer now than we was when this all happened.”

Participant 6: “I think like my mum especially we are more connected she knows the things I’m worried about with the HIV thing.”

Participant 8: “Yeah I’d say HIV made us closer because we had to talk more and think about each other more it made me make more of an effort and without that we would probably still be fighting all the time. I think it has brought me closer to my brother and my mum specially my brother we do everything together now.”

Category 4 – HIV Burden

Number of sources: 5

Description: All participants reported the ways in which HIV presents a burden to them thinking in detail about the ways HIV presents challenges to them that they otherwise believe they would not face in the absence of HIV.

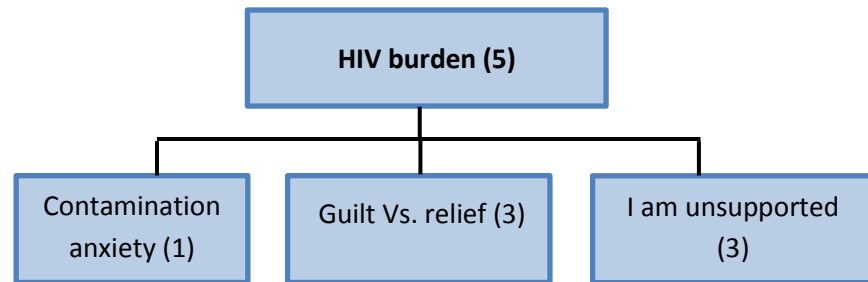


Figure 14 - Subcategories contributing to the HIV negative group data – Category 4.

Subcategory 4a: Contamination anxiety

Number of sources: 1

Description: One participant offered a powerful account of his intense anxiety relating to becoming HIV positive himself. He described in detail how this preoccupied his thoughts and interfered with his mood and behaviour on a daily basis.

Examples:

Participant 6: “Sometimes I feel like I could get it as well, like what if they have a nose bleed or hurt themselves and there’s just blood lying around and stuff, blood can get everywhere.”

Participant 6: “I don’t hate them because they have it but what if I got it as well and I don’t want to have that sometimes I just get worried that I might catch the virus as well.”

Participant 6: “It’s something that goes through my mind every single day, it’s not something good to have I need to make sure I’m careful so I go for tests and things and get checked I haven’t got my results back yet from my last test.”

Participant 6: “There are other people out there that have it you know what if I meet a girl yeah and she’s too ashamed to tell me, my own family didn’t tell me at first so why would somebody else, I won’t tell anybody else about us. I really worry about girls and things like that you read in the papers some people pass it on intentionally to get revenge or something.”

Subcategory 4b: Guilt vs. relief

Number of sources: 3

Description: Many participants in the HIV negative group reported an internal conflict between feelings of guilt that they were not diagnosed with HIV whilst their siblings were and feelings of relief that they were not HIV positive. This appeared to form a vicious cycle in which the feelings of relief would retrigger the feelings of guilt.

Examples:

Participant 2: "I just keep thinking but why not me, why my sister. I'm the oldest it should have been me. But at the same time I don't want HIV really I just want it to go away out of our lives."

Participant 8: "It's hard to talk about it sometimes, we're twins basically, and I think how, why has he got this and I haven't. He must be thinking the same thing we were born together and he was born with this condition and I wasn't its weird. I'm glad I don't have it but at the same time why me why was I the lucky one he doesn't deserve this he didn't ask for HIV."

Participant 10: "I think it depends on the type of person you are and I think it would have been better if it was me, I would cope better I think. I'm the oldest I should protect him and I'd take it for him if I could."

Subcategory 4c: I am unsupported

Number of sources: 3

Description: Many participants in the HIV negative sibling group discussed a feeling of being unsupported and largely fulfilling the role of the supportive person for their diagnosed sibling and other relatives. This was discussed in terms of resources being directed towards the HIV positive sibling at the expense of participants in this group.

Examples:

Participant 4: "Oh no, no I don't get support but then it's not me that has this condition."

Participant 6: "I'm not the one with HIV so I'm not the one people worry about you know? But I have worries and things, I could use support but it doesn't really happen much."

Participant 10: "I have my own problems too, it's not on-going but I still have my own problems."

3.4 Analysis of both groups.

This section will outline an analysis of the data as a whole, offering a synthesis of the information elicited from all 10 interviews in an attempt to describe the overall experiences as described by the participants of this project. A theoretical formulation will be provided and discussed, capturing the essence of the participants accounts as described previously.

10 young people participated in this research project consisting of 5 sibling pairs in which one was HIV positive and the other was HIV negative. Analysis of the data at a group level (HIV positive and HIV negative groups) revealed strikingly similar themes. This is perhaps unsurprising considering participants were encouraged during interviews to think about the broader family experiences, including familial relationships, as well as their own. As such, similar patterns emerged given that participants were part of the same families and were describing a similar phenomenon simply from a different perspective. Despite this, participants' personal experiences and methods of managing the impact of HIV also appeared to overlap suggesting that to some extent there may potentially be a shared journey of HIV, albeit an individual and 'lonely' journey for participants. It appears that HIV was experienced in similar ways by both HIV positive and HIV negative siblings at the individual, family and societal level.

3.4.1 Theoretical formulation

Using Grounded Theory analysis a theoretical formulation was constructed for both participant groups. Both formulations captured the unique processes young people with HIV in the UK today employ in order to manage the psychological factors associated with HIV. Both groups reported very similar strategies and experiences of utilising these. According to participants, the difficulties and challenges associated with HIV are no longer of a physical nature given that physical health in the context of those receiving HIV treatment was considered to be excellent, suggesting those young people diagnosed considered themselves very healthy but also acknowledging concerns for the future too. The difficulties experienced were psychological in

nature. Participants describe the need to navigate differing social pressures and psychological barriers to well-being, inflicted upon them at different levels; the individual, the family, the romantic, the community and the society level. Each distinct level presents unique and on-going pressures for young people affected by HIV to navigate. Despite both HIV positive and negative siblings reporting benefits associated with HIV and feeling HIV is normal for them, they remain cautiously aware that the boundary outside of the family remains unsafe and threatening. This theoretical formulation is depicted in the diagram below shown in Figure 15. The theoretical formulation embraces the interacting processes as described by all participants, but also demonstrates the pressures placed on HIV positive and negative siblings in parallel to those young people stepping out into those domains e.g. romantic relationships and society and trying to navigate the challenges and pressures in those areas.

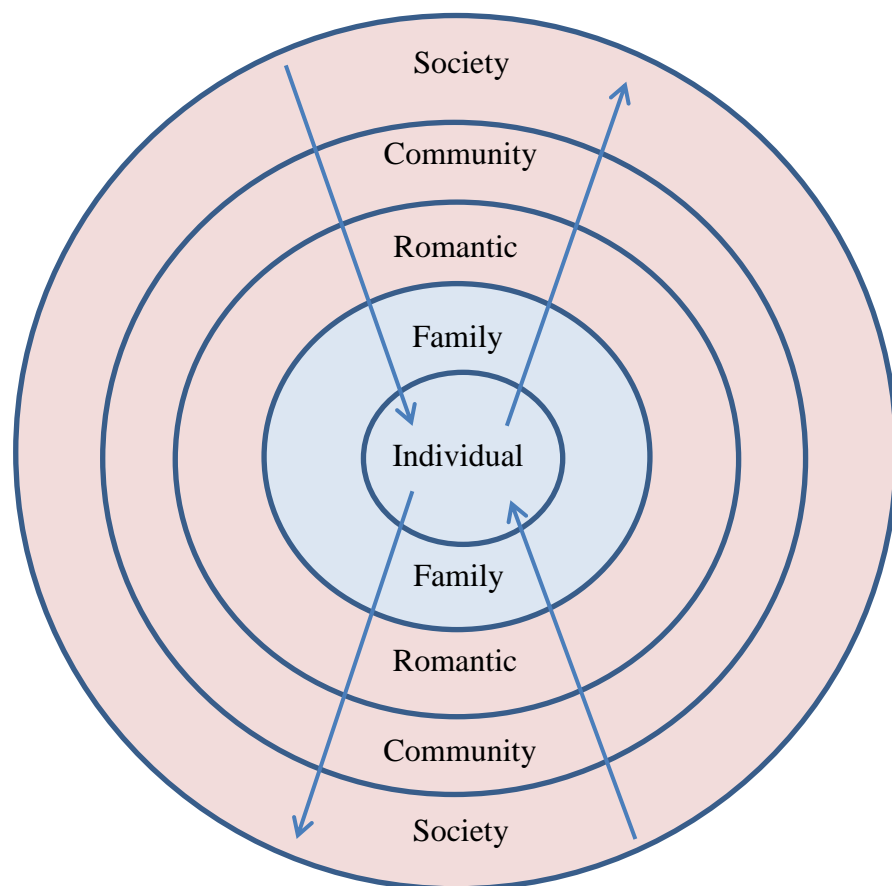


Figure 15 - Theoretical formulation of both sibling groups

3.4.2 Description of the inclusive theoretical formulation

Individual

The majority of participants reported an internal conflict resulting from many felt pressures associated with HIV. Examples include but are not limited to;

- ‘I need support’ vs. don’t upset others
- longing for openness vs. withdrawal from others
- support my sibling but don’t talk about HIV and upset them
- I feel guilty but I am also relieved I don’t have HIV
- I am normal vs. I am abnormal

Participants attributed many of these daily challenges to the stigma they felt came from an external perspective. For example, parents felt anxiety relating to their children’s safety and well-being and therefore placed pressure upon both siblings to maintain an air of strict secrecy that became both comforting and frustrating for participants. The young person was then responsible for managing the pressures placed upon them and in some cases they had internalised this stigma e.g. “I am dirty” or “I’m the mutant”.

Family

Participants reported significant pressures within the family. It was discussed during interviews that the families of the participants tended to distance themselves from the topic of HIV and this was rarely discussed within the family. This created pressure for both siblings to avoid ‘causing upset’ to family members and maintaining the notion that discussing HIV is not only bad but that this is unhealthy for family well-being and relationships. Despite this, it appears that these conditions facilitate, in most cases discussed, the strengthening of the bond between siblings who find ways, where possible, to support each other. Disclosure anxiety based on the perceived threat of social attitudes towards HIV appears to be shared by the whole family and participants found this protective and nurturing in terms of family dynamics.

Romantic relationships

Although this is understandably more prominent for the HIV positive sibling group it is not without complication for the HIV negative siblings who often reported guilt associated with forming romantic relationships themselves or anxiety regarding the potential for romantic partners of their HIV positive siblings to expose HIV and put the family at risk of perceived rejection. HIV positive participants reported that this domain heightened the sense of being abnormal particularly given their age and desire to explore their sexuality which can be restricted due to HIV.

Community

Participants from both groups reported experiences of hearing friends at school or in other groups making fun of HIV and perpetuating this stigma. This presented a challenge in that participants felt responsible to undermine inaccurate and negative perceptions but in some cases felt powerless to do so fearing that others might wonder about the origins of their HIV knowledge, again placing them and their families at risk.

Society

This level refers to the overarching societal attitude towards HIV which participants of this research found to be negative in nature. Participants from both groups reported reading stories in newspapers around HIV or hearing jokes on television which were demeaning and factually inaccurate. The difficulty with such an engrained and stigmatised attitude at this level is that this presents a systemic and on-going problem for siblings and their families in that this exerts pressure and influence on all other systems which is not conducive of psychological well-being for families affected by HIV.

3.4.3 Summary

Overall participants report a deeply complex interplay between the external society and the internal self, the complexities of which are difficult to reduce down to a simple theory. However, on the whole, it would appear that young people affected by HIV today are able to adjust and manage well. The difficulties do not appear to be located within the person but rather externally. Any difficulties that arose for participants appeared to have their origins in a system external to them. Participants were functioning very well given the pressures placed upon them.

4.0 Discussion

The aim of the discussion chapter is to revisit the design and aims of the study, provide a summary of the results and relate the findings of the current research to the existing literature. In addition, the discussion chapter will critically evaluate a number of methodological considerations, discussing the clinical implications of this research and providing some recommendations for future research.

4.1 Revisiting the research aim

The principal research aim was to qualitatively explore the consequences of HIV from the perspective of young sibling pairs in which one gave the perspective of being diagnosed with HIV and the other offered the perspective of being HIV negative, but still affected by HIV. This project sought to investigate the psychological impact of HIV and how this is adjusted to in adolescence, focusing primarily on the emotional and social aspects of this condition but with the secondary aim of exploring the impact HIV is potentially having upon the sibling relationship.

Ten participants (five HIV positive and negative dyads) were interviewed, discussing their experiences regarding the impact of HIV on many areas of their life; personal, familial, physical and social. Using GT methodology, a theoretical formulation encapsulating the experiences of HIV, as described by the participants, was developed. The theoretical formulation described the perceived internal and external pressures and psychological processes experienced by participants at different systemic levels. It is hoped that the findings of this project may offer a contribution to the wider existing psychological literature pertaining to the experience of paediatric HIV particularly within a sibling context.

4.2 Summary of results

The GT analysis uncovered a complex picture of cognitive, affective and behavioural responses to managing the consequences of HIV, with the sibling relationship appearing to be an important element and one that potentially increases

or moderates the impact of HIV. The above processes are also directly influenced by participants' interactions with the multiple systems in which they must function i.e. the family, the community or society.

Participants were prompted by a semi-structured interview that appeared effective in initiating detailed conversations allowing for the opportunity to gain rich and complex accounts regarding the impact of HIV for both sibling groups. Both the HIV positive and negative sibling groups spoke in detail about the perception of a stigmatised cultural attitude towards HIV held by others in their community. Participants further discussed how this impacted upon the family and was associated with a breakdown in communication amongst family members who appeared to be closing down discussion of HIV as a way of managing difficult emotions. This appeared to exacerbate a growing sense of the burden HIV imposed on siblings. Secondary to this finding was an exploration of the impact HIV has had on familial relationships. It appears that HIV was creating a 'push/pull' effect in terms of family relationships in that families either became united together against HIV and the associated stigma or they became more distant and disjointed. This is supported by the literature describing centrifugal and centripetal forces exerted on families during times of chronic illness (Combrinck-Graham, 1985). Although the theoretical formulation was very similar for HIV positive and negative siblings, this also highlights how the same phenomena can be experienced from differing perspectives, providing insights concerning the experiences of young people affected by HIV.

4.3 Results in the context of existing literature

The following section will outline the findings of this project and consider the application of these to the existing literature in order to assess whether this project supports the current understanding of the experiences of HIV or presents something new. This will be achieved by utilising a framework based on ecological systems theory (Bronfenbrenner, 1977). This broad framework identifies five environmental systems that an individual interacts with. This section will be structured through relating the themes of the current project to each of the five individual systems identified in chapter 3 (individual, family, romantic, community and society). Relevant themes from that data that apply to those areas will be highlighted before moving on to discussing any links those findings have with existing literature.

4.3.1 Society

Participants from both groups discussed the overarching negative societal attitudes they had experienced towards HIV and the detrimental impact of this upon their emotional well-being. Within this section the author will describe the core category of stigma and the sub-category of cultural experiences which appeared to have salience for participants relating to the societal system.

4.3.1.2 Stigma

The core category of ‘stigma’ was described by both participant groups as particularly influential on their overall experience of HIV. For participants, the stigma described at the societal level appeared to have an impact upon other systems such as community and romantic relationships, which therefore left participants to experience stigma at all levels. Participants said that for them the stigma perpetuated at the societal level appeared to legitimise stigma at all other levels to a degree that the family felt the impact of this stigma, and in some cases the individual may internalise the external stigma. This appears to be consistent with the current view that stigma remains a stable and prominent part of the experience of HIV (Stackpool-Moore et al. 2013). However, the current study also highlights the experience of HIV related stigma from the perspective of the HIV negative sibling. Literature regarding the experience of HIV associated stigma is understandably focussed on the HIV patients’ experience. However, this study supports the view that stigma is also felt on the part of the HIV negative sibling. Bogart *et al.* (2008) investigated the experience of stigma from the perspective of the whole family and found that all families recounted experiences of stigma towards HIV. These findings were broken down to demonstrate that 100% of mothers, 88% of fathers, 79% of children and 60% of caregivers said that they had experienced stigma towards HIV. It was further reported that 97% of families described discrimination fears and that 79% of families had experienced actual discrimination. Within the current project 90% of participants reported experiencing stigma relating to HIV to differing degrees. Therefore, this particular finding is in support of the current research suggesting that stigma continues to have a powerful impact on families affected by HIV.

Participants from both groups also discussed the negative impact that stigma within the media has had on their well-being and also how this impacted others’

negative views of HIV. For example, at the time of interviews an “A-list” celebrity (Charlie Sheen) went public with his HIV diagnosis. The media subsequently covered this story by reporting on the blackmail Charlie Sheen had experienced from others who were aware of his diagnosis. This also prompted the media to link HIV to less socially acceptable behaviours such as drug taking and promiscuous sex. This had an apparent impact on one participant in the HIV negative group. Participant 6 reported *“It makes me so angry, like all this stuff with Charlie Sheen. I went on YouTube and read all the negative comments and just thought that’s what people would say about us they’ll blame us for it.”* The findings of the current study around the negative effects of the media in terms of reinforcing societal stigma towards HIV is consistent with the current literature (Babalola, Fatusi, & Anyanti, 2009; Hutchinson, Mahlalela, & Yukich, 2007). However, there is a paucity of empirical research investigating the effects of the media on HIV related stigma within the UK. Therefore, it could be argued that the current project is able to offer a partial insight into the effects of this on a UK youth population.

4.3.1.3 Cultural Experiences

One might argue that HIV related stigma is rooted in culture and consequently it is important to consider stigma within the context of culture (Zang, Guida, Sun, & Liu, 2014). For the participants in the HIV negative sibling group the sub-category of cultural experiences also appeared to have relevance for the societal system. Participants discussed comparisons of cultural attitudes towards HIV between the UK and Sub-Saharan Africa. Two participants in this research expressed the view, that cultural attitudes towards HIV in parts of Sub-Saharan Africa were less stigmatising and more positive in nature. Participants described a culture in which others were more open to discussing HIV and supporting those who were affected. Perhaps this is reflective of the increased numbers of individuals affected by HIV within those cultures, therefore reducing potential stigma somewhat if HIV is more prevalent and less taboo. In contrast, the UK experience of HIV was described as one of strict secrecy and threat of rejection as well as one that offers little support. This finding is interesting in terms of considering the differences between individualist and collectivist cultures.

The cultural experiences expressed by the participants of this study supports those described in the existing literature. In a US study Ojikutu *et al.* (2013) investigated the differences in the experience of stigma amongst non-US born and US-born black individuals who are HIV positive. Results indicated that non-US born participants were significantly more likely to experience stigma than their US-born counterparts. However, this study is open to criticism in that this does not specify whether this group was stigmatised solely due to HIV. For example, research has shown that immigrants are subject to higher levels of stigma (Amri, & Bemak, 2013) and perhaps some of the stigma experienced by this group was not due to HIV. Similarly, this research was conducted on a black American population and as previously discussed in chapter 1, some individuals already hold negative views towards minority groups such as black people, gay men, drug users and immigrants (Garcia *et al.* 2015). Therefore, one might argue that this population was already vulnerable to stigma and stigma may have been attributed to multiple factors and not simply HIV.

In a similar research project Genberg *et al.* (2009) explored the differences in HIV related stigma across four countries; Tanzania, Zimbabwe, South Africa and Thailand. Results from this study indicated that higher rates of stigma towards HIV were found in countries with a lower prevalence of HIV such as Tanzania and Thailand. Furthermore there was a greater perceived discrimination towards people living with HIV in countries such as Tanzania. These findings reflect those of the current study in that participants also experienced higher rates of stigma in the UK where the prevalence of HIV is much lower than their country of origin. However, a search of the literature did not reveal any research that specifically compares HIV related stigma in the UK to other countries and therefore this cannot be explored further at this time. However, this does perhaps highlight a potential insight offered by the current research.

4.3.2 Community

Participants from both groups also discussed the negative attitudes towards people living with HIV that they had experienced within their community. Stigma experienced within this system was felt to be more threatening and less abstract than stigma felt at the societal level. Once more, the core category of stigma was most salient for the community system. However, this was explored from a different

perspective from both groups. This differing perspective will be discussed in the following section and links to the current evidence base will be drawn.

4.3.2.1 Stigma

The core category of ‘stigma’ was described by both participant groups as having an impact both in terms of how individuals interacted with their community and also how they perceived the community would treat them if HIV was disclosed. In particular, the sub-categories of ‘disclosure anxiety’ and ‘perceived rejection’ are relevant to this system. Participants from both groups discussed a perceived threat from their local community should HIV within the family become exposed. Some participants directly explored this sense of threat from the community should HIV be exposed, for example participant 6 stated “*My family runs a business people might use it to blackmail us or people might not want to do business with us if our reputation is ruined.*” The issues of disclosure anxiety as discussed by participants of this study are consistent with the existing literature suggesting that disclosure is still a key challenge for people affected by HIV, with disclosure rates amongst young people with perinatally acquired HIV remaining low, ranging from 33-48% (Tassiopoulos et al. 2013; Birungi et al. 2009 and Lee & Oberdorfer, 2009). Hogwood, Campbell & Butler (2013) support this in their UK study regarding adolescent attitudes towards disclosure: that many young people with perinatally acquired HIV are opting not to disclose their HIV status. However, they also caution that this is a complex decision-making process that is also affected by the felt stigma and cultural attitudes towards HIV. The sub-category of disclosure anxiety is further supported by Rydstrom *et al.* (2013). Rydstrom and colleagues highlight a theme of ‘protect self from stigma’ referring to a significant anxiety experienced by participants in relation to the onward disclosure of one’s HIV status. Rydstrom *et al.* discuss the importance of secrecy for their participants who reported only disclosing HIV in healthcare situations, and in an attempt to mitigate stigma and rejection from others did not reveal their HIV status to other individuals.

Again, both groups identified disclosure as being associated with heightened anxiety and perceived negative consequences for the entire family in terms of a threat of rejection. As a result, participants felt unable to disclose either their own or their sibling’s HIV status to friends or seek support for any personal challenges as

the primary concerns was maintaining the HIV secret. This, according to some participants, was reinforced by the experience of hearing derogatory jokes or comments made by friends and classmates at school relating to HIV. These first hand experiences of stigma appear to have confirmed for those participants that a stigmatised attitude is present within their community. Consequently, a need to take protective measures such as maintaining secrecy regarding HIV in the family was imperative for both sibling groups.

Further to the above, the effects of stigma within the community presented a clear threat to the participants of the current project marking a significant stressor for both sibling groups. Although this project was not tasked with identifying or describing mental illness it is clear that the effects of stigma as described by participants of this research are associated with poor mental health (heightened anxiety, a sense of social isolation and low mood). Although there is no information on the presence of clinically significant mental health problems in the participants in the current study, it was clear during interviews that many had experienced clear psychological distress in relation to HIV. This is consistently supported by the literature reporting that rates of mental illness are significantly higher in a population of people affected by HIV than in the general population (Mellins & Malee, 2013; Mutumba *et al.* 2016; Mellins *et al.* 2012; Gadow *et al.* 2012; Gadow *et al.* 2010; Malee *et al.* 2011). Participants in the current project discussed complexities that are linked to poor mental health that are consistent with the wider evidence base.

The results discussed here can also be considered within a social psychology perspective of stigma (Phelan, Link & Dovidio, 2008). Social psychology would view stigma in the context of HIV as holding the function of disease avoidance, keeping the ill at a distance. From an evolutionary perspective, stigmatising certain infectious illnesses promotes the social exclusion of the stigmatised group and therefore provides a sense of safety from infection. More recently, Pryor and Reeder, (2011) proposed a conceptual model of stigma encompassing four component types of stigma. (I) Public stigma – public stigma represents the social stigma and negative attitudes towards someone with a stigmatised condition. (II) Self-stigma – This describes the experiences of possessing the stigma and the fear of this being discovered as well as the internalisation of the negative attitudes expressed by others. (III) Stigma by association – This considers the psychological reactions to those

associated with the stigmatised person such as friends and families. (IV) The fourth and final stigma is structural stigma. This refers to stigma at the societal level and methods society uses to legitimise stigma towards a condition. Results regarding the experiences of stigma within the current project mirror those of the above conceptual theory of stigma at all four levels.

On the whole, the experiences of stigma at the community level for participants, particularly anxieties around disclosure and the perception that others may reject them, is consistent with the existing literature (Mburu et al. 2014; Rochat, Arteché, Stein, Mitchell & Bland, 2015). However, despite the overall theme of stigma being somewhat predictably consistent with HIV stigma research, the experience of HIV negative siblings in relation to stigma offers an original contribution to the field, particularly in terms of UK research into youth HIV.

4.3.3 Romantic Relationships

At the forefront of conversation during interviews were the issues of romantic relationships and the complications of entering into and sustaining a relationship. Whilst this was understandably a more significant concern for the HIV positive group that is not to say that the HIV negative siblings did not also express difficult experiences within this system. The core category of ‘HIV burden’ appeared most salient to this category although this was explored through very different viewpoints according to each sibling group.

4.3.3.1 HIV Burden

The core category of HIV burden appeared to be the most prominent category in exploring romantic relationships for both siblings. Many sub-themes from both groups seem to play an important role within the romantic system such as transmission and contamination anxiety as well as the threat of rejection of individuals or exposure for families.

Some participants in the HIV positive group spent time discussing their anxieties regarding their potential to pass HIV onto another individual, namely, those who they enter into romantic relationships with via sexual contact. According to those participants this had an impact upon their confidence and self-esteem as they anticipated rejection from potential partners due to HIV. In addition, participants viewed themselves as potentially threatening to others due to HIV. This resulted in

those participants avoiding possible relationships and viewing themselves as unlikely to enter into a romantic relationship due to fears of HIV transmission. When asked about their future, those participants did not consider a family or romantic relationship. This was also a fear for them that was expressed by their HIV negative siblings who referred to them not ‘settling down’ or ‘being happy’. Participants expressing this view appeared upset upon reflecting on their perception that it was unlikely they would become parents. This particular finding is in contrast to the generally more positive approach of most participants. Becoming a parent is something those participants desired in their future, suggesting that HIV is having an impact on how individuals view themselves in their present but also impacts upon how they envisage their future. For example participant 7 said “*But I am just thinking how am I supposed to have babies? It probably is something I want yeah but I don’t really let that cross my mind now.*” This suggests that HIV is having an impact upon the entire timeline of possible romantic relationships, the formation of relationships, disclosing one’s HIV status, sex, and including a future focused view of having children. As such, findings here may represent a view that HIV compromises the societal norms (marriage, children) that individuals may desire.

The findings discussed here regarding participants’ views that they are unlikely to become parents due to the barriers presented by HIV, are challenged within the literature. Evangelini *et al.* (2014) offers an alternative perspective in a UK qualitative study that found young HIV positive individuals reported high rates of parenting intentions. Furthermore, it was reported that although some HIV related barriers did have an impact upon parenting intentions for participants not all barriers were directly connected to HIV. Evangelini *et al.* (2014) concluded that for the most part participants held a desire to become parents despite the challenges HIV posed for them.

In support of Evangelini *et al.* (2014), Van Nuil *et al.* (2014) also discuss young peoples’ parenting intentions in the context of HIV. It was noted that some young people discussed a desire to avoid becoming parents owing to fears of having HIV positive children. However, Van Nuil *et al.* (2014) offers a balanced view in that some participants had considered adoption as an alternative to becoming a parent and this appeared to mediate worries around transmitting HIV to future children and demonstrated a clear desire to become a parent. Van Nuil *et al.* (2014) further support Evangelini *et al.* (2014) in highlighting that participants acknowledged

the barriers to becoming parents presented by HIV but participants largely reported that they would overcome these and achieve their goal of becoming parents.

The findings of the current project regarding transmission anxiety are often overlooked in the HIV literature in favour of focusing in more detail on transmission prevention strategies. However, the findings of the current study are in support of a small pool of research suggesting that a key concern for HIV positive young people is a worry of transmitting HIV to sexual partners (Busza *et al.* 2013; Greenhalgh *et al.* 2013). Cooper, Harries, Myer, Orner, & Bracken (2007) conducted a qualitative investigation into the reproductive intentions of HIV positive men and women in Cape Town, South Africa. It was found that being HIV did not remove the desire to become parents but it did adversely affect any intentions to do so. Participants reported a desire to avoid pregnancy owing to fears around partner or infant infection. Whilst those findings are reflected in the current research it is important to acknowledge that this research was conducted in South Africa in which there are cultural expectations for child bearing. Also, this culture has societal norms around marriage and child bearing that are an important component of married life. Therefore, one might expect that this experience is somewhat different amongst the UK population studied in the current project.

On the other hand, one participant from the HIV negative sibling group discussed the opposite experience in terms of high levels of a contamination anxiety, fearing he would become HIV positive himself. However, similarities were observed in this participant regarding his anxiety to enter into romantic relationships fearing that others would conceal their HIV diagnosis and consequently he would become infected. This also impacted significantly on the ways this young man interacted with others and his anxiety towards ‘catching’ HIV was significantly affecting his mood.

A search of the literature found no studies that have investigated anxieties around ‘catching’ HIV from the perspective of family members of those who are HIV positive. Although, only one participant mentioned this within the current research, this was a highly relevant aspect of this interview that was clearly causing emotional distress for that young man. Therefore, given the apparent importance of this for the participant and its salience with the ‘transmission anxiety’ reported by participants in the HIV positive group, it is important to acknowledge and consider in terms of the wider evidence base. This is tentatively a novel insight into how those

who are affected by HIV but who are not themselves HIV positive respond to the condition and its impact on an emotional and behavioural level.

Further to anxieties regarding transmission or contamination all participants spoke of fears around trusting others with the family secret of HIV and the anxiety disclosure caused. HIV negative siblings spoke at length about possible partners of their HIV positive siblings later revealing HIV within the family to others if relationships did not end on good terms. Similarly, HIV positive siblings anticipated rejection from partners or worried that partners may disclose their HIV status to others. The two groups reported markedly different interactions within romantic relationships, with the HIV negative siblings reporting having healthy relationships but this inciting guilt for their sibling, whilst the HIV positive siblings reported having to carefully manage intimacy. The findings regarding HIV positive siblings are supported by the current evidence base. Fair and Albright (2012) interviewed 35 African-American HIV positive young adult women regarding their romantic relationship and exploring areas such as disclosure anxiety. Results indicated that HIV positive young adults struggle with intimate relationships. Participants reported a need to cautiously manage intimacy using a number of strategies; delaying intimacy, terminating relationships or 'taking it slow.' This research again is conducted on a sample outside of the UK using an exclusively adult population. Although the current study supports this research, there remains a small number of projects that specifically investigate romantic relationships of a youth population in the context of HIV. The current project is therefore able to offer some insights into how young people both diagnosed and affected by HIV are responding to romantic relationship demands that are typically considered as a key part of this developmental stage.

4.3.4 Family

As a goal of this project was to explore the impact of HIV on the sibling relationship, it is understandable that in-depth discussions regarding the family system came to the fore. Although both sibling groups were encouraged to discuss their families in the context of HIV, all siblings spoke at length about this and this felt important to all participants. The core categories of 'distance from HIV' and 'self-growth through HIV' are particularly salient within the 'family system'. This

section will discuss the unity or distancing of families, the family avoidance strategy in relation to HIV as well as discussing the impact of HIV on the sibling relationships as experienced by participants.

4.3.4.1 Distance from HIV

The participants all collectively discussed the tendency of families to place distance between themselves and HIV. This was observed by participants through family members actively avoiding the topic of HIV which according to all participants was seldom discussed, leaving both siblings to develop their own strategies of managing HIV. It was discussed during interviews that not talking about HIV within the family served the function of not causing upset or 'stirring up' difficult emotions for loved ones. Participants from both groups recounted historical experiences of family members becoming upset when HIV and its impact was discussed as a family, and therefore they felt that the family actively avoided such discussions, with the exception of practicalities such as hospital appointments. This resulted in both sibling groups often feeling unable to express their emotional difficulties and having to find alternative strategies to manage them.

The experiences described by participants of this project in relation to families collectively avoiding conversations focused on HIV are supported by the research of Rydstrom *et al.* (2013), whose participants experienced the topic of HIV as taboo within the family, and described conversations about HIV as rare and limited to medical appointments. Participants in Rydstrom *et al.*'s study also reported the expression of negative attitudes towards HIV positive individuals by other members of the family and that this - in addition to a desire to protect family members from stigma and prejudice - reinforced the avoidance of conversations about HIV.

In the present study, an additional factor may be prior experiences of parental and familial death as a result of HIV, with subsequent grief contributing to avoidance in talking about HIV. This has previously been noted by Dorell *et al.* (2008), who described major themes of living with loss and death in adolescents with HIV, many having experienced HIV related family deaths and reporting an increased sense of their own mortality. Therefore, it could be argued that young people affected by HIV may also avoid discussing this topic as this may be linked with anxieties around

death. Conversely, parents and carers of young people affected by HIV may also sense that this is upsetting for young people and seek to avoid this.

The accounts of the participants of this project can also be considered in terms of attachment theory (Bowlby, 1973; Ainsworth and Bell, 1970). Attachment theory, according to Ainsworth and Bowlby, explores the dynamics of infant relationships and how this ‘maps’ onto how adult relationships are defined. A central component of attachment theory is that an infant will seek proximity to a primary care giver in the presence of any perceived threat in an attempt to elicit emotional support from that caregiver. Attachment theory asserts that a core function of infant attachment behaviours is to facilitate the infant in regulating their emotions. If we consider this in the context of the experiences reported by participants of this research, it would appear that participants have a desire to utilise the family and in particular parents as a secure base when experiencing distress. Participant 10 said *“We probably should talk about it as a family. Maybe we handle it in a way that’s a bit abnormal. It’s kind of highlighted a communication breakdown in my family where we just don’t speak about it.”* This arguably signals a desire to utilise the support of the family in regulating emotions destabilised by HIV. This finding suggests that those participants are attempting to deal with HIV in much the same way as any other stressor by returning to their safe base (family) and eliciting emotional support. However, HIV presents a unique barrier to achieving this in that the stigma associated with the condition and the internal experience of shame/guilt may disrupt familiar attachment behaviours leaving those young people with the burden of silence and managing their difficulties in secret. It would appear that attachment behaviours are disrupted in some ways (in terms of not talking about HIV) but possibly strengthened in others (in terms of proximity to family).

Participants of this research also discussed dynamics within the family shifting in response to HIV. This was discussed in terms of the family uniting together in support of each other and in opposition of HIV, or the family becoming more fragmented and distant in response to the condition. Participants discussed this in terms of a barrier to gaining emotional support but also in terms of a sense of secrecy within the family. Particularly for those siblings who are HIV negative, who were not always informed at the point of diagnosis and may have learnt about HIV (sometimes much) later. Those participants reported a sense of anger towards the

family who they felt mistrusted them. Furthermore, those participants felt out of sync in terms of their adjustment to HIV in comparison to family members, further isolating them. Although no literature could be found detailing specifically sibling-to-sibling disclosure of HIV, there is a wealth of literature pertaining to parent-to-child disclosure (Dematteo et al. 2002; Lee & Rotheram-Borus, 2002; Tiendrebeogo, 2013). Kennedy (2010) qualitatively investigated parental disclosure of HIV to children. Parents reported that disclosure was often not as problematic as feared. However, analysis within the family revealed disagreement with children regarding unplanned disclosure. Findings suggest that disclosure should be addressed within the family in a planned way in order to facilitate the coping of children. The findings of the current project support the notion that HIV disclosure within families should ideally be planned and discussed as those siblings who had not experienced this or had an unplanned exposure to HIV appeared to struggle with this.

4.3.4.2 Self-growth through HIV

In contrast to the above finding, participants also discussed the opposite reaction in that some families experienced becoming unified and closer in response to HIV. This was observed particularly within the sibling relationships as many participants of this research expressed that they felt closer to their sibling in light of HIV. Those participants expressed that having a sense of a shared journey of HIV in addition to a sense of protecting and caring for one another was a uniquely bonding experience that both siblings valued. Although, many of those participants who felt HIV had unified the family still discussed the families overall approach as being avoidant, their experience within the sibling relationship was one of being open and supportive in nature. Siblings often relied on each other for emotional support and both appeared to feel, in many cases, that their sibling was perhaps the only person they felt able to open up to, again facilitating the bonding of siblings.

The findings of this research can be considered in the context of the centrifugal/centripetal developmental model of family systems (Combrinck-Graham, 1985). This model suggests that in response to chronic illness families experience emotional pulls either pulling them towards unity, holding the family together, or pushing them towards divergence, promoting differentness within the families coping experiences. This model also proposes that the adolescents affected by illness

may experience a desire to pull away from the family in an attempt to assert their independence but become conflicted as they are also dependent on the family regarding their health needs. It would appear that the findings of this research suggest that within the family, siblings experienced an inward pull towards each other in an attempt to care for the emotional needs of both siblings. This appears to occur even in the context of families that become fragmented in the context of HIV, suggesting the sibling relationship has the potential to increase or decrease the emotional challenges introduced by HIV.

4.3.5 Individual

Although a goal of this project was to explore the sibling relationship in HIV discordant sibling pairs, it was also imperative to attempt to understand the individuals' accounts. Within the 'individual system' the core category of 'desire to fit in' emerged strongly for the HIV positive sibling group. Additionally, the core category of 'self-growth through HIV' also appeared salient for this system.

4.3.5.1 Desire to fit in

Within the HIV positive group, a prominent area of discussion was focused around the desire of those individuals to fit in with their community and peers and feel accepted. Participants discussed this in terms of them feeling both 'normal' and 'abnormal'. Participants made reference to HIV rendering them 'abnormal' in the sense that HIV was a somewhat rare condition that was outside of the norm for their own and their peer's experiences. Despite this, participants in the HIV positive group reflected on the many ways in which they felt 'normal' and remarkably similar to their peers considering aspects such as good physical health, good mobility and no observable disability. Participants would often consider the ways in which HIV made them feel 'abnormal' and then almost defend their position of being normal during interviews by listing the ways in which HIV cannot impact them and therefore allows them to feel no different from peers.

A search of the literature did not reveal any studies that described the experience of a desire to fit in or feelings of abnormality vs. normality in people living with HIV. However, this particular finding can be discussed in terms of social comparison theory (SCT; Festinger, 1954). SCT posits that every individual is innately driven to gain accurate self-evaluations. It is suggested that as individuals

we evaluate our own personal worth based on how we perceive ourselves in comparison to others. Therefore, constant evaluations are made of others and the self in order to ascertain our worth in a variety of domains, examples include; attractiveness, intelligence and wealth. When considering the findings of this research regarding participants' desire to fit in one could argue that those participants were making social evaluations of themselves in comparison to others, others who are not HIV positive. It would appear that participants are evaluating others as normal and themselves as abnormal and as such considering the traits in others that are enviable and drawing negative comparisons based on this. Subsequently, participants are also drawing on positive comparisons in forming the conclusion 'I am normal' by focusing on traits in others and noticing similar traits in themselves, traits that HIV is currently not impacting upon. On the whole, it appeared that those participants held a strong identity as somebody who is 'normal' and largely unaffected by HIV physically, but rather experienced HIV as a social issue leaving them feeling 'abnormal' based the perceived perception that others would view HIV negatively.

4.3.5.2 Self-growth through HIV

Participants discussed the ways in which they felt HIV had contributed a valued aspect to their lives. For some of the HIV negative participants, this referred to a sense that participants developed an increased empathy, viewing themselves as caring people that have high levels of compassion for others. For the HIV positive participant group this was discussed in terms of HIV serving as a driving force in their lives motivating them to achieve and strive for success in many aspects of their lives, showing a determination to not let HIV take away from their lives. Participants from both groups discussed this in the context of how HIV shaped them, making them the people they are today and placing great value upon this whilst also maintaining a negative view of the condition itself.

These findings can be discussed in the context of the literature regarding benefit-finding in chronic illness. Benefit-finding refers to the individuals perceptions of positive changes following major life events such as serious illness (Janoff-Bulman, 1989). People experiencing serious illness often report benefits arising from their experience including strengthened relationships, personal growth

or spiritual growth (Hefferon, Grealy, & Mutrie, 2009). Siegel and Schrimshaw (2000) reported that 83% of women living with HIV reported at least one positive change in their life that was attributed to their illness. It is suggested that an event such as major illness has the potential to significantly disrupt the individual's network of cognitive schemas that inform a sense of meaningfulness of the world as well as a sense of self-worth. These schemas provide the person with a degree of predictability in their lives which is then potentially undermined by HIV. The findings of the current project appear to be consistent with the literature pertaining to benefit-finding given those participants from both groups were able to identify strong personal characteristics resulting from HIV that facilitated personal growth. Although the findings here mirror those expected according to benefit-finding theory, what is also offered in this instance is an account of benefit finding on the part of the HIV negative sibling. This is of interest as benefit finding research is largely focused upon the person with the chronic illness despite literature continually demonstrating that siblings and relatives of chronically unwell patients' experiences significant difficulties. Therefore one might expect those individuals to also seek benefits resulting from their experiences.

4.4 Methodological considerations

The following section will outline methodological considerations for the current project. Firstly, the limitations of the research methodology will be discussed before an evaluation of the methodological strengths of the current study is offered.

4.4.1 Methodological limitations

Researcher bias

Arguably, some degree of researcher bias is present in all forms of qualitative research (Morse, 2015). Qualitative research, by its very nature, relies upon the qualitative researcher to obtain large amounts of data that then has to be reduced and deconstructed into small but meaningful 'chunks' of data and subsequently reconstructed into a more manageable structure that both conveys the meaning of participants' accounts and does so in a succinct manner that is understandable to the researcher and the reader. This is achieved through the interpretation of the qualitative researcher who brings with them their own unique experiences and ways of understanding material. Indeed, the constructionist view of GT asserts that

researcher bias is unavoidable when employing this methodology (Charmaz, 2006). Furthermore, Critical Psychologists claim that the same remains true of all scientific research and the notion that the researcher is capable of both objectively interpreting their findings as well as neutrally reporting them is rejected (Hook, 2004). Therefore, this creates the added necessity on the part of the researcher to bring into conscious awareness the ways in which their own personal processes may have had an impact on the process of carrying out the research and to consider any influence this potentially had on data analysis (Bryant & Charmaz, 2007). Section 2.9.4 highlights the author's previous personal experiences, his clinical influences throughout clinical training and his strong emotional reactions to the interviews. It is hoped that this sheds some light onto some of the sources of potential bias for the author, understanding that not all sources of bias can be captured here or can be fully understood and appreciated by the author.

Considering the potential sources for bias outlined in section 2.9.4, arguably the most prominent form of bias is the author's previous personal experience with chronic illness. This was perhaps reflected in some of the follow-up questioning in response to participants comments. However, extensive measures were taken by the author to limit this at every stage. Interview questions were designed in collaboration with supervisors and memos and reflections on interviews and the emerging themes of the data also attempted to monitor for potential biases. During research supervision the author and supervisors regularly paid attention to possible biases and every effort was taken to limit these. In addition to this, both research supervisors work clinically in the area of health psychology. Although every effort was made to limit potential biases it could be argued that a research team consisting of different supervisors and a different researcher, all of whom had no personal or clinical experience of chronic health, may have been better able to remain completely objective during the research process.

A further potential bias is that the researcher is a white working class male from a western culture, and therefore, understandably, carries with him an inherently individualistic view of the world (Joshanloo, 2014). Whilst the current research also included participants from western cultures, as previously discussed, some participants, and in particular their families, came to the UK from different cultures. Therefore, this potentially presents a researcher bias in the interpretation of

participants' accounts. Joshanloo (2014) suggests that eastern cultures embrace both the positive and negative sides of life. This was observed most noticeably in participant five who recounted a strikingly positive experience. Participant five originated from Sub-Saharan Africa and it is likely that his family values instilled this positive attitude towards his condition. Something the researcher, at the time, failed to recognise instead interpreting those responses as a coping response or a signal this participant did not want to explore those particular questions. Similarly, it is important to note that one of the main findings of this research centres around the distancing of the self and family from HIV. Perhaps, this can be explained in light of cultural phenomena for some of the families who participated.

Recruitment bias

It could be argued that those who self-selected to participate in this research were reasonably well adjusted to HIV and the psychological consequences of this illness, and therefore experiencing fewer difficulties than others. One might anticipate that an interview concerning emotional and psychological responses to HIV to be particularly difficult if currently struggling with those issues. On the other hand it is also possible that those who were currently struggling emotionally may have been eager to participate and may have valued the opportunity to discuss those difficulties. As such, it is likely that this research is only able to account for those young people who are relatively well adjusted to HIV to the detriment of understanding more fully a holistic view of those who are affected by HIV today. Although, this is intriguing given that the levels of shame and secrecy were elevated in those who did participate. Therefore, one might hypothesise that the general picture of siblings both diagnosed and non-diagnosed with HIV is one of significantly greater struggle and emotional difficulties.

Participants access to internal processes

Qualitative research that ultimately relies on the participants expressions regarding their unique and personal processes is open to criticism. Namely, this relies on the participants' ability to access and report upon internal cognitive and emotional processes. The criticism lies in that participants of any research are only able to access processes at a conscious level (Elliot, 1986). Furthermore, even

accounts accessed by participants during qualitative interviews still remain subject to the participants' perceptions and interpretations (Charmaz, 2006). Another concern for this research is that participants may be fully aware of particular influences on their behaviour, but for a number of reasons be reticent to communicate those with the researcher. This is highly likely to have occurred during the current interview process. It was noted following interviews that siblings would often provide additional information regarding situations that the other sibling stopped short of elaborating on. It was felt at the time that certain participants remained uncomfortable to share aspects of their experience with the author. Again given the focus on secrecy within HIV this was unsurprising but does highlight the potential for such research to be thwarted in accessing rich and pertinent data for analysis.

Although it is believed that many participants spoke openly and honestly throughout interviews, the above issues cannot be ignored, particularly understanding that not all participants were so forthcoming. The author is also aware that even those participants who appeared comfortable during interview may have also opted to conceal elements of their experience that they felt uncomfortable to share.

Finally, it is important to recognise that the premise of this research essentially tasked young participants to openly discuss an emotive and highly sensitive topic that all participants were well experienced in concealing from others. Therefore, asking participants to discuss their experiences relating to HIV was to challenge their usual coping strategy. This potentially puts participants in an uncomfortable and anxiety provoking situation that may not be conducive to understanding the phenomena studied. Furthermore, the author had no relationship with any participants and was further tasking them to divulge emotionally sensitive information to a complete stranger, potentially heightening any possible sense of threat. Therefore, we must acknowledge that the task for participants was onerous in nature and interviews are then vulnerable to partial data and incomplete accounts by participants.

Sample

As with any form of qualitative research it is important to consider any issues arising regarding the sample of participants recruited. Willig (2008) suggests that a researcher should strive for maximum homogeneity within a sample with the aim of

ensuring that those who participate are relaying accounts of the same phenomena and from a similar perspective. Although participants of the current project shared many similar demographic characteristics (e.g. they all either had a sibling who was HIV positive or were HIV positive themselves, all were between the ages of 14-21, and all lived in England), there are also differences within and across both groups that must be acknowledged. Firstly, a clear difference was the number of HIV positive siblings within a family. Within both groups participants were recruited where either they were the only HIV positive sibling or the only HIV negative sibling. Again this family structure in terms of who is HIV positive and who is HIV negative can be expected to have an effect on how that participant makes sense of and adjusts to their experiences. If a participant has other siblings in similar circumstances to them and understands the same applies to their sibling this potentially eases the pressures experienced by both siblings. This may reduce the loneliness experienced by some participants given that their experiences are in some cases unique to them within the family, whereas a shared journey of HIV appeared to be valued in other participants.

Furthermore, there were also differences in the geographical location participants were recruited from. Recruitment was designed to occur nationwide and although the majority of participants were recruited in one major city others were recruited from other cities in England. Although it is difficult to suggest to what extent geography may have played a role in sample bias, it can be suggested that the communities in which participants lived may have slightly different approaches and attitudes towards HIV, however subtle. Arguably, the experience of growing up affected by HIV in one English city could be different to growing up in another and this perspective may have come across in interviews. It is also important to highlight that the two sibling pairs who were not born in the UK, have different cultural experiences of attitudes towards HIV. This also provides a different perspective and set of experiences that could play out during interviews and also reduce the homogeneity of the sample recruited.

An obvious limitation of a homogenous sample however, is that the smaller and more defined the characteristics of the sample, the less possible it becomes to generalise the findings outside of that research and the specific sample studied to the more general population studied (Smith, 2008) such as 'all siblings who are affected by HIV'. However, it could be argued that the same remains true of all qualitative research as this relies upon smaller sample sizes to extrapolate rich detailed

accounts. In doing so all such research lacks the ability to demonstrate applicability of those findings to the wider population studied and can only make claims regarding those who participated. However, this does not indicate that those findings do not shed some valued light onto the phenomena studied and as such recommendations can be made on that basis. Alongside this tentative clinical implication of such research can also be discussed.

In addition, it is also important to consider the sample studied in terms of who was invited to participate. This project intentionally recruited sibling pairs from the same families as opposed to separate groups of HIV positive young people and a group of HIV negative young people who had a sibling who was HIV positive. It is understood that either related sibling pairs or non-related samples from each group would have both provided an adequate sample in order to carry out this research, both presenting strengths and limitations in terms of what could be offered to the project. The limitation of selecting related sibling pairs in this instance is that this recruitment strategy unintentionally increased the variability in the age range of participants with the youngest participant being 14 and the oldest being 21. Consequently, this resulted in a sample which included two HIV negative adults as opposed to a complete adolescent sample as intended. This leads to a number of limitations. First, including adult participants reduces the comparability of those participants both to the HIV positive group studied and also to the wider adolescent population who are affected by HIV. Second, this research was primarily focused on understanding adolescent experiences regarding the impact of HIV. Therefore, including an adult perspective potentially limits the ability to fully address the question asked of the research. However, despite the apparent limitations this recruitment strategy presents, the rationale for this strategy was to intentionally include related siblings to consider in greater depth the impact upon families. It was considered that siblings from the same family would then be able to explore the same family processes within the same family structures but from differing perspectives, increasing the comparability of both groups studied. Although an adult perspective is included it is also considered that this provided the sample with opportunities to reflect upon and explore the same family processes and therefore other variables are held constant such as socio-economic status and cultural background which may have otherwise limited the ecological validity of the findings further. Therefore, the

recruitment strategy used controlled for variability of experience and allowed the researcher to consider the experiences reported in depth.

Topic guides

A potential limitation of this project is the focus of the topic guide that guided the author during interviews with participants. It could be argued that both topic guides (i.e. for HIV positive and negative siblings) place an emphasis on the HIV positive child. Although the topic guide for the HIV negative sample was designed to elicit experiences fundamental to the experience of this group, it is acknowledged with hindsight that several questions do direct participants to consider their HIV positive sibling, which might otherwise not have been a focus generated by these participants (for example “*Could you tell me some of the ways that your sibling having HIV might have been difficult for you?*”). Therefore, this presents a potential limitation of this project in that HIV negative participants may have been more directed than was desired in some parts of the interview, restricting the researcher’s opportunity to understand the participants’ experiences. However, in practice during the interviews it was felt that HIV negative participants were encouraged to raise any issues that felt relevant to them, and all interviews diverged substantially from the topic guide that began the conversations, allowing each individual interview to focus on the young persons’ unique responses. Therefore, it is likely that despite limitations in the interview schedule, the interviews themselves were able to elicit the information that was required of the project. This is evident in the difference between sub-categories between the two sibling groups demonstrating that despite similar interview schedules, participants were able to communicate their experiences that were different from the HIV positive sibling group. Nevertheless, the author acknowledges that the core-categories for the two groups were similar and this could be explained in part by the direction imposed by similar interviews, though it is also possible that the two groups share similar experiences and views, given that their family environment is similar. Finally, the focus of the current project was predominantly to explore sibling experiences within the context of HIV. Therefore it is unsurprising that the topic of HIV became a central component of both interview schedules regardless of participants HIV status.

Study Design

A further limitation of the current project may lie in the way this research was conducted. For example, this project sought to interview sibling pairs and the design was such that siblings were interviewed directly after one another. Given that both siblings were aware that their sibling was in the waiting room or might ask about the content of interviews post interview, it is reasonable to assume that this may have impacted upon participants perceptions that they could be open, honest and reflective in this regard. Therefore, this may have understandably had a direct impact on the findings of this research or limited the projects ability to uncover data that might have been important here. In particular, this may have limited the current projects ability to develop a comprehensive understanding of the characteristics and qualities of the sibling relationships, therefore potentially weakening any claims made. It is possible that siblings of this study felt uncomfortable to discuss in detail any potential difficulties arising regarding qualities of the sibling relationship as such caution must be exercised when applying the findings discussed here to other siblings who may have entirely different experiences. Perhaps interviewing sibling separately on different days may have overcome this however this would have incurred more time and resources on behalf of the author. Furthermore, the study design was also such that recruitment was established through AALPHI alone thus this project was only able to access siblings that were in contact with AALPHI. This may potentially exclude sibling pairs that are less supported by services and therefore possibly experiencing greater levels of need or mental health difficulties. When considering these limiting factors it must be considered that these may have directly impacted upon the findings of the study and in particular the ability of others to transfer the findings discussed here to other sibling pairs. Finally, sibling pairs opted to participate and HIV positive siblings selected which sibling they would like to invite to interviews. As such, it must also be acknowledged that HIV positive siblings may have been more likely to select siblings with whom they had a stronger relationship. Therefore, this study may have been unable to ascertain information regarding sibling relationships who were less close and secure and this may have provided a bias in the data obtained.

Context of the findings

It must be considered how applicable the findings of the current study will be over time. Advances in the prevention of mother-to-baby transmission of HIV may give rise to a change in the population of young people who are affected by PHIV. More specifically, over time, there may be considerably less young people affected by PHIV. Therefore, if the numbers of HIV positive young people continue to decrease, as observed by the CHIPS cohort data, then it is reasonable to assume that the findings described by the current study will gradually become applicable to a smaller pool of service users nationwide. It could be argued that this project may have captured some experiences that may become less common and as such this research has the potential to become less valid in the near future. Further to this, the project must bear in mind that as other medical and sociological advances within the field occur so too will the experiences of those affected by PHIV, again leaving the results identified by this project dependent upon context and time. Nevertheless, it could be argued that all research to varying degrees is vulnerable to similar criticisms and this does not impact upon the current applicability of the findings described.

4.4.2 Methodological strengths

Contribution to the field

To date there has been much interest and investment into research concerning people who are HIV positive. The research, as discussed previously, becomes sparser when investigating the psychology rather than the biology of HIV (Betancourt, 2013) and even sparser still when focusing on the experience of children and adolescents as opposed to adults (Sherr, Cluver, Betancourt, Kellerman & Richter, 2014). In addition, much of the worldwide research into HIV has been conducted outside of the UK in areas such as Sub-Saharan Africa, the US and Canada (Salomon, Gakidou & Murray, 1999). Therefore, a research study that explores the impact of HIV from both those perspective, with a UK adolescent population is able to contribute to the wider evidence base but also explore a previously under researched area and hopefully offer new insights.

HIV positive and negative sibling perspectives

The current project demonstrates a key strength in exploring the impact of HIV as considered from two different perspectives; those young people who are HIV positive and their HIV negative siblings. Developing an understanding of the HIV patients' experience is clearly an important research aim. Furthermore the detrimental effects in terms of the mental health difficulties of the siblings of young people with other chronic illnesses are well documented (Barlow & Ellard, 2006; Waite-Jones & Madill, 2008). However, there remains a paucity of empirical data regarding the experiences of siblings in the context of HIV and given some of the unique challenges presented to families affected by HIV it was imperative that this be investigated and reported upon. Therefore, this project is able to contribute something relatively novel to the evidence base.

Reducing Bias

Researcher reflexivity

Throughout this project steps were taken at every stage to ensure the limitation of potential research bias. The author was particularly concerned with reducing bias wherever possible in an attempt to make the voices of the participants heard as accurately as possible. As such, the author reflected on his role as a researcher considering how his age, ethnicity, gender, personal circumstances and emotional reactions to participants may have had an influence on any aspect of this project. The author is introduced in section 2.9.4 so that the reader may understand some of the potential biases discussed.

Credibility checks

The author received regular research supervision in which the organisation of the emerging themes from the data were discussed. Additionally, the author maintained regular contact with a fellow Trainee Clinical Psychologist also utilising GT for his research throughout this project. Furthermore, the author invited another Trainee Clinical Psychologist and a non-psychology post graduate to assess the coding and grouping of themes in order to check the level of agreement with the author's categories. This was completed with the aim of assessing the credibility of the analysis but to also ensure that the perspective and interpretation offered was not exclusively that of the author's. It would have perhaps been useful to revisit a

participant from each group and feedback the findings in order to assess whether this reflected their experience accurately. However, due to participants being located across the UK this was difficult to achieve within the time frame of this project. Participants were also subject to multiple AALPHI based and other research projects and to ask for further time and participation may have presented an ethical dilemma in that participants may have felt obliged to participate which may have caused a strain on their time and resources.

Semi-structured interview

A semi-structured interview was used in order to facilitate a general discussion but participants were able to build upon this, and did during interviews, to portray the aspects of their experience that felt important to them. This suggests that participants were freely able to provide an account personal to them and weren't constrained by the interview schedule.

The Grounded Theory Methodology

The use of GT allowed for systematic and methodical approach to data collection and the analysis of themes generated. The use of this approach alongside regular research supervision enabled the use of an audit trail which allowed the research team to ensure methodological rigour, reduce potential biases and adhere to GT methodology as was designed. Therefore, it can be argued that the theoretical formulation developed was firmly 'grounded' in the data.

The diagrammatical depiction of the theoretical formulations put forward by this project is also considered to be a strength. This allows the author to communicate the findings of the study in a succinct format. It is hoped that the written account of the theoretical formulation helps elaborate on this to describe in more detail, the complex interactive processes experienced by participants.

Finally, the researcher was not familiar with GT prior to undertaking this project and therefore this may provide a further strength of this project given that the author naturally developed the GT approach to coding and developing a theoretical formulation and with a high awareness of bias. This reduces bias in that the author was not preoccupied with existing knowledge of GT and had to familiarise himself with those methods for the first time.

4.5 Summary

There are a number of methodological limitations of this project that the reader should remain aware of in the interpretation of the results in chapter 3. There may be unintended limitations in potential research bias that the author himself remains unaware of. However, multiple and rigorous steps were taken in order to reduce this bias where possible. On the whole, it can be argued that the results discussed in chapter 3 offer novel and theoretical insights that are ‘grounded’ in the participants’ experiences of HIV and its impact on the many systems they engage with on a daily basis.

4.6 Clinical implications

The current project offers insights into the challenges experienced by young people who are affected by HIV and the barriers they face in terms of their emotional well-being. Although this project relies on a small sample size, the accounts shared by the participants of this research may contribute something of value to clinicians working with those affected by HIV as well as service users themselves and their parents or carers. As such, the following section will make tentative recommendations in terms of clinical practice based on issues arising from the data.

Services for HIV negative siblings

The current project highlighted that those siblings who are HIV negative are experiencing high levels of emotional distress associated with HIV. The understanding that the healthy sibling of a young person diagnosed with a chronic illness is at risk of psycho-social difficulties is supported by a wealth of literature pertaining to healthy siblings of chronically unwell children (Barlow & Ellard, 2006; Waite-Jones & Madill, 2008; Fleary & Heffer, 2013; Alderfer, 2010). It was evident from the accounts presented by the HIV negative group that emotional difficulties were an ever present and destabilising factor in terms of the psychological well-being of these young people. This highlights a key need for support to be provided for the HIV negative siblings of young people who are HIV positive. It is also vital that parents, carers and clinicians collectively bear in mind the impact of HIV for both siblings and not just the young person receiving a diagnosis. Therefore a clinical implication of this research is that services that support the needs of HIV positive young people also offer a service to the HIV negative siblings where a need

is identified. It is understood that voluntary, charitable and third sector organisations do offer supportive services for HIV negative siblings however this is not the norm and services would benefit from considering the provision of such support on a wider scale in order to promote emotional well-being for young people affected by HIV and their families. Guidelines regarding the care of HIV positive young people are very well documented (BHIVA, 2011; CHIVA, 2013) however specific guidance regarding the care of HIV negative siblings is lacking. This is understandable given that services are commissioned and funded to support those who are physically unwell in terms of receiving a diagnosis of HIV, however this leaves a gap in service provision for those who may require psychological support. Although it is recommended here that services be expanded to cover HIV negative siblings, it is also acknowledged that this is fraught with multiple difficulties around where the funding for such resources would come from, what the provision of such services would look like, and whether this would be a regional or local service that currently a financially struggling NHS would find difficult to implement. Therefore, although this need is identified, it is acknowledged that this would be a challenging practice to implement for many reasons. At present HIV negative siblings experiencing psychological distress are able to access their GP or be sign posted to child and adolescent mental health services should this be indicated.

Early disclosure for HIV positive and negative young people.

This project highlighted that non-disclosure of HIV to the HIV negative siblings in some cases was cited by the individuals as a causal factor for emotional distress later in adolescents. In the first instance it is perhaps prudent for clinicians to consider making parents and carers aware of the potential difficulties that face both HIV positive and HIV negative young people so that they may remain mindful and attentive to the needs of those young people, encouraging, where possible, that parents and carers inform all children of HIV. This initiative may compliment the WHO (2011) guidance suggesting parents and carers inform HIV positive children of their diagnosis as soon as possible. Although this does not cover HIV negative young people, it is perhaps a clinical implication of this research that HIV negative children are also informed of HIV within the family as early as possible in order to protect from difficulties associated with non-disclosure in later adolescents. HIV

negative participants of the current project explored their upset towards feeling mistrusted by the family and the challenges they faced from late disclosure. Although the WHO suggest that early disclosure is a protective factor for later difficulties with HIV positive young people, it is also acknowledged that for many reasons such as fear of causing distress in young people, or fear of the consequences of HIV related stigma, parents and carers struggle with anxiety relating to informing young people of HIV within the family. Although it is suggested here that young HIV negative siblings be informed of HIV within the family, this must be balanced with the individual needs of all children and protecting other young people who do not wish their siblings to be aware of their diagnosis. Perhaps services could prioritise supporting families to disclose HIV in the family setting at the point of diagnosis and again making families aware of the benefits and difficulties associated with this.

Facilitate open communication within families

A key finding of this project was that HIV appears to be a taboo subject within the family often leaving young people feeling unable to explore their concerns or worries associated with HIV for fear of causing upset for family members, in particular parents and carers. The notion of HIV remaining a taboo subject within the family setting is supported by the literature (Rydstrom *et al.* 2013). This lack of communication understandably places young people at risk of psychological difficulties if these anxieties are unable to be identified, understood and explored and indeed the literature consistently reports that increased mental health difficulties are observed in populations affected by HIV (Mellins & Malee, 2013; Nkomo, Kafaar & Kelly 2007). As such, a clinical implication of this project is that clinicians working with those affected by HIV encourage and facilitate open communication between family members. This may help those affected by HIV increase their access to support and potentially mitigating factors associated with poor mental health such as isolation and lack of emotional support. This may improve low mood and anxieties that can be explored and challenged within the family. On the other hand, of course, forcing conversation around HIV would potentially be equally unhelpful for many families, depending upon the context and the presence or absence of additional stressors. Clinicians may consider regularly asking service users during routine

appointments about the nature of support they are receiving and sign post to external support services where necessary. First and foremost it is vital that parents and carers understand the difficulties that are associated with avoiding the topic of HIV within the family, allowing those families to individually take advice to inform decision making around HIV.

Cultural experiences of stigma

A particularly interesting feature of some interviews arose from those participants who had come to live in the UK from Sub-Saharan Africa, thus experiencing HIV related stigma across different cultures. Those participants discussed the cultural disparity between the felt stigma in both cultures, clearly reporting that HIV related stigma was greater in the UK. This finding may be surprising for some as one might assume that in a western society where access to healthcare is greater and easily accessible, in addition to the economic and security benefits of living in the UK, that the experience of HIV would be better both from a physical and psychological view point. This did not appear to be the case. Nonetheless, this finding is in support of the literature pertaining to cultural differences in HIV related stigma suggesting that stigma associated with HIV is considerably greater across different cultures (Ojikutu *et al.* 2013; Genberg *et al.* 2009). Additionally, Genberg *et al.* (2009) also assert that higher rates of stigma towards HIV were found in countries with a lower prevalence for HIV. As such, the UK has a significantly lower prevalence rate of HIV in comparison to Sub-Saharan Africa and the current project therefore supports those findings. Perhaps the treatability of HIV and the success in managing the condition in the UK has led to HIV patients and their families being more able to conceal this and therefore less open to discussing it. As a result of this it is possible that the prevailing stigma attached to HIV in the 1980's remains unchallenged. Indeed the notion that despite medical advances the stigma towards HIV remains a key challenge for those affected by HIV, is supported by the literature (Stackpool-Moore *et al.* 2013). As such, it could be argued that although in terms of healthcare HIV is better treated in the UK, the psychological experience is exacerbated and worsened by the lack of support and the marginalisation of those affected within western culture. This is reflected in most participants' experiences of HIV as a social and political issue rather than a physical

health issue. A clinical implication of the current research would therefore be a recommendation that clinicians remain mindful of the impact of a cultural shift in the intensity of the socio-political consequences of HIV related stigma. This is particularly relevant given that 58% of those diagnosed with HIV in the UK are of black-African ethnicity (Public Health England, 2015). Therefore, a portion of those most affected by HIV (those who were not born in the UK) may need support in managing any potential changes in the impact and effects of stigma. This may allow for a greater understanding of the challenges experienced by patients who came to the UK from a different culture and promote a more targeted and individualised package of care that truly benefits the patient and their families. Arguably the cultural difference felt in stigma towards HIV are experienced by many others affected by HIV and promoting an understanding of this is of benefit to both services and their service users.

4.7 Implications for future research

Continued research into secrecy within the family

A clinical implication of this project is that clinicians may provide a greater service to families by thinking carefully with families about when to challenge the secrecy between relatives in terms of HIV, a notion also supported by the WHO (2011) guidance. It would be interesting to conduct further research that assessed the effectiveness of an intervention in this area and considered, from the families' point of view, the impact of openly discussing HIV on emotional well-being. This could potentially be achieved using additional qualitative research. An IPA study that focused both on clinician's experiences of facilitating open communication regarding HIV for families as well as the experiences of the family of being more open may provide a valuable contribution to the field. This research may utilise a semi-structured interview that seeks to develop an understanding of the difficulties and challenges imposed on more open families by HIV, further helping to understand any psychological distress related to HIV. This research may then provide a comparison to families who avoid communication regarding HIV in order to help clinicians understand how best to approach familial disclosure and consider how this impacts upon service users. Furthermore, this may also help clinicians understand and overcome barriers to disclosure helping reduce rates of onward

transmission of HIV, improve adherence to treatment as well as reduce psychological distress experienced by service users. However, it is also acknowledged here that forcing open communication for all families would be inappropriate and therefore an overall approach of encouraging this would also be unsuitable. As such, further research that develops our understanding of when it would be useful to facilitate such conversations and when not to would be prudent before intervening with individuals and their families.

Whole families' perspective

Although the remit of this project was to consider the impact of HIV on siblings it was evident during interviews that other family members may also experience difficulties such as anxiety and depression associated with HIV. Participants from both groups alluded to parents becoming tearful when talking about HIV and a clear observation of parental avoidance of HIV as a topic. Therefore, it would be interesting to conduct a similar research project that incorporated the perspectives of the entire family. This potential future project could help shed further light onto the family processes of managing HIV and be able to offer insights that clinicians could use to help families break unhelpful cycles that maintain emotional distress. Such future research may make further use of qualitative methodology such as GT in order to develop a theory regarding the family processes in managing the challenges imposed by HIV. This would further the findings of the current project to incorporate the wider family system alongside the sibling relationship. A semi-structured interview that was designed to elicit family processes of approaching or avoiding HIV and the impact of this on individual and familial well-being would provide a much needed contribution to the field. The development of such a theory would complement the BHIVA (2011) and CHIVA (2014) guidance and empower NHS clinicians to effectively attend to the psychological needs of individuals accessing HIV services.

Quantitative research

It has been acknowledged that the current research makes inferences based on a small sample size. Nevertheless, some interesting and important findings are discussed and as such future research could seek to build upon this. Perhaps, the results found in this research or similar family based projects, could be used to

inform a quantitative research questionnaire or brief interview that could be administered by clinicians as part of routine HIV appointments nationwide. This would provide potential corroboration or disaffirmation of the current findings but also such research would be in a stronger position to generalise findings to the wider HIV community and therefore inform practical family based interventions that support those who chose to access this. It would perhaps be fruitful to consider collating core-categories identified by this research and other qualitative research that makes reference to family and individual processes in terms of managing HIV (Rydstrom *et al.* 2013). The themes here could be used to inform a questionnaire making use of open or closed questions relating to family processes whilst also obtaining some brief qualitative response. This could then be subject to a statistical analysis on a grand scale helping further understand on a national level, the issues affecting families affected by HIV. The analysis at this stage could also be broken down into locality to understand which areas people struggle in most and help identify areas of need clinically for intervention.

5.0 CONCLUSION

In response to the research question and aims, a number of conclusions can be drawn. Firstly, an overall theoretical formulation is presented providing a model of the samples' experiences regarding the impact of HIV. The theoretical formulation utilises a structure reflecting the ecological systems theory in order to demonstrate the way in which the author has related the categories emerging from this research to the broader external and internal systems that participants interact with. Therefore, this illustrates a picture of the internal and external pressures exerted on participants in the different systems they function within. Results indicate that HIV appears to have a bonding effect on the sibling relationship with participants from both groups discussing feeling closer to their siblings. Although, some of the findings of this research were expected and indeed are in support of existing theory and literature, the theoretical formulation provided adds a richer and more collaborative account of those perspectives from both sibling groups, which is seldom achieved within the current evidence base. Finally, this project also highlights some original findings such as an exploration of the sibling relationship in a HIV discordant sample, an exploration of the family coping methods in response to

HIV, an exploration of the 'HIV burden' in terms of transmission and contamination anxiety experienced by participants in addition to an exploration of the desire to fit in amongst HIV positive young people.

During the 1980's it was clear that HIV presented a global public health crisis with investment and research being focused upon understanding HIV from a biological perspective. As time moved on and our understanding of this condition progressed, the psychological impact of HIV was studied across the world, albeit largely within an adult population. To date, there is little empirical research that details the psychological responses of the family members of those who are HIV positive, specifically within sibling relationships. This research is one of the first studies to explicitly detail the psychological impact of HIV in the context of discordant siblings specifically, highlighting clinically relevant findings that may expand our understanding in a previously unstudied area.

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APPENDIX 1: LETTER OF ETHICAL APPROVAL



UNIVERSITY OF LEEDS

Faculty of Medicine and Health Research Office
School of Medicine Research Ethics Committee (SoMREC)

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19 October 2015

Mr Adam McLaughlin
Psychologist in Clinical Training
Institute of Health Sciences – School of Medicine
University of Leeds
LEEDS LS2 9TJ

Dear Adam

Ref no: SoMREC/14/076

Title: **Amendment 1 - What is the psychosocial experience of siblings who are HIV discordant?**

We are pleased to inform you that your amendment to your research ethics application has been reviewed by the School of Medicine Research Ethics Committee (SoMREC) and we can confirm that ethics approval is granted based on the following documents received from you:

Document	Version	Date submitted
SoMREC14076 Signed Amendment_form	1	12/10/2015
AALPHI sub-study permission email	1	09/10/2015
NRES AALPHI approval letter	1	08/10/2015
Information sheet V5	5	08/10/2015
Consent Form V5	5	08/10/2015

Please notify the committee if you intend to make any further amendments to the original research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please contact the Faculty Research Ethics Administrator for further information (fmhuniethics@leeds.ac.uk)

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

We wish you every success with the project.

Yours sincerely

Dr Roger Parslow
Co-Chair, SoMREC, University of Leeds

Dr Ruth Brooke
Co-Chair, SoMREC, University of Leeds

(Approval granted by Dr Ruth Brooke on behalf of SoMREC Co-Chairs)

APPENDIX 2: PARTICIPANT INFORMATION SHEET

**Clinical Psychology Training Programme
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UNIVERSITY OF LEEDS

Information Sheet Version 5: 08th October 2015

Research project: How do siblings make sense of their experiences when one is HIV positive?

Introduction:

We would like to invite you to take part in a clinical psychology research study about your experiences of living with HIV. Before you decide, it is important to understand why this research is being done and what you will be doing if you decide you would like to take part. Please read this information carefully, if there is anything that is not clear or if you would like some more information please contact us using the details below and we will be happy to talk to you.

Why is this research important?

This study aims to look at the experiences of young people who are HIV positive and their HIV negative siblings (brother or sister). We are interested in understanding how HIV affects young people day to day, the positive and negative aspects of this illness as well as considering how HIV might affect thoughts about the future. This will provide up to date information about how HIV is affecting young people with HIV and their siblings who do not have HIV. We hope that this research can give us more information about what people living with HIV might need, such as support. The research will be carried out by Adam McLaughlin, as part of his training to be a Clinical Psychologist.

At the moment very little research focuses on the needs of young people with HIV and their siblings, particularly in the U.K. where young people make up 5% of all people who are diagnosed with HIV. When we also think about the siblings of those diagnosed and the impact HIV could have for both, the number of people who may need our support grows. Therefore, it is important for researchers to invest time and resources into finding out what impact HIV is having for both siblings, and the best way is to talk to them.

Why have I been invited?

We are asking you to take part in this research because you have previously taken part in HIV research with AALPHI and we feel that you could offer some valuable information that could help with this research.

Do I have to take part?

No. You can decide whether or not to take part. Also, if you do decide to take part you are free to stop at any time during your interview, without giving a reason. After this you will have three days only to contact the researcher and let him know that you do not want your interview to be included in the research. This will not affect the services or support you receive from your clinic or AALPHI.

How do I take part?

After you have had a conversation with a research nurse at AALPHI you can think about whether you want to take part in an interview. If you do want to take part you can let the research nurse know and she will pass your contact details onto me. I will then contact you and your sibling to arrange a time that is best for you both to interview. It is important to know that you and your sibling must both agree to take part for interviews to be arranged. If you are HIV positive and you have more than one sibling who is HIV negative, you will be able to nominate a sibling of your choice to take part.

What will I have to do?

You will be asked to read the information sheet and complete the consent form. After this you will be asked to take part in one interview with Adam at a time that is best for you. Interviews will last no more than one hour. Siblings will also be interviewed by themselves, one sibling after the other.

Confidentiality

Interviews will be voice recorded. All information collected about you throughout this study will be kept strictly confidential. The only reason why we might have to consider passing on anything you said to someone outside the study team would be to protect you or someone else from serious harm. We would discuss this with you first. You will be able to pick a false name that you would like to be known by in the study, so that your real name will not be used and nobody will know who you are. Furthermore, none of your personal information will be included in the final report.

What are the potential benefits of taking part?

We hope that your taking part in this study and sharing your personal experiences will help us to learn about the impact HIV has on young people and their siblings. The information received may also be used to help improve the care and support that families affected by HIV need.

What if there is a problem or I want to complain?

If you have any concerns about any aspect of the study or you wish to complain you may do so by contacting Dr Gary Latchford and Dr Fiona Thorne who are research supervisors for this project based at The University of Leeds. You may also speak with the School of Medicine Research and Ethics Committee at the University of Leeds.

What will happen to the results of the study?

The results from this study will be published in medical journals and presented at conferences and seminars. You will not be identified in anyway in published reports or presentations. You can be made aware of the results if you wish.

Who is organising and funding this research?

This study is organised by the Leeds Institute of Health Sciences at the University of Leeds. The study is funded by a grant from the University of Leeds. Contact details provided below.

Who has reviewed this study?

All research conducted on behalf of The University of Leeds is looked at by an independent panel of people, called a Research Ethics Committee in order to protect and ensure your safety, rights, and wellbeing.

Where can I find out more information about this research?

If you would like more information about this research please contact Adam McLaughlin or the other members of the research team, who will be more than happy to answer all your questions.

Mr Adam McLaughlin

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Thank you for thinking about participating in this study.

APPENDIX 3: CONSENT FORM

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UNIVERSITY OF LEEDS

Consent Form

Version 5: 08th October 2015

What name would you like to be known by for this study? _____

Study title: How do siblings make sense of their experiences when one is HIV positive?

We would like your permission to take part in a research project today, looking at your experience of living with HIV.

Please initial box

1. I confirm that I have read the information sheet given to me by AALPHI and I understand what I will be asked to do to take part in this study.
2. I understand that taking part is voluntary and that I do not have to take part if I do not want to.
3. I also understand that I can remove my data from the research completely up to three days after this interview.
4. I understand that if I don't want to answer a particular question I do not have to and do not need to give a reason why.
5. I agree to this interview being voice-recorded
6. I understand that if I share any information that makes the researcher think I am a risk of harm to myself or others then the researcher has a duty of care to share this information with the appropriate people.
7. I have had the opportunity to ask the researcher questions.
8. I agree to take part in this study

Name of participant

Date

Signature

Thank you for your much appreciated participation!

APPENDIX 4: HIV POSITIVE INTERVIEW SCHEDULE

Topic guide

Questions for HIV positive young person

Can you tell me a little bit about yourself?

Could you tell me who lives in your household?

Can you remember when you were first aware you were HIV positive?

When did you find out? How were people told? Who knows about your diagnosis?

Is there anybody else in your family with the same condition?

What is it like day-to-day for you living with HIV?

Has being HIV positive affected you in any way?

If so what's changed? How has this affected you?

Does having HIV impact at school or on your social life?

How do you feel about being HIV positive?

What's it like in the household?

what do you think people at home think about HIV?

Has having HIV had any impact on your relationships with family?

Could you tell me about some of the ways having HIV might have been difficult for you

In what ways has HIV been a negative in your life? If so why?

Could you tell me about some of the ways having HIV might have been useful for you

Has HIV been a positive in your life? If so why?

Do you think HIV has affected you emotionally?

What emotions come to mind when you think about HIV?

Has HIV had an impact on you physically? If so how do you feel about this?

Do you feel supported with your condition?

Who supports you?

Are there barriers to getting support?

Anyway in which you would like support but cannot get this? If so why?

Is the support you receive different from the support your sibling receives? If so how?

Does HIV affect your relationship with your sibling in anyway?

Both positively and negatively

In 10 years from now what do you imagine your life will be like?

Where might you be, what might you be doing? Work, personally, family. Where do you see yourself?

In 10 years from now do you think HIV will have an impact on your life in anyway?

Will HIV stop you doing some of the things you want to do or might it help you in other ways with the things you would like to achieve.

- *Is how you see your life with HIV in 10 years different from now? If so how? is that good or bad?*

In 10 years' time what do you think your sibling might be doing (personally, professionally, family)

If this is different from where you see yourself why might that be?

APPENDIX 5: HIV NEGATIVE INTERVIEW SCHEDULE

Topic guide

Questions for HIV negative young person

Can you tell me a little bit about yourself?

Could you tell me who lives in your household?

Can you remember when you were first aware your sibling was HIV positive?

When did you find out? How were people told? Who knows about your siblings' diagnosis?

Is there anybody else in your family with the same condition?

What is HIV in the family like for you day-to-day?

How do you feel about your sibling being HIV positive?

Do you think things are different for you because your sibling is HIV positive than they might be for young people whose siblings are not HIV positive?

Has your sibling being HIV positive affected you in any way

If so what's changed? How has this affected you?

Physically, well-being?

Do you think your sibling having HIV has affected you emotionally, what emotions come to mind when you think about your sibling being HIV positive?

Do you feel you get the support you need for the way that HIV has affected you?

Is this support different from the support your sibling receives? If so how?

Who supports you? Are there barriers to getting support i.e. anyway in which you would like support but cannot get this? If so why?

Does your sibling having HIV impact on you at school or in your social life?

What is it like growing up with HIV in the family?

Do you think HIV has changed things for your family or means that things are different for your family? What about you?

Has your sibling having HIV had any impact on your relationships with your family?

Does HIV affect your relationship with your sibling in anyway?

Both positively and negatively (I.e. sibling relationship improves well-being?)

Could you tell me about some of the ways that your sibling having HIV might have been difficult for you?

In what ways has his/her HIV been a negative in your life?

Could you tell me about some of the ways that your sibling having HIV might have been useful for you?

Has his/her HIV been a positive in your life? If so why?

In 10 years from now what do you imagine your life will be like? Where might you be, what might you be doing?

Work, personally, family etc.

Do you think your sibling having HIV will have an effect on you in anyway 10 years from today?

Might this change any of the things we talked about in the last question e.g. where you see yourself in 10 years.

Is that different from now? If so how? is that good or bad?

Where do you see your sibling in 10 years' time?

Do you think having HIV affects their future and how might this be different from yours?

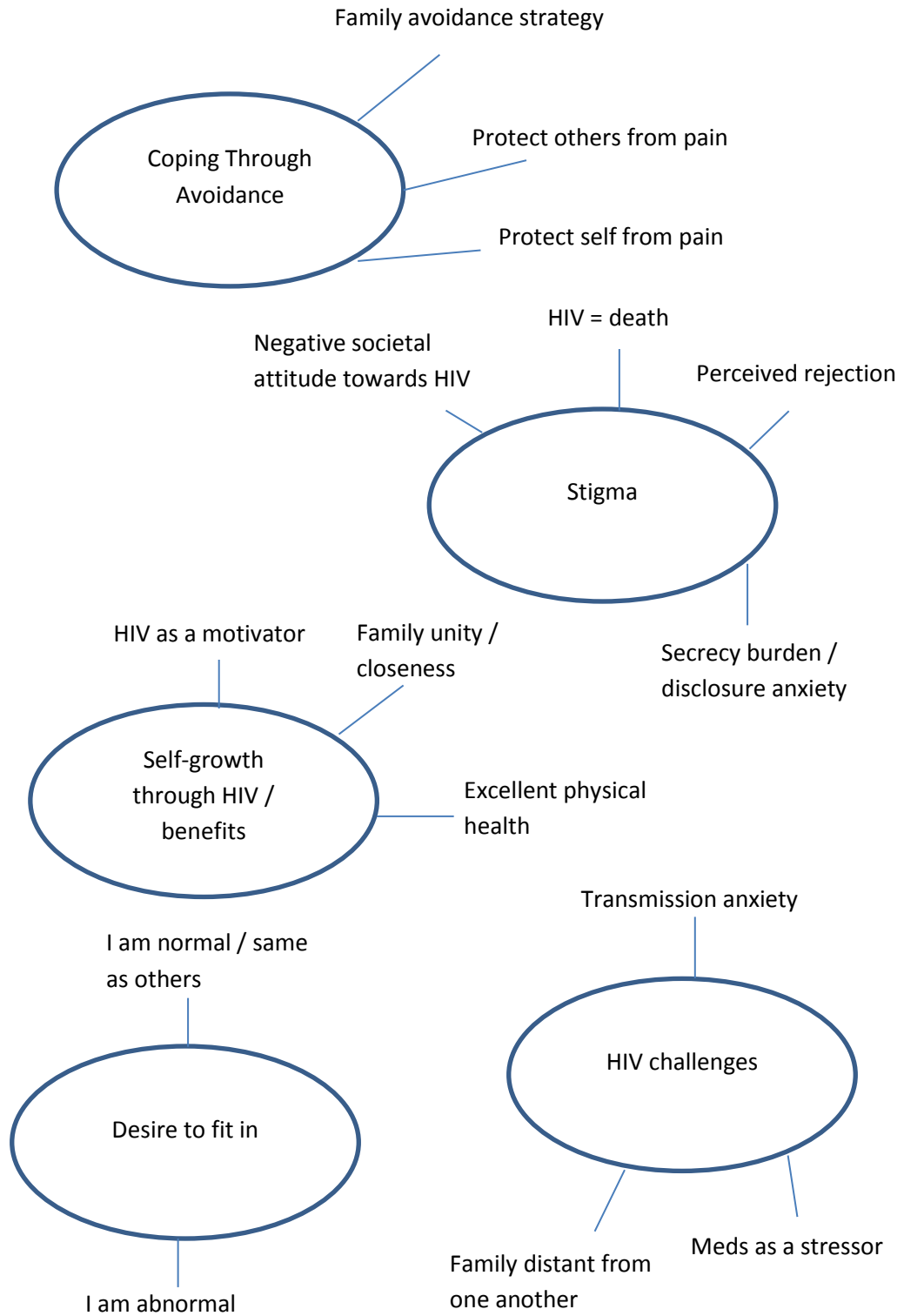
APPENDIX 6: EXAMPLE OF OPEN CODING PROCESS WITH MEMOS

Transcript	Memo's	Open Code
468 "theres no difference really"	Sense of normality? This keeps emerging in the data.	HIV is normal.
469 "I cant do anything about it either"		Powerless position in relation
470 "If I am going to have an sex I should be protective"		Sexual risk posed to others.
471 "I cant do anything about it but protect myself"		Powerless position in relation
472 "I can protect my self from catching anything else or passing it on"	Similar to other interview re transmission worry. Other was negative this ppt positive.	Transmission worry.
473 "I cant do anything about me having HIV"		Powerless position in relation
474 "So if I didn't have HIV I wouldn't be thinking about condoms bla bla"		HIV makes me safer.
475 replied no when asked directly.		No impact on school or scioal I
476 "I don't think about it at all, I just don't"		Don't think about HIV
477 "I just don't like it when people try and bring it up"		Upset if others talk about HIV.
478 "I know some people my age with chlamydia but they don't know I have HIV"	Family only secret again perhaps?	Friends unaware
479 replied no when asked directly.		Not fearful of disclosure/expc
480 "But I am just thinking how am I supposed to have babies?"	Tie in with relationship focused responses?	Fear wont have own family
481 "Yeah probably something I might want"	Most people this ppts age think about this, maybe more so that it might be harder?	Becoming a parent important
482 "Meds make my counts very very low and make you safer"		Meds = health and safety.
483 "No it don't really cross my mind you know"		HIV not on mind much
484 "Nothing I can do about it really"		Powerless position in relation
485 "I don't have time for this yeah"		No time for HIV in headspace.
486 "I don't care"		Don't care about HIV
487 "I cant do anything about it its out of my hands"	Thinking about HIV is a waste of time almost? Due to powerlessness?	Powerless so why think about
488 "Crying wont solve it"	Justification for not addressing sadness? But is he sad maybe not?	Won't cry
489 "Research might make it better and I hope that might come"	similar to other ppt talk of a cure?	Hope
490 replied no when directly asked		Family ok with HIV
491 replied no when asked directly.	This has come up time and time again. Every interview.	Family don't talk about HIV
492 "Its none of my business"	Justification for not asking/talking about HIV - avoiding emotions?	Family HIV not his business
493 "I didn't give myself HIV so I know its not my fault"	Blame in HIV	HIV not my fault
494 replied no when asked directly.		No impact on family relationsl
495 "Its just something that's in the back, I just do my own thing".		HIV in bacground not foregrou
496 "I was yeah, I just took it out of my head"		Push HIV away.
497 "I mentioned the condom thing"	HIV positives - safer sex, better health, close to family.	HIV makes me safer.
498 "Youre already a little bit of an expert in something"	Knoweldge is comforting?	Im a HIV expert.
499 replied no when asked directly.		No emotional effect of HIV
500 "I hardly get ill"		No physical effect of HIV
501 "Yeah by the hospital and that"		Feels supported
502 "that's it"	Only hospital support him though?	Feels supported
503 "We don't talk about it at all"		No fmaily support
504 responded no when asked directly		Not want to talk about HIV
505 "It's a negative thing so there is no point in bringing it up"		HIV is bad - wants cure.
506 "If you keep talking about it its going to get to you eventually"		Talking about HIV = pain
507 "This sort of thing we don't talk about"		Don't talk about HIV
508 "It's a negative thing"		HIV is bad.
509 "Me misbehaving yeah, then I don't have to, I dnt know"	Bad behaviour is more positive than HIV chat. HIV talk is sp stressful?	Being told of better than talki
510 "I'm not any easy type to talk in a way. I just keep myself to myself"	Isolated from others, deals with HIV on own?	Withdrawn

APPENDIX 7: EXAMPLE OF AXIAL CODING PROCESS

Book1 (1) - Microsoft Excel					
File Home Insert Page Layout Formulas Data Review View					
G1					
A	B	C	D	E	F
1	Conceptual categories	Axial coding	Conceptual Categories	Axial coding	Conceptual Categories
2	Secrecy Negatives	<i>Secrecy Negatives</i>	Negative emotions	<i>Negative emotions</i>	Emotional experience
3	Keep my secret	<i>Secrecy Positives</i>	HIV = Sadness	Own Future	Heartbreaking
4	Keep the family secret	<i>Emotional experience</i>	Low frequency sadness	Sibs future	Fear
5	Protect self	<i>Avoid HIV</i>	Occasional Sadness	Family unity	Paranoia
6	Protect the family	<i>Support</i>	HIV is upsetting	HIV as normal	Huge anxiety
7	Family secrecy burden	<i>Family experience</i>	Own Future	Denial/avoidance	HIV = stress
8	HIV is concealable	<i>Death and HIV</i>	Future outlook good	Disclosure ok	HIV = depression
9	Secrecy Positives	<i>Understanding of HIV</i>	Ambitious	Sibs emotions are difficult to manage	HIV = anger
10	Secrecy = safety	<i>Future</i>	Future is positive	Understanding of HIV	HIV = Shame
11	Secrecy = comfort	<i>Personality</i>	HIV wont effect my future	Family Experience	Feels guilt.
12	Secrecy = limited worry		Sibs future	Negative focus	HIV positives
13	Secrecy = Happiness		Siblings future uncertain		Closer to mum
14	Emotional experience		Siblings relationships will be ok		HIV negatives
15	Entire family struggle		HIV impact on sibs future uncertain.		Less close with Siblings
16	Very emotional		Family unity		Sadness at loss of sib rel
17	Family emotional		Family all care for eachother		HIV neg impacts sib rel
18	HIV = sadness		HIV = family closeness		Future
19	HIV is tough		HIV has a positive = family unity.		Future outlook positive
20	Sadness isnt normal.		HIV as normal		Relationships will be ok
21	Talking about HIV = pain		HIV has no impact at all		Attitude towards HIV
22	Thinking about HIV = pain		HIV isnt on my mind much		HIV is negative
23	emotions of family hard to manage		HIV is ok		HIV is bad
24	Difficult to support positive sibling		HIV is normal		Anger towards HIV
25	Sadness for others effected by HIV		No physical effect		Denial/Protective thoughts
26	Why not me?		No worries re HIV		HIV is normal
27	Guilt		No effect on school		HIV is ok
28	Guilt/ it should be me.		No effect on social life		HIV has no difference
29	HIV is stressful		HIV feels ok		I feel safe
30	HIV is negative.		No different to having sib without HIV		HIV doesn't bother me
31	Protective		Im the same as my peers		Avoid HIV
32	Avoid HIV		HIV is no different		I don't think about HIV
33	Supress emotions		Denial/avoidance		Family don't talk about HIV
34	effort not to be negative		HIV has no impact at all		Never talk about HIV
35	Avoid thinking about HIV		No emotional effect		Try not to think about HIV
36	Positive focus needed		HIV is not difficult		Distraction to avoid HIV thoughts
37	family narrative of if negative avoid it.		Family don't talk about HIV		Attitude towards siblings
38	Be positive can control emotions.		Unaware of who has HIV in family		They are still human
39	Support		Disclosure ok		Close to sibilings
40	Family support		People outside family are aware.		Still love siblings
41	Charity support		Sibs emotions are difficult to manage		Id never reject siblings
42	Feels supported		Im upset due to sibs difficulties		Not siblings fault
43	HIV community helpful		Im upset due to sibs diagnosis		No negativity towards siblings
44	Happy with support		Understanding of HIV		Beliefs about HIV

**APPENDIX 8: EXAMPLE OF CORE AND SUB-CATEGORIES
HIV POSITIVE SIBLING GROUP**



**APPENDIX 9: EXAMPLE OF CORE AND SUB-CATEGORIES
HIV NEGATIVE SIBLING GROUP**

