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An exploration of the lived and educational experiences of young people living with Human Immunodeficiency Virus (HIV)

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Student declaration

I hereby declare that, except where explicit attribution is made, the work presented in this thesis is entirely my own.

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Abstract

Human Immunodeficiency Virus (HIV) is a condition that requires medical management, such as daily antiretroviral treatment, which can lead to side effects that can affect physical and mental health. This can impact an individual's experience of education and friendship. Yet, past research has neglected this area, and little is known about the support mechanisms available.

The central focus of this study was an exploration of the lived and educational experiences of young people living with HIV. This was explored through in-depth semi-structured interviews and a qualitative content analysis of the websites of three key charities and organisations who support people living with HIV.

A key finding from the interview data relates to how young people make sense of, and ultimately represent, HIV. Receiving a diagnosis of HIV ignited a meaning-making process for young people, whose representations of the medical condition and their identity developed over time. Additionally, participants alluded to difficulties with physical and mental health, predominantly in relation to taking medication and stigma, which were experienced through interactions with peers, in school, and wider society. However, young people emphasised the support received from family members, peers, teachers, healthcare professionals, and external organisations as fundamental.

A qualitative content analysis demonstrated the powerful role of organisations in supporting the development of an understanding of expert knowledge related to HIV, associated psychosocial difficulties, and the facilitation of a sense of group membership.

These findings have implications for schools and Educational Psychologists (EPs) as they indicate the need for a higher level of support in schools. It was

concluded that EPs may have an important role in advocating for such young people, supporting the school system to consider appropriate provision, delivering training around HIV-friendly schools, and increasing parents' awareness of the role of EPs.

Impact statement

This thesis explored the lived experiences of young people living with HIV, with a particular focus on their educational experiences. Due to the small sample of participants, it was possible to conduct in-depth semi-structured interviews in order to provide a detailed exploration of these experiences. This piece of research addressed a clear gap in the literature in terms of eliciting the views of young people in the UK around their educational experiences. The findings explored the ways in which young people's representations of themselves as individuals living with HIV and of HIV as a medical condition were influenced by interactions within a range of different systems, such as the family, the peer group, the education system, and experiences with professionals. In addition to the findings presented in relation to the interview data, a qualitative content analysis of the websites of three key charities and organisations who support people living with HIV indicated that these organisations support people living with HIV through providing them with a sense of group membership, and through supporting the development of understanding both the expert knowledge and the psychosocial difficulties associated with HIV.

This research has highlighted the need for school staff to be aware of the needs of children and young people living with HIV in school settings, so that they are able to access appropriate support in order to ensure that they can progress and develop alongside their peers. It is clear that children and young people experience a multitude of difficulties in relation to both physical and mental health, highlighted in the literature review and findings sections of this study, which can impact on their learning. Therefore, this research has a range of implications for EPs and educational settings around the ways in which children and young people living with HIV should be best supported in schools. Support at the individual level through advocating for young people living with HIV, at the group level by providing parents with information and support around the role of EPs and how they may be able to offer support, and the organisation level by providing training and guidance in order to support schools to become HIV-friendly were considered as ways in which EPs could support such individuals.

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Chapter 1: Motivation

Before commencing the Professional Doctorate in Educational, Child and Adolescent Psychology, I volunteered for a charity based in inner London that supports children and families living with and affected by Human Immunodeficiency Virus (HIV)[1]. There, I worked with children and young people between the ages of 12 and 18 years who were living with or affected by HIV. My role included supporting a monthly workshop that focused on providing the children and young people with opportunities to access physical, social, and emotional support, through a range of different workshops, activities, and access to communal settings. The safe, inclusive space created within the charity provided the children and young people with an abundance of opportunities to access support from both their peers, facilitators and the volunteers and facilitated a range of possibilities for them to discuss HIV-related issues and concerns.

Through this voluntary role, I gained valuable insight into some of the key issues experienced by children and young people living with and affected by HIV. I learned that many of the children and young people had encountered bereavement and loss at some stage in their lives, difficulties with medication adherence, difficulties with mental health and emotional wellbeing, and difficulties with relationships and social wellbeing. However, it was also apparent that the charity that I volunteered for, and similar charities and organisations, were a key source of support for such children and young people.

Throughout my time working with this charity and though undertaking the Professional Doctorate, I wondered about the potential role schools and Educational Psychologists (EPs) are able to play in supporting children and young people living

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[1] Henceforth referred to as HIV

with HIV. Although school staff may not always be aware of children and young people’s HIV status, it seems clear that schools and EPs have the potential to play a key role in supporting such individuals, particularly in the area of pastoral care. Yet, upon investigation, there are few resources available and few studies which identify the issues that children and young people living with HIV need support with.

Given this, I sought to undertake research to explore the lived experiences of children and young people living with HIV with a specific focus on educational experiences in order to explore how school settings can appropriately offer support in the future. I strongly believe that schools and EPs have the potential to offer key support to such individuals.

Chapter 2: Introduction

HIV is a virus that damages the cells in an individual's immune system, thus weakening their ability to fight against everyday infections and disease (National Health Service, 2018). HIV is present in the blood, breast milk, semen and vaginal fluids of people living with HIV and can only be transmitted if these fluids enter another person's body through unprotected sexual intercourse, sharing of infected needles, and from mother to baby through pregnancy, birth, or breastfeeding. Acquired Immune Deficiency Syndrome (AIDS) is the number of potentially life-threatening infections and illnesses that occur when an individual's immune system has been severely damaged by HIV (National Health Service, 2018). HIV can be transmitted from one person to another, however, AIDS cannot.

The population of individuals living with HIV in the United Kingdom (UK) at the end of 2018 was 103,800 (Public Health England, 2019). It was reported that 2.9% of this population are aged 0-25 years old.

Brief history of HIV/AIDS in the UK. The first reports of HIV/AIDS were in the United States (US) in 1981, with the virus initially being labelled the 'gay-related immune deficiency'. In the early days following its discovery, there was an incredible amount of stigma and misinformation surrounding the medical condition and those living with it. Terrence Higgins was the first person in the UK whose death was related to AIDS in 1982. In 1983, scientists discovered that the Human Immunodeficiency Virus (HIV) was behind the new medical condition. A public information campaign followed in 1986, which was found to be labelled as 'Don't Die of Ignorance' and 'Don't aid AIDS', in order to warn people about the condition, thus contributing to stigmatised views around HIV. Highly active antiretroviral therapy was introduced as a treatment in 1995, with pre-exposure prophylaxis (PrEP) being introduced as the first drug to prevent the contraction of HIV in 2012.

There has been significant progress made in antiretroviral treatment in the UK, ensuring that people living with HIV are now able to live longer lives. Many people living with HIV will take antiretroviral medicines which prevent the virus replicating in the body and helping the immune system to repair (National Health Service, 2021). These medicines are usually taken every day, with people who have just been diagnosed with HIV taking between 1 and 4 pills a day (National Health Service, 2021). Antiretroviral medication can cause a range of different side effects, such as fatigue, headaches, nausea, loss of appetite, and difficulties with sleeping. People living with HIV receive treatment and care through attending specialist HIV clinics, with appointments occurring two to four times per year, and will often involve having blood tests to explore both the CD4 count (white blood cells that fight infection) and viral load (the amount of virus in a person's blood).

Despite the fact that there has been significant progress made in antiretroviral treatment in the UK, people living with HIV are at risk of experiencing a multitude of psychosocial challenges. It has been widely reported that people living with HIV are exposed to different forms of stigma, can experience difficulties with medical adherence, and can experience a range of different mental health difficulties (Malee et al., 2011; Mellins & Malee, 2013). Such psychosocial difficulties experienced by people living with HIV can potentially have an impact on their quality of life, mental health, and emotional wellbeing.

Definitions. Throughout this report, I will use the terms 'living with HIV' and 'affected by HIV'. In addition, I will refer to HIV as a 'medical condition', as this was the preferred term used by many of the participants. The definitions of the terms ‘living with HIV’ and ‘affected by HIV’ (Ipsos Healthcare, 2014) are as follows:

- ‘Living with HIV’ refers to individuals who are HIV positive, and therefore living with the virus.
- ‘Affected by HIV’, refers to any individual who may be affected by HIV, such as living with a relative who is HIV positive, but who are not living with the virus themselves.

2.1 Rationale for the research study and expected contributions

Throughout the literature, there appears to be an absence of qualitative research providing rich, detailed descriptions of the lived experiences of children and young people living with HIV in the UK. In addition, there have been few studies of the educational experiences of children and young people living with HIV in the UK. As educational settings are a context in which children and young people spend a significant amount of time and are likely to provide children and young people with access to appropriate support, understanding the forms of support such individuals want to receive at school, and their experiences of existing, effective support in this context, is important. Therefore, the purpose of this research was to explore the lived experiences of children and young people living with HIV in order to consider how they can be appropriately supported in school. This was explored through in-depth semi-structured interviews and a qualitative content analysis of the websites of three key charities and organisations supporting people living with HIV. Therefore, the purpose of this research study was twofold. The qualitative content analysis explored the information available on the three websites and explore the ways in which this content aims to support people living with HIV.

2.2 Relevance to educational psychology practice

The Equality Act (2010) states that individuals should have access to services and opportunities regardless of their age, disability, gender, ethnicity, religion, beliefs, and sexual identity. EPs are responsible for delivering services to children and young people from the age of 0 to 25 years, and therefore work with a wide range of individuals. EPs predominantly adopt a person-centred approach, focusing on placing the individual at the centre of planning. The Special Educational Needs and Disability (SEND) Code of Practice (2015) highlights the importance of including the voices of children and families in the planning, commissioning, and reviewing of services. Therefore, it appears to be necessary to explore the views of children and young people living with HIV in order to consider appropriate ways of supporting them in schools.

This research study will focus on gaining the views of children and young people living with HIV in order to explore their lived experiences. In addition, the study will seek to highlight some of the ways in which children and young people living with HIV have been effectively supported or not supported in school and community settings in the past, and the forms of support they would like to receive in these settings. In doing this, the aim of the study is to increase awareness and understanding, primarily within the Educational Psychology profession, of some of the issues experienced by children and young people living with HIV, so that EPs can appropriately support such individuals in school settings.

2.3 Research questions and aims

This study seeks to answer the following primary research question:

1. What are the lived experiences of children and young people living with HIV?

Its secondary research questions are:

2. What are some of the protective factors that have supported children and young people living with HIV?
3. What are the educational experiences of children and young people living with HIV?
4. To what extent does the information, advice and guidance provided by charities and organisations align with the views of children and young people in relation to their lived and educational experiences?

Lived experiences in qualitative research can be defined as:

> “a representation and understanding of a researcher or research subject’s human experiences, choices, and options and how those factors influence one’s perception of knowledge”. (Given, 2008 p.2)

The aims of the study are as follows:

- To gain a greater understanding of the lived experiences of children and young people living with HIV.
- To gain a greater understanding of the lived experiences of children and young people living with HIV in school and other community settings, such as support groups for people living with HIV, in order to explore the protective factors that have supported young people in these settings and to explore the ways in which young people living with HIV can be appropriately supported in these settings.

- To explore the ways in which the information, advice, and guidance provided by charities and organisations align with the views and experiences of children and young people living with HIV.

2.4 Structure of the thesis

In this thesis, I first explore the relevant literature, drawing on existing knowledge of the difficulties experienced by children and young people living with HIV as learnt through my work experiences highlighted in Chapter 1. This literature review will seek to explore existing knowledge of the experiences of people living with HIV, with particular consideration given to psychosocial difficulties. In addition, an exploration of the existing knowledge around the sources of support, e.g., school, for people living with HIV will be of focus. The use of Bronfenbrenner's (2005) Process-Person-Context-Time (PPCT) model was an ideal lens through which to explore this literature. Considering elements of the 'Context' component of Bronfenbrenner's PPCT model, e.g., the individual, microsystem, exosystem, and macrosystem, allowed for an exploration of some of the psychosocial difficulties experienced by people living with HIV in the context of these inter-related systems. The areas explored throughout the literature review were related to mental health, physical health, quality of life, stigma, disclosure, secrecy, non-disclosure, and education and the community.

As this thesis predominantly focuses on the experiences of young people living with HIV, the importance of the meaning-making processes undertaken by young people who are seeking to familiarise themselves with the expert knowledge associated with HIV was explored through the use of Social Representations Theory (Moscovici, 1961, 1988, 2000). This theory was employed alongside Bronfenbrenner's PPCT model due to the importance of exploring the ways in which young people living with HIV were able to make meaning and explore their identities within the range of contexts present in Bronfenbrenner’s PPCT model. The time element of both theories was of particular relevance to this study. Bronfenbrenner’s PPCT model focuses on time and proximal processes to explore the ways in which individuals develop over time through interactions and experiences across different contexts. In addition, Social Representations Theory highlights the importance of our developing social representations and identities over time and therefore, the use of both theories to carry out this study was deemed appropriate. An in-depth exploration of both theories and how they were utilised to inform the research is highlighted in Chapter 3.7, in which I outline the theoretical approaches that were adopted while carrying out the research study. I then highlight my epistemological and ontological position, before detailing the methods section. The findings sections for both the in-depth semi-structured interviews with young people living with HIV and the qualitative content analysis of the websites of three key charities and organisations who support people living with HIV will be outlined. A discussion of these findings will then be included in the context of the relevant literature and theory pertaining to these findings. Finally, the thesis will explore limitations, implications for educational psychology practice, reflections, and conclusions.

Chapter 3: Literature review

3.1 Search strategy

A range of databases and search engines were used to carry out a review of the relevant literature. These included: British Education Index (BDI), Education Resource Information Centre (ERIC), PsycINFO, SCOPUS, and Web of Science. The following search terms were explored due to the existing literature, and the fact that they were related to some of the experiences of young people discussed through my experiences of working with young people living with HIV highlighted in Chapter 1 and through the exploration of the brief history of HIV in the UK in Chapter 2.

- HIV and mental health
- HIV and anxiety
- HIV and school
- HIV and camp
- HIV and quality of life
- HIV and health-related quality of life
- HIV and adherence
- HIV and stigma

Following my initial review of the relevant literature through this search, I undertook an additional search through perusing the reference lists of the articles in order to further explore relevant articles used by the authors.

3.2 Introduction

The studies explored in the literature review include qualitative and quantitative studies, longitudinal studies, meta-analyses, cross-sectional analyses, surveys, and review studies.

The literature review focuses on i) mental health, physical health, and quality of life, ii) stigma, disclosure, secrecy, and non-disclosure, and iii) education and the community. The theoretical approach that will be employed to explore the lived and educational experiences of children and young people living with HIV in this research study will be outlined in this section.

The review was undertaken using the above-mentioned search strategy and is inclusive of research from both within and outside of the UK. This is due to the fact that the research into HIV has predominantly taken place in non-UK settings, likely because of the higher prevalence of HIV in particular countries. Given that the social and cultural factors may differ significantly in these contexts, it is possible that the findings of these studies will not be fully generalisable to UK settings. It is also noteworthy that the literature on those living with and/or affected by HIV has focused in the main on adult populations, another consideration to bear in mind when attempting to extrapolate the findings to the population of interest to the present research study. In cases where children and young people have been involved, such studies will be highlighted.

3.3 Mental health, physical health, and quality of life

Mental health, physical health and more broadly ‘quality of life’ are each areas that have been considered in the literature on living with HIV. In particular, the mental health and emotional wellbeing of people living with HIV, who are considered to be a vulnerable, minority group, has been widely explored in previous research.

As stated throughout the literature review, people living with HIV are highly likely to experience a significant amount of stigma as a result of their HIV-status. The impact of this HIV-related stigma can lead to a multitude of psychosocial difficulties, such as difficulties with medication adherence, mental health, and physical health difficulties (Brandt et al., 2017; Bucek et al., 2020; Copelyn et al., 2019; Crockett et al., 2019; Le Prevost et al., 2018; Malee et al., 2011; Mellins & Malee, 2013; Nanni et al., 2015; Rueda et al., 2016).

Of particular relevance to the present research study, Malee et al. (2011) explored the mental health of 416 children and young people either living with or affected by HIV through an interview with both the individual and their caregiver, using the Behaviour Assessment System for Children 2nd Edition. Findings from this study indicated that this population of individuals experienced mental health difficulties at a higher rate than the general population in the United States (US). Such findings were replicated by the authors in subsequent research (Mellins & Malee, 2013). Their 2011 study also found that children and young people affected by HIV experienced higher rates of mental health difficulties than those living with HIV. This is potentially due to the fact that children and young people living with HIV are more likely to have access to support from mental health professionals than those affected by HIV (Gadow et al., 2012). Malee et al. (2011) also state that both children living with and affected by HIV can potentially experience difficulties in relation to school adaptation, emotional regulation, and internalising and externalising behaviours. In addition, Mellins and Malee (2013), through an extensive review of relevant literature that was mostly taken from the US and Europe, found that factors such as parental physical and mental health difficulties and experiences of adverse life events, i.e., stressful events that occur either in childhood or adulthood, can potentially lead to children and young people living with HIV experiencing mental health difficulties.

Further to these studies that have highlighted the potential associations between HIV and an increased risk of mental health difficulties in general, researchers have also sought to understand the specific risks to experiencing mental health difficulties that children and young people living with and affected by HIV are vulnerable to experiencing. For example, Nanni et al. (2015) carried out a review focusing on depression in people living with HIV across the world. The authors highlight depression as a mental health difficulty commonly experienced by people living with HIV due to a range of potential factors, such as medication adherence, effects of antiretroviral treatment, societal stigma, and coping with living with a lifelong illness. In another study, Brandt et al. (2017), who carried out a critical review and integrative synthesis of the empirical literature in order to explore anxiety symptoms and disorders among adult populations across the world, reported that anxiety is commonly experienced by adults living with HIV. However, due to the focus on adult populations in the study, the findings may not be transferable to children and young people, which is the main focus of the current research study.

A recent study by Le Prevost et al. (2018) explored the rates of anxiety and depression in 283 young people living with and affected by HIV in England. The authors reported that 40% of the young people experienced mild symptoms of anxiety, and 15% of the young people experienced mild symptoms of depression. In addition, Le Prevost et al. (2018) reported lower rates of self-esteem in young people living with and affected by HIV in comparison to normative data. In light of these findings, it appears that children and young people living with HIV are at risk of experiencing mental health difficulties. In addition, Bucek et al. (2019) explored the rates of psychiatric disorders and substance-use disorders in children and young people affected by HIV through a longitudinal cohort study in the US. The authors found a high prevalence of psychiatric disorders and substance use disorders in the young people affected by HIV, with anxiety being the most commonly experienced mental health difficulty within this population. The young people affected by HIV in this study had slightly higher rates of mental health difficulties than the general population in the US. Further to these studies, Copelyn et al. (2019) examined the prevalence of self-harm in young people living with HIV in England, finding that rates of self-harm were not too dissimilar from a comparison group of HIV-negative young people. However, females living with HIV were identified as disproportionately experiencing incidents of self-harm, which reflects general trends in normative data (The Children’s Society, 2018). In light of these findings, it appears that children and young people living with HIV are at greater risk of experiencing mental health difficulties than their non-HIV affected counterparts and are at particular risk of developing anxiety.

Researchers have also sought to understand the risk factors associated with experiencing mental health difficulties for those living with and affected by HIV, with scholars such as Mellins and Malee (2013) suggesting that HIV itself may not be the primary cause of mental health difficulties in this population. Rather, the detrimental impact of factors such as adverse life events and parental physical and mental health may be linked to the increased risk of people living with HIV experiencing mental health difficulties. Crockett et al. (2019) explored the impact of internalised stigma, the process by which individuals accept and apply the negative labels associated with HIV to themselves, on people living with HIV and their vulnerability to mental health difficulties in central Georgia. The authors found that stress (defined as the negative impact of different incidents of enacted stigma) mediated the relationship between HIV-related discrimination and internalised stigma. Thus, HIV-related discrimination can lead to stress, which can further lead to an individual experiencing internalised stigma. Crockett et al. (2019) further identified that experiencing internalised stigma can have an impact on mental health and wellbeing, namely experiences of depression, and increased levels of alcohol use in people living with HIV. This was measured through the use of the internalised stigma section of the HIV Stigma Mechanisms Scale (Earnshaw et al., 2013). However, this study was conducted in central Georgia, with participants aged 18 years or older, and therefore findings may not be applicable to children and young people in a UK context. In addition, the study only explored HIV-related discrimination and internalised stigma. Therefore, a range of different forms of stigma, for example those related to actual experiences of discrimination, and anticipating experiences of discrimination, were not explored.

Quality of Life (QOL) can be defined as an individual’s state of physical, mental, and social wellbeing, and may therefore be viewed as a holistic measure of wellbeing. QOL is a concept that has been explored within the HIV literature (Balayan & Sudfeld, 2020; Chapman Lambert et al., 2020; Nobre et al., 2017), and appears to be an appropriate measure used in order to attempt to capture the impact of different issues on the lives of people living with HIV, such as mental health difficulties, and HIV-related stigma, to name a few. Nobre et al. (2017) found that the QOL scores of people living with HIV in Finland were similar to the general population. The authors indicated that factors such as high education and employment rates in this study sample may have influenced the seemingly high rates of QOL found. However, experiencing physical or mental health difficulties in addition to living with HIV was reported to impact on QOL.

In addition to the concept of QOL, an individual's mental and physical health have also been explored in association with QOL. Health-related quality of life (HRQOL) can be defined as an individual's state of physical and mental wellbeing. Balayan and Sudfeld (2020) explored the HRQOL of adults in Armenia living with HIV, finding that mental HRQOL scores were lower than physical HRQOL scores, and that emotional and social support were factors associated with higher HRQOL overall. Chapman Lambert et al. (2020) provide a further exploration of the HRQOL of adults living in the US. The authors found that women were more at risk of experiencing worse HRQOL than males. It was reported that experiencing a lack of social support, stigma, and depression contributed towards lower HRQOL in women. Despite the interesting findings in relation to QOL and HRQOL across the studies, they were carried out in countries outside of the UK (Finland, Armenia and the US, respectively). In addition, the studies focused on adult populations and therefore findings may not be applicable to children and young people living with HIV.

In relation to physical health in particular, studies have shown that people living with HIV may experience difficulties with medication adherence due to the experience of stigma. Turan et al. (2017), for example, reported that perceived community stigma can potentially lead to internalised stigma. This in turn can lead to anticipated stigma (i.e., expecting that you will encounter negative experiences due to HIV-status), which can have a detrimental impact on an individual's medication adherence. This finding is extremely concerning, as medication adherence is crucial in ensuring that the health needs of people living with HIV are met.

The literature outlined above in relation to QOL and HIV provides a further understanding of the impact of psychosocial factors on people living with HIV. However, QOL measures have been criticised for their lack of subjectivity and studies employing the construct have been criticised for their focus on the QOL of groups of patients as opposed to individuals (Carr & Higginson, 2001). Nevertheless, findings both from studies focusing on mental health difficulties and studies focusing on QOL make clear the fundamental need for young people living with and affected by HIV to access support to ensure that their physical health, mental health, and social wellbeing needs are met.

3.4 Stigma, disclosure, secrecy, and non-disclosure

3.4.1 Defining stigma

Stigma is the disqualification of an individual from full social acceptance (Goffman, 1963). Stigma is related to a process of being labelled, negatively stereotyped, excluded and discriminated against (Major & O'Brien, 2005). It may therefore be defined as related to the disapproval of and discrimination towards an individual based on social characteristics that serve to isolate them from other members of society. Sociologist Ervin Goffman (1963) highlights the fact that stigma has an impact over everyday interactions and those that are stigmatised may choose not to engage with people who are not part of the stigmatised group. Howarth et al. (2004) state that social representations, i.e., the systems of social knowledge generated about a particular phenomenon, can play a role in defending and maintaining stigma. The authors highlight the fact that stigmatising representations, in relation to health and illness, can have a detrimental impact on an individual's daily practice, interactions with others, and self-perception.

3.4.2 Stigma and HIV

Earnshaw and Chaudoir (2009) developed a conceptual model, the HIV Stigma Framework, in order to study the different forms of stigma experienced by people living with and without HIV. This framework refers to three distinct forms of stigma: i) anticipated, ii) internalised, and iii) enacted. These forms of stigma can affect people living with and affected by HIV. i) Anticipated stigma refers to the expectation that individuals will experience stigma due to their HIV status and therefore may be unlikely to disclose their status to others. ii) Internalised stigma is the process by which an individual applies the negative, stigmatised views of HIV held by some members of society to the self, i.e., accepting the stigmatised beliefs that have been directed towards them. Internalised stigma thus impacts on an individuals' self-esteem, emotional wellbeing, and mental health. Finally, iii) enacted stigma is associated with an individual's actual experiences of prejudice and discrimination related to their HIV status, e.g., being verbally or physically abused.

In addition to the aforementioned forms of stigma, Turan et al. (2017) refer to a further form of stigma experienced by people living with HIV: perceived stigma in the community. Perceived stigma in the community relates to an individual's perceptions surrounding the severity of the stigma that already exists in the community. Turan et al. (2017) state that this form of stigma is a further way in which people living with HIV are affected by stigma due to the potential association with the aforementioned forms of stigma.

Stigma is a significant issue for people living with and affected by HIV. The UK Stigma Index, a survey of more than 1,500 people living with HIV, found that a high proportion of people hold stigmatising views and negative attitudes towards both gay and heterosexual men living with HIV (Hibbert et al., 2018). Within this survey, participants reported that they were worried about and experienced gossip, sexual rejection, work-related difficulties, exclusions from social situations, and verbal and physical abuse. Another study, conducted by the National AIDS Trust (NAT) (2014), found that a considerable number of people had little awareness of how HIV is treated and how it can be transmitted. Taking the findings of these studies together, it may be the case that a lack of awareness and understanding of HIV that results in the stigmatising views held by people who are not living with or affected by HIV.

3.4.3 Stigma, HIV, and health outcomes

A significant amount of the HIV literature alludes to the association between HIV and different forms of stigma and health outcomes. A study by Rueda et al. (2016) identified the potentially negative impact of HIV-related stigma on both mental health and physical health, finding that people living with HIV can adopt damaging coping strategies, which can affect medication adherence[2] and treatment as a result of both anticipated and enacted stigma. In another study, Sweeney and Vanable (2016) reported that HIV-related stigma can have a detrimental impact on medication adherence for people living with HIV.

In addition to the negative impact of stigma on the social, emotional, and mental health of children and young people living with HIV, it may be that the stigmatising beliefs held by society can potentially impact on an individual's willingness to disclose their HIV status. The study carried out by Rueda et al. (2016) found that stigma can be a potential barrier faced by people living with HIV when

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[2] Medication adherence can be defined as the extent to which an individual follows the advice and recommendations from a health care provider (Brown & Bussell, 2011).

disclosing their HIV-status to a range of significant others, such as family, friends, and professionals.

3.4.4 Disclosure, secrecy, and non-disclosure

Many people living with HIV will experience disclosure, secrecy, and non-disclosure to varying degrees which may have a significant influence over their lived experience. Liamputtong (2016) states that these concepts are closely related to stigma. Through a perusal of the relevant literature, it was clear that disclosure occurs at different levels, such as between a parent and their child and between an individual and significant others (such as friends, family). In a study about parents and carers' disclosure of a child's HIV status to the child, Das et al. (2016) carried out interviews with 34 parents and carers of children, aged 8-15, living with HIV, in West Bengal, India. Das et al. (2016) found that the parents of children living with HIV involved in the study highlighted the fact that disclosing the HIV-status to children living with HIV is an important factor in that it can be associated with improvements in their medication adherence and ensuring that the child has access to sources of support. Further to this, it has been reported that disclosing HIV status can provide people living with HIV with increased social support (Liamputtong & Haritavorn, 2014). However, Das et al. (2016) also reported that the parents and carers involved in this study viewed personal and societal fears as barriers to disclosing a child's HIV status. These findings appear to relate to the concept of anticipated stigma as also highlighted by Rueda et al. (2016). In addition, participants involved in this study reported that the perceived reaction of peers was a potential barrier to disclosing HIV status to a child living with HIV. The fears reported by parents and carers in this study appear to reflect some of the reasons that people choose not to reveal their HIV status to wider society. Non-disclosure within the family has also been explored, with researchers stating that secrecy within families has led to feelings of isolation for children and young people living with HIV in British Columbia, Canada (Fielden et al., 2006). In this study, Fielden et al. (2006) carried out a qualitative case study of older children (9-16 years old) living with HIV, with participants reporting that stigma, sexual, and mental health were areas of concern for children and young people living with HIV.

Liamputtong (2016) reports that secrecy (i.e., non-disclosure) is a way in which people living with HIV hide their status as a result of belonging to a stigmatised group. This is reflected in a study carried out by Persson et al. (2016), who carried out interviews with 12 young people living with HIV in Australia. The authors stated that fears of stigma, discrimination, ostracisation, and being rejected can lead to secrecy, concealment, and non-disclosure. As stated previously, disclosing HIV status can lead to increased social support, and therefore, conversely, non-disclosure may lead to isolation.

3.5 Education and the community

Forming social and interpersonal relationships with others has been found to be a protective factor for people living with HIV and can play a role in alleviating the experience of mental health difficulties, such as depression, according to a meta-analysis by Rueda et al. (2016). In terms of the social support that may be useful to those living with and affected by HIV, it seems that educational settings may be a key protective factor for children and young people living with HIV with support offered by teachers and peers leading to positive experiences in educational settings. Although not yet extensively researched, in addressing this topic, Campbell et al. (2014) carried out exercises with 128 children aged 10-14 in rural Zimbabwe in order to explore their perceptions of the support school can offer to an HIV-affected peer. The authors found that children identified teachers, peers, distraction from suffering, and a sense of positive identity as key support mechanisms within educational settings. However, the children in this study also placed an emphasis on the physical, emotional, and social challenges that are faced by children living with HIV in rural Zimbabwe. These included social neglect, isolation and abuse in the home, physical ill-health, social isolation, bullying, and experiencing HIV-related stigma, to name a few. Moreover, they suggested that teachers were predominantly providers of material support (e.g., stationery) as opposed to emotional support. The findings from this study appear to provide an insight into the challenges that may arise in supporting children living with HIV within school settings, although it is worth noting that the HIV-status of the children participating in this study was not known to researchers, and that those who did participate were asked to reflect upon the experiences of ‘an HIV-affected peer’, rather than their own experiences.

In a later study, which focused on the perspectives of teachers also based in rural Zimbabwe, Campbell et al. (2016) found that teachers reported requiring additional recognition and resources in order to provide effective support for children living with HIV. In particular, the teachers in this study suggested that a higher level of systemic support from school settings would provide teachers with time, recognition, and links with local health, welfare, and community settings, and would therefore facilitate a greater level of support for children living with HIV. In addition, Andersen et al. (2014) highlighted the fact that establishing referral systems between the school and community settings (such as non-governmental organisations and community-based organisations), overcoming stigma, encouraging transparent communication between schools, teachers, community members, carers, children and young people, and supporting teachers, were important elements in enabling schools to create a supportive context in order to facilitate their ability to support children living with HIV.

Beyond research on the potential significance of education settings, charities and organisations that support children and young people living with and affected by HIV have been shown to provide a safe space for individuals to learn more about their diagnosis and to offer social support from peers and staff members. For example, Gillard et al. (2011) explored the outcomes of a camp for young people living with HIV, through carrying out observations, interviews, and focus groups. The authors found that the camp had been a positive experience for such young people, insofar as it exposed them to high levels of social support, social interactions, and increased opportunities for learning about HIV-specific issues. Further to this, Evangeli et al. (2019) carried out a quantitative evaluation of a camp for young people living with HIV, using a pre- and post-assessment to evaluate the camp intervention. The authors found that HIV knowledge acquired during the camp increased after the information sessions delivered during the camp and were maintained over time. Additionally, Lut et al. (2017) carried out a further qualitative study into the impact of the camp intervention. The children and young people reported that the camp offered them increased opportunities to form peer relationships, increased knowledge about both HIV and living with HIV, opportunities to develop a positive self-image, opportunities to engage with the HIV community, and increased self-confidence. These positive findings were corroborated by clinicians' reports of the impact of the camp on participating children and young people (Evangeli et al., 2019).

A study by Ipsos Healthcare (2014) highlighted teachers' experiences of working with children and young people affected by HIV. The study found that 39%

of teachers have never taught a lesson about HIV with 25% of participants reporting that they have taught a lesson about HIV but not considered whether one of the pupils may have been affected by HIV. In addition, many teachers were unaware of accurate information around the transmission of HIV.

The findings of these studies suggest that support at the community level for children and young people living with HIV appears to be a protective factor that allows some children and young people living with HIV to thrive. It is possible that the principles adopted within certain settings (e.g., the camp) could be adopted in other contexts, thereby raising awareness of HIV-related difficulties and potentially reduce stigma through disseminating knowledge. This study demonstrated some of the clear gaps in knowledge among teachers around supporting children and young people living with HIV in the UK.

3.6 Summary

Throughout this literature review, the multitude of psychosocial difficulties experienced by children and young people living with HIV have been outlined. Children and young people living with and affected by HIV are likely to experience difficulties with mental health, physical health, and quality of life. This can often be related to the different forms of stigma experienced by people living with HIV, which often appear to arise from a lack of education and understanding of HIV in society around how it is transmitted and treated. A clear limitation of the studies highlighted throughout this literature is the fact that there appears to be a lack of qualitative studies exploring the lived experiences of children and young people living with HIV and a significant lack of exploration into children and young people’s educational experiences in the UK. Previous research appears to be predominantly quantitative, widely focuses on adult populations, and is frequently based outside of the UK. The qualitative studies reported in this literature review that gather the views of children and young people living with HIV (Andersen et al., 2014; Campbell et al., 2014; Campbell et al., 2016; Fielden et al., 2006; Gillard et al., 2011; Lut et al., 2017; Persson et al., 2016; Petersen et al., 2010) are based on school settings outside of the UK or focus on the impact of camp interventions within the UK. Therefore, there is a clear need of a qualitative study in the UK that explores the lived experiences and educational experiences of young people living with HIV. It is also important to explore some of the protective factors that have allowed some young people to thrive in school and community settings. This information will help to raise awareness and understanding among professionals working with children and young people living with HIV. It will also serve to change the narrative around HIV and reduce HIV-related stigma and discrimination.

3.7 Theoretical approach

This section will outline the theoretical approach adopted in order to carry out this research. Bronfenbrenner’s (2005) Process-Person-Context-Time (PPCT) model, a developmental model, was utilised as it focuses on the systems around a child, thus providing an ideal way of exploring the protective factors for young people living with HIV. In addition, Social Representations Theory (Moscovici, 1961, 1988, 2000), a social model, was used to underpin this study and was a lens through which to explore the research questions, as it lent itself to exploring the lived experiences of young people living with HIV.

3.7.1 Process-Person-Context-Time (PPCT) model

Bronfenbrenner's (1979) Ecological Systems Theory offers the perspective that human development can be understood within a context of inter-related systems, with the developing individual at the centre. These inter-related systems initially included the individual level, microsystem level, mesosystem level, exosystem level, and macrosystem level. Bronfenbrenner (1989) extended the model to include the chronosystem level (see Figure 1), with each system detailed below.

Individual level. The individual, or the person as referred to in the PPCT model, is placed at the centre of a framework surrounded by different contextual levels.

Microsystem. The 'microsystem' includes the individual and their immediate setting, such as the family, peer group, school, etc. This level clearly includes social support, which been widely explored as a significant factor for children and young people living with HIV in the literature review.

Mesosystem. The 'mesosystem' refers to the interactions between the different settings within the microsystem, i.e., how the different settings (e.g., family and school) communicate with each other. It will be important to consider the influence of the microsystem on an individual within this research due to the issues around disclosure and non-disclosure as reported in the literature review (Liamputtong, 2016).

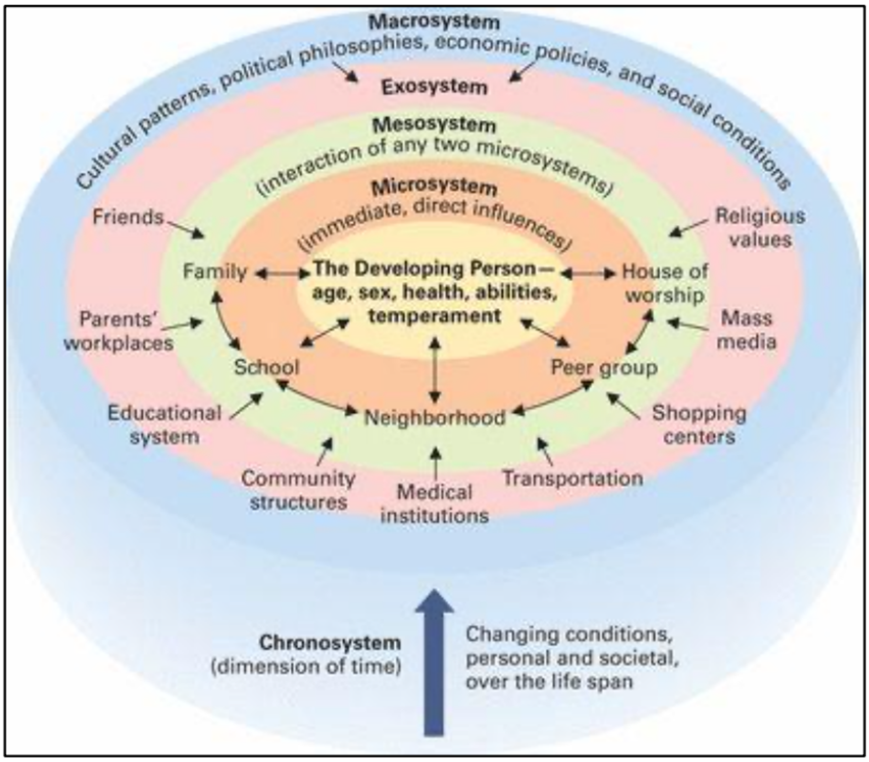
Exosystem. The 'exosystem' includes systems that are not directly linked to the individual, but may have an indirect influence on their development, for example, the media, social care, legal services, and frameworks for people living with HIV. In relation to the present research study, charities and organisations that arrange camps for young people living with HIV fall into this level of support.

Macrosystem. The 'macrosystem' considers the wider social and cultural values and belief systems, for example, the government, and the impact these systems have on an individual's development. The macrosystem will consider the impact of stigma on children and young people living with HIV (Earnshaw & Chaudoir, 2009).

Chronosystem. The ‘chronosystem’ refers to development of a child across these different levels over time.

Figure 1

Bronfenbrenner’s (1989) Ecological Theory of Development



Bronfenbrenner critiqued his earlier work and developed his theory to include the concept of proximal processes. Bronfenbrenner’s (2005) PPCT model considers the process, person, context, and time as factors affecting an individual’s development, and is detailed in Figure 2.

Process. The ‘process’ element of the model refers to the fact that the relationship between an individual and their context is dynamic and therefore changes over time. Considering proximal processes appeared to be an appropriate lens through which to explore the lived experiences of children and young people living with HIV, as their relationship with society may be extremely dynamic depending on their disclosure or non-disclosure.

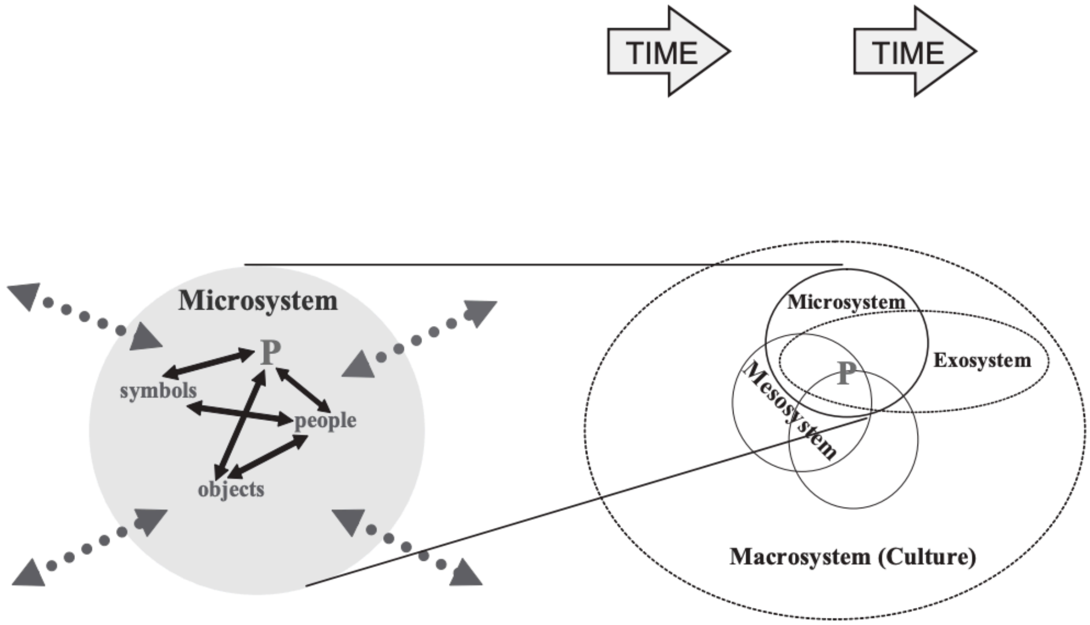
Person. The ‘person’ element of the model focuses on demand characteristics, such as gender, ethnicity, and age, resource characteristics, such as developed skills, and force characteristics, such as temperament. Tudge et al. (2009) posit that the PPCT model highlights the role of the individual in changing their context, both passively (through being present in the environment and reacting to others and being reacted to by others differently in relation to demand characteristics) and actively (through the ways in which the person changes their environment in relation to resource characteristics and force characteristics). It will be important to consider the ‘person’ element of the model in order to explore the ways in which children and young people living with HIV’s demand, resource, and force characteristics influence their interactions with their environment.

Context. The ‘context’ element refers to the aforementioned inter-related systems within Bronfenbrenner’s Ecological Theory of Development.

Time. The ‘time’ element of the model refers to immediate experiences, consistency, historical events, and length of time.

Figure 2

Bronfenbrenner's (2005) PPCT model (Tudge et al., 2012).



This research study is underpinned by Bronfenbrenner's early ecological systems theory and will also consider his developed PPCT model to explore the lived experiences of CYP living with HIV and how best to support them in educational and community settings.

3.7.2 Social Representations Theory

Social Representations Theory (Moscovici, 1961, 1988, 2000) is considered to be a Social Constructionist approach to understanding the world and forming assumptions about reality. Social Representations Theory emerged in response to a crisis in social psychology (Farr, 1996), and Moscovici (1972) sought to explore what the focus of study within the discipline should be. He initially introduced Social Representations Theory through his exploration of the ways in which psychoanalysis, a relatively novel phenomenon at the time, was interpreted by different social groups in France, titled “La Psychanalyse, son image et son public” (Moscovici, 1961). For him, the purpose of social representations was to make familiar something that is novel or unfamiliar (Moscovici, 1984). Common sense knowledge and understandings are at the forefront of the theory, with social representations being described as:

> systems of values, ideas and practices with a twofold function; first, to establish an order which will enable individuals to orient themselves in their material and social world and to master it; and secondly to enable communication to take place among the members of a community by providing them with a code for social exchange and a code for naming and classifying unambiguously the various aspects of their world and their individual and group history. (Moscovici, 1973, pp. xiii)

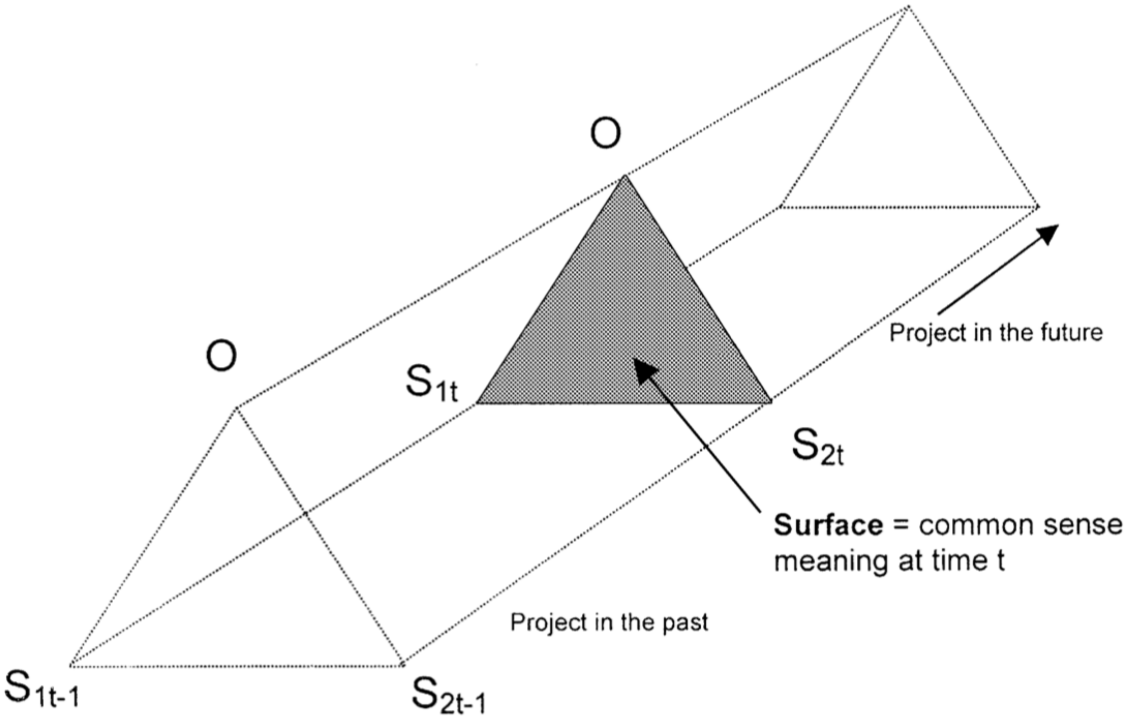
The process of forming a social representation involves a triadic relationship between the self, a social other (such as another individual, another group, or the media), and an object. This triadic relationship has been conceptualised in a range of visual models, such as the Toblerone Model (Bauer & Gaskell, 1999), the Wind Rose Model (Bauer & Gaskell, 2008), and the Sociogenesis of Social Representations (Wagner et al., 1999). The Toblerone Model will be of particular relevance to this study and is highlighted in Figure 3. Within this model, the authors highlight the relationship between two subjects (S) and an object (O), which is the relationship through which we make meaning. This model also includes an element of time and demonstrates the fact that it is important to consider this meaning-making process within the context of time. Therefore, Bauer and Gaskell (199) include projections (P) across past (shown as S1t-1 and S2t-2 in Figure 3 to demonstrate past understandings), present (shown as S1t and S2t in Figure 3 to demonstrate understandings at time t), and projections into the future within this model.

Duveen (2001) highlights that there is a key focus on collective and shared representations, which is closely associated with the social psychology field. Flick and Foster (2008) argue that the social process of forming social representations, which are developed through social groups sharing and drawing on existing knowledge, become the way in which individuals understand the world. In addition, social representations can be viewed as beliefs shared by members of certain groups, which aim to provide a social function in that it facilitates communication and can influence behaviour (Joffe, 1996).

In their study of the role of social representations in community-based health research, Howarth et al. (2004) state that Social Representations Theory places a significant emphasis on the relationship between expert and lay forms of knowledge, the maintenance of stigmatising views and practices, and the impact on identity and wellbeing.

Figure 3

The Toblerone Model of social representations, depicting the meaning-making process over time (Bauer & Gaskell, 1999)



Exploring expert and lay forms of knowledge. Social Representations Theory alludes to two distinct forms of knowledge, reified and consensual universes, in order to conceptualise the difference between expert forms of knowledge (such as science) and lay forms of knowledge (such as common-sense understandings). The approach considers the differences between expert and lay forms of knowledge in relation to how social representations are formed. Social representations are formed through communication and social interactions and therefore relate to the values and beliefs of society. Social Representations Theory is concerned with the process by which expert knowledge translates to lay knowledge. Expert knowledge predominantly transforms to lay knowledge through processes such as mass media and mass communication. Joffe (1996) reported that lay knowledge around AIDS in Great Britain and South Africa was developed through mass communication despite the fact that little was known about the phenomenon. Therefore, expert knowledge was transformed to lay knowledge through the media. Within this research study, children and young people living with HIV will be forced to interpret and understand expert knowledge from professionals, such as doctors and nurses, and form their own social representations around this information which may impact on their wellbeing and behaviour.

Howarth et al. (2004) report that different groups are likely to hold different social representations due to the fact that there are multiple systems concerning social phenomena. The authors consider the significant contribution of social, economic and political factors on forming social representations and highlight the fact that these factors can lead to inequalities around health experiences and access to treatment. Howarth (2001) states that social representations can contribute towards sustaining social exclusion through the marginalisation of people labelled as ill.

It is important to consider the ways in which social representations are developed in response to unfamiliar or novel phenomena. Anchoring, objectification, and naturalisation are processes that contribute towards the formation of social representations.

Anchoring, objectification, and naturalisation. Moscovici (2000) refers to the concepts of anchoring and objectification as processes in which new concepts become transformed into lay knowledge and thus perceived as less threatening. Anchoring is a process through which unfamiliar concepts are compared to prior knowledge in order to assimilate the new or novel ideas or phenomenon into pre-existing frameworks as a means of making sense of the new concept. The process of objectification differs in that it focuses on the ways in which complex concepts and phenomenon are presented visually in order to provide more concrete understandings. In addition, Philogene (1994) discusses naturalisation as a process which concludes the transformation of the novel concept into social reality by becoming validated by social interaction and communication.

The relationship between identity construction and social representations. The relationship between identity construction and social representations has been widely explored by Social Representations scholars. Moscovici (1973) makes reference to key functions of social representations as allowing for personal orientation and interpersonal communication. This concept of personal orientation seemingly speaks to the ways in which individuals seek to develop a sense of belonging through the process of identity construction. Howarth et al. (2004) make reference to the relationship between social representations of health on an individual's identity. The authors further reflect on the function of social representations, stating that representations are utilised to communicate, develop connections, and identify differences between social groups. An important point to note here, is the debate around whether social representations precede social identities or vice versa (Duveen & Lloyd, 1990). However, some scholars have argued that this is dependent on the case (Duveen, 2001; Duveen & Lloyd, 1990). The latter argument is that which will be considered throughout this study due to the dynamic nature of identity construction and social representations.

Dominant social representations can serve to stigmatise and marginalise minority groups, such as people living with HIV, through stigmatising views, prejudice, discrimination, and the use of negative labels. However, Duveen (2001) refers to the ways in which individuals from marginalised groups can resist and reject the negative representations of others. This notion was reflected in Howarth's (2002) research into the ways in which young black teenagers adopt strategies to protect their sense of self, i.e., their identity. Therefore, it appears that individuals belonging to minority groups, such as people living with HIV, develop protective factors in order to develop positive social representations and construct their own identities and sense of self in response to the negative representations held by others in society. Adopting these positive representations and identities can be a method of empowering individuals and groups and changing the dominant discourse.

A further key point to consider is the notion of an identity project, a concept that sheds light on the fact that identities can change and develop over time (Bauer & Gaskell, 1999). This will be an important point to consider in this research study as the lived experiences of children and young people living with HIV will be explored. This group are forced to make sense of the expert knowledge delivered by doctors and nurses, and therefore their representations and identities are likely to change and develop over time.

3.7.3 Summary

Bronfenbrenner's (2005) PPCT model will be used in the present study in order to explore the systems around young people living with HIV and how these have been supportive or unsupportive. In addition, the changes in these experiences over time will be considered. Social Representations Theory will be utilised to explore young people's lived experiences of living with HIV both in society and school settings and to analyse the ways in which young people make sense of an unfamiliar concept and the range of expert information that they are expected to understand in relation to their medical condition.

Chapter 4: Methodology

This chapter outlines the underlying paradigms used in this research, the research design, the procedures used for data collection and data analysis, and the ethical issues considered throughout the research study.

4.1 Epistemological and ontological position

A social constructionist approach was the underlying philosophy employed to undertake this research study. Social constructionists place significant emphasis on the importance of language and the social interactions between individuals (Burr, 2003). Those adopting the perspective of social constructionism acknowledge that everyday social interactions between individuals facilitate the development of meaning, knowledge, and an increased understanding of the world (Liamputtong, 2019). For this reason, a social constructionist approach was the most appropriate means of eliciting the views of children and young people living with HIV in order to understand their lived experiences.

Robson and McCartan (2016) report that critical realists view knowledge as a social and historical product in which reality is viewed as complex and made up of different layers, such as the individual, group, and societal. These layers are closely related to the systems highlighted in Bronfenbrenner’s (2005) PPCT model and thus closely relate to the underlying theoretical approach to this research study.

The critical realist perspective is best understood as a combination of ontological realism, epistemological relativism, and judgemental rationalism (Booker, 2021). Therefore, in accordance with the work of Willig (2008) and Nightingale and Cromby (2002), who allude to a critical realist constructionism as having greater utility than alternative approaches, this study adopts a critical realist perspective that is compatible with its epistemological foundation.

Related to this, is the important assumption of ontological realism; that ideas exist independently of our knowledge about them. This refers to the fact that the world existed before and after we are born and therefore our individual existence is temporary (Pilgrim, 2020); and is related to the intransitive reality, i.e., the notion that some mechanisms exist regardless of human existence.

Epistemological relativism refers to the notion that knowledge is socially constructed, and relates to the transitive reality, i.e., the fact that knowledge can change over time. Pilgrim (2020) highlights the fact that we interpret the world, reflect on it, and discuss it. These interpretations develop over time. This then appears to fit within the realm of the other important theory I draw from, Social Representations Theory, which posits that our representations can change and develop over time. This will be of particular relevance to this research study in its focus on the meaning-making and lived experiences of children and young people living with HIV over time. Epistemological relativism highlights the fact that all knowledge is fallible.

Alderson (2021) refers to judgemental rationalism as an individual’s ability to reflect on ontology, epistemology, and morality in order to consider alternative futures. The consideration of alternative futures is important in this research study, as I set out to consider appropriate support mechanisms for children and young people living with HIV through an exploration of their views and lived experiences.

The adoption of the critical realist perspective thus allowed me to place emphasis on the importance of the meaning-making of participants, but also acknowledge the fact that participants are referring to a world that exists outside of their meaning-making, in line with Social Representations Theory.

Scholars of critical realism also refer to the importance of methodological pluralism, i.e., the use of a range of different research methods. As previously highlighted, methodological pluralism is a key feature of Social Representations Theory, and thus highlights the synergies between the epistemological and ontological positions of this work. Similarly, Robson and McCartan (2016) allude to the emancipatory approach of critical realism. This is considered to be of significant importance to this research study, as I seek to explore the views of a group of children and young people who are highly likely to experience stigma, prejudice, and discrimination, and consider appropriate support mechanisms for children and young people living with HIV.

The focus on language and social interactions within the social constructionist perspective lends itself to the use of qualitative approaches in order to explore how individuals understand issues (Creswell & Creswell, 2018). The use of interviews with open questions and responses are commonly utilised by social constructionists. This approach is an ideal method for gaining the views of children and young people living with HIV. Moreover, the critical realist perspective is useful in terms of understanding and making recommendations for best practice, which aligns with the aims of the study.

4.2 Research design

As stated in Chapter 2.3, the research questions that were addressed in this study were:

1. What are the lived experiences of children and young people living with HIV?
2. What are some of the protective factors that have supported children and young people living with HIV?
3. What are the educational experiences of children and young people living with HIV?

4. To what extent does the information, advice and guidance provided by charities and organisations align with the views of children and young people in relation to their lived and educational experiences?

Willig (2013) states that qualitative methods allow participants to challenge and question the researcher. Such methods often take place in the participants' environment (such as schools, youth settings), and include an element of reflexivity such that the researcher is continuously reflecting on their role within the research (the notion of reflexivity is further discussed in Chapter 4.6). Willig (2013) refers to semi-structured interviews as the most commonly used method of qualitative data collection. This interviewing technique lends itself well to exploring the experiences of individuals. Flick and Foster (2008) also argue for the use of qualitative methods, such as open interviews and focus groups, to carry out research in order to understand people's perspectives within their own context and to consider the impact of additional factors in a person's social life. Social Representations Theory (one of the main theories I am using) has been widely used to make sense of or to understand science, health and illness, mental health, and community research (Joffe, 1996; Philogene, 1994; Howarth et al. (2004). The same is also true of Bronfenbrenner's PPCT model (Eriksson et al., 2018; Hayes, 2021).

The present study adopted a multi-strategy design, using two methods of qualitative data collection, in-depth semi-structured interviews, and a qualitative content analysis, in order to explore the aforementioned research questions. Scholars refer to the methodological pluralism of Social Representations Theory, which provides flexibility in terms of research methods and approaches. Research adopting this approach often incorporates a triangulation of different methods. The in-depth semi-structured interviews were utilised in order to gather rich data from participants and explore the situations and experiences of children and young people living with HIV. These interviews were conducted remotely through the use of Microsoft Teams, a video conferencing platform[3]. The in-depth semi-structured interviews addressed research questions 1, 2, and 3. Flick and Foster (2008) allude to the analysis of representations in newspapers, television, etc. as important due to the significant role of the media. Therefore, the qualitative content analysis was completed in order to analyse the documentation, information, audio and video files available to support young people living with HIV on the websites of three of the largest charities and organisations for children, young people and families living with HIV in the UK. This analysis sought to explore research question 4.

4.3 Participants, sampling, and recruitment

Participants were considered for this study if they were living with HIV and aged between 12 and 25 years old. Participants were recruited through pre-existing links between the researcher and a professional who works for an organisation that specialises in supporting children and young people living with HIV in the UK. Due to the sensitive nature of the research, the gatekeeper suggested the most appropriate children and young people to take part in the study during the time of data collection (January 2021). Therefore, a purposive sampling method was adopted. A total of seven participants took part in the study (see Table 1 for information about participants).

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[3] The interviews were conducted remotely due to the government enforced lockdown as a result of the Covid-19 pandemic.

Table 1

Table of participants

Pseudonym	Gender	Age	Migrated to the UK?	Gatekeeper Present?
Sarah	F	20	Yes	Yes
Ellie	F	19	No	Yes
Josh	M	20	No	No
Eva	F	14	No	Yes
Amelia	F	17	No	Yes
Georgia	F	22	Yes	No
Caroline	F	24	Yes	No

The information included in this table, such as whether participants were born in the UK or migrated to the UK, will be referred to in findings and discussion sections, in order to explore differing representations between children and young people living with HIV.

The research study was introduced to potential participants through a research advert (Appendix A), which included information about the researcher, the research study, and the purpose of the research. The research advert was disseminated by the gatekeeper and the researcher to a range of children and young people living with HIV associated with the organisation. Due to the government enforced lockdown as a result of the Covid-19 pandemic, it was not possible to meet with the children and young people associated with the charity in person (e.g., at events), in order to further discuss the research study and provide the opportunity to express their interest in engaging in the research. This posed challenges, as meeting potential participants in person would have provided an important opportunity to build rapport with some of the children and young people whom the organisation supports. In order to overcome this issue, I met with a small group of children and young people remotely in order to introduce myself, the research study and provide an opportunity to reflect on the draft interview schedule questions. This remote meeting took place on Zoom, the video conferencing platform used primarily by the organisation during the Covid-19 pandemic. Once children and young people expressed interest in taking part in the study, information sheets and consent forms (Appendix B & C) were disseminated to both participants and their parents or carers (if under 16) by the gatekeeper in order to provide additional information about the study. Further to this, participants who took part in the study had already consented to participating in research studies and projects through their role and involvement in the organisation. Participants were provided with the opportunity to discuss the information sheets and provide informed consent before taking part in the study.

4.4 Procedures for data collection and analysis

The research study gained ethical approval from the UCL Institute of Education Research Ethics Committee (Appendix D).

4.4.1 In-depth semi-structured interviews

Participants were invited to take part in a remote interview via Microsoft Teams. As the age of participants ranged from 12-25 years old, the interview schedule was tailored to meet the needs of different age groups. This provided me with the opportunity for a deeper exploration of participants' responses, where appropriate (see Appendix E for interview schedule). Interviews ranged from 40-80 minutes. The gatekeeper offered to be present during the interview for participants due to the sensitive nature of the interview. It was thought that this would provide the participants with a sense of safety, security, and containment, and increase their likelihood to feel comfortable in participating in the interview. In addition, participants were offered the opportunity to debrief with the gatekeeper and reflect on the process, without the presence of the researcher, after the interview took place.

It was considered that the remote nature of the interviews would lead to various limitations. Considering the context in which this research study was taking place, i.e., during the Covid-19 pandemic, was of significant importance. Researchers have alluded to the ethics of recruiting people to participate in interviews during the Covid-19 pandemic, the lack of time participants may have, and considering the fact that this may be a particularly anxious time for many people (Faircloth et al., 2021). In addition, it was thought that it would be challenging to establish rapport with participants remotely, and therefore it was necessary to ensure time and space to get to know the participants further and establish rapport before starting the interview process. Further to this, Musselwhite et al. (2007) state that a limitation of conducting interviews remotely is the fact that it can cause difficulties in engaging participants and limits the amount of non-verbal communication that is gathered within regular face-to-face interactions. However, due to the sensitive nature of the research, it was considered that the participants may experience a sense of safety and security in the fact that they would not have to take part in a face-to-face interview.

Once the interviews were completed, they were transcribed verbatim. Interview transcripts were anonymised, and thus did not include any of the participants' personal data or identifying information. The interview transcripts for each participant were analysed through the use of Thematic Analysis (TA) (Braun & Clarke, 2006), an approach to analysis that has been employed when using Social Representations Theory as a lens through which to carry out research (Herzlich, 1973). TA involves identifying codes in the data, i.e., applying labels to relevant parts of the data, sorting codes into themes that appear to map onto the research questions, and undertaking a process of reviewing, defining and naming themes (Clarke & Braun, 2013). It was decided that TA would offer an accessible and flexible approach for identifying and analysing themes within the data (Robson & McCartan, 2016). Braun and Clarke (2006) refer to six phases of TA: familiarisation, coding, searching for themes, reviewing themes, defining and naming themes, and producing the report, which will be addressed below.

Familiarisation (Phase 1). After transcribing the interviews verbatim, I read and re-read the data in order to familiarise myself and become immersed in the data collected.

Coding (Phase 2). After familiarising myself with the data, I continued to read through the transcripts in order to develop a greater understanding of some of the patterns arising from the data. I began to generate initial codes through identifying relevant and interesting sections of the data, e.g., those related to school and disclosure. These sections of the data were highlighted and coded through the use of the software Nvivo. In addition, two of the interview transcripts were coded separately by myself, my supervisors, and a peer. The codes generated (Appendix F) were discussed in order to ensure the validity of the research. This process supported the generation of initial subthemes and themes and ensured that some of the codes made sense to a range of audiences.

Searching for themes (Phase 3). During this phase, I read through all of the codes in order to search for patterns and these were collapsed in order to form more meaningful initial themes that addressed the research questions. At this stage, I developed an initial thematic map, in which groups of codes made up the subthemes, which fell under an overarching main theme. Initially, seven themes were generated, which included ‘Learning more about HIV’, ‘Experiences of taking medication’, ‘Information sharing’, ‘Stigma, prejudice, and discrimination’, ‘Protective factors and coping mechanisms’, ‘Impact on emotional wellbeing and mental health’, and ‘Educational experiences’.

Reviewing and defining themes (Phase 4 and 5). Further discussions with my supervisors supported the reviewing and defining of themes. The initial themes were developed and revised in order to collapse the seven themes. The use of Social Representations Theory supported this process in order to consider the themes in relation to the participants’ different representations of HIV. In addition, Bronfenbrenner’s (2005) PPCT model supported the development of themes in relation to the systems around young people living with HIV. Thematic maps were then generated and further condensed (Appendix G & H) in order to define the final themes: ‘Representations of HIV’, ‘The physical and mental health of young people living with HIV’ and ‘Systems around young people living with HIV’. These themes, along with the subthemes, were illustrated in the final thematic map (Appendix I).

Producing the report (Phase 6). The final phase involved producing a report of the findings from the data collected through the interviews with young people living with HIV. This involved presenting key quotations that were related to each subtheme and main theme and reflecting on the literature and theory related to the quotations.

4.4.2 Qualitative content analysis

The qualitative content analysis involved analysing the content available on the websites of three key charities and organisations that support children, young people and families living with HIV in the UK. The websites appeared to have a range of target audiences, such as children, young people and adults living with HIV, parents, and professionals. A search of relevant material was carried out based on the key findings from the literature review of Chapter 3, i.e., content related to stigma, disclosure, secrecy, non-disclosure, medication, medication adherence, mental health, emotional wellbeing, and education.

Macnamara (2005) describes qualitative content analysis as a method that analyses the relationship between text and the meaning the text is likely to have for its audience. The method relies on the researcher’s interpretation and understanding of texts in order to provide an in-depth exploration and examination of the meaning the text has for its range of different audiences. Neuendorf (2017) also reflects on the significant role of the researcher, alluding to the importance of the human contribution (as opposed to the use of computers) towards content analysis. Macnamara (2005) highlights the fact that text analysis, which is the predominant method used to carry out a qualitative content analysis, draws on narratology and semiotics. Narratology is described as the narrative present within the text and the meaning that is elicited through the choice and use of words. This differs from semiotics, which focuses on the signs within texts and how these may be interpreted by the reader. Neal (2013) refers to semiotic analysis as an approach that focuses on assigning meaning.

In accordance with the methods utilised during a qualitative content analysis, narratology and semiotics were used to analyse the text available on the three websites. In addition, the transcription of audio and video files was carried out in order to collect further data available on the websites. Initial codes were produced to organise the data. Once these codes were produced, they were grouped together to generate broad themes. These themes were ‘HIV-related information’, ‘School-related information’, ‘Talking about HIV with others’, ‘Stigma’, and ‘Emotional support’. Deeper exploration of the text and further collapsing of the themes led to the generation of the three final themes: ‘Being part of a collective’, ‘Supporting the development of understanding expert knowledge’, and ‘Supporting the development of understanding psychosocial issues’.

4.5 Materials

The materials that were used in this study included a password-protected laptop, an interview schedule, and interview transcripts. Interviews were carried out on Microsoft Teams and recorded using the record function on the video conferencing platform. Microsoft Stream, a video service, was used to store the recordings during the transcription of the data in order to ensure data security. NVivo was used to organise and analyse the data.

4.6 Reflexivity

Creswell and Creswell (2018) refer to reflexivity as the process by which a researcher considers the ways in which their own personal beliefs, values, culture, and past experiences have the potential to shape the meaning and interpretations that they ascribe to the data. These may include for example, the ethnicity, culture, socioeconomic status, past educational or work experience, that directly link the researcher to the research. Yardley (2000) further states the importance of highlighting the assumptions, intentions, and actions that may influence the research study. In addition, Flick (2018) states that researchers' subjectivity and reflections become part of the process of the research. I adopted a reflexive stance throughout the research study, and discuss my positioning, beliefs, and relationship with the organisation below.

4.6.1 Researcher positioning

I am a young male of Black African and White British heritage and identify as mixed race. I previously held a voluntary role supporting children and young people living with and affected by HIV, while working for a charity in London. My previous experience led me to pursue this research topic in order advocate for children and young people living with HIV and explore their educational experiences. Therefore, it was important to reflect on my positioning within the interviews in order to ensure that I adopted a neutral, non-biased stance. In addition, the majority of participants were from Black or mixed-race backgrounds, and therefore my own identity may have had an influence on the nature of the interviews, such as how the participants related to me, addressed the interview questions, and how I interpreted their responses. My current role is a researcher and Trainee Educational Psychologist (TEP) working for a Local Authority in an inner-London borough. Through my role as a TEP, I am constantly engaging in reflective and reflexive practice. In addition, promoting equality and diversity is a fundamental element within my role. Therefore, this may influence my understanding of the experiences of the participants.

I believe that there remains a strong stigmatised view of people living with HIV, which has become apparent through my experiences of the media, the use of language within society, and the experiences shared by children and young people living with HIV during my previous voluntary role. Therefore, I have a strong interest in advocating for people living with HIV in order to continue to attempt to change some of the stigmatising beliefs held within society and to consider the ways in which children and young people living with HIV can be better supported within the different settings they interact with, for example, school. I believe that as a TEP, I am well-placed to promote change and provide support to schools who are supporting the needs of children and young people living with HIV.

I believe that it was important to consider the fact that I was not associated with the organisation in which I conducted the research study. Therefore, I did not have well-established relationships and connections with the children and young people who took part. It was also important to make explicit the fact that my research was separate from the work of the organisation so that participants felt comfortable in sharing as much and as little as they felt comfortable. In addition, I ensured that the participants were aware of the reasons for my interest in conducting the research and my previous work experiences.

4.7 Ethical and Professional Considerations

This study was submitted for ethical approval to the UCL Institute of Education Research Ethics Committee. The British Psychological Society (BPS)’s Code of Ethics and Conduct was used to ensure that the research was adhering to the BPS ethical guidelines. The following issues were addressed i) sampling, recruitment, and gatekeepers, ii) informed consent, iii) privacy and confidentiality, and iv) wellbeing of participants.

4.7.1 Participants, sampling, recruitment & gatekeepers

As participants were recruited through an organisation that supports children and young people living with HIV using pre-existing links, it was considered that it was likely that the purposive sampling method employed will potentially pose some bias. The gatekeeper selected the pool of potential participants, and therefore it was thought that there may not have been opportunities for all children and young people living with HIV's voices to be heard. In addition, children and young people were associated with the same charity, and therefore it was essential that participants committed to ensuring that they did not disclose details of their participation to others, so that they could not be identified by other children and young people associated with the organisation. The gatekeeper was not involved in each interview, and only attended those at the request of the participant.

4.7.2 Informed Consent

Participants and the parents of participants under 16 years of age were provided with an information sheet and consent form (Appendix B & C) so that they were able to provide informed consent to take part in the study. In addition, participants were asked to provide informed consent at the start of the interview and their consent for the interview to be audio-recorded.

4.7.3 Data storage, privacy, confidentiality, and anonymity

During the remote interview process, it was essential to state that participants were able to ensure that they were able to carry out the interview in a safe, private environment (where possible) so that their responses remained private. Interview recordings were saved using Microsoft Stream in order to ensure data security. Interviews were anonymised during the process of transcription and the interview transcripts therefore did not contain any personal data or identifying information that could reveal participants' identities.

4.7.4 Wellbeing of participants

Participants included children and young people living with HIV, a vulnerable group, and therefore it was essential that participants were aware of the fact that they had the right to refuse or withdraw from the study at any point in time without having to provide any reasoning. Due to the sensitive nature of the study, it was essential to identify the Designated Safeguarding Lead at the organisation prior to the research commencing, and it was important to discuss the protocol for reporting concerns in order to escalate any safeguarding issues that arose through the interview process with the gatekeeper whom I was liaising with. Participants were made aware of this protocol.

In addition, this study explored a sensitive, personal area of research, and therefore it was considered that some participants would potentially find the discussions upsetting. Participants were informed at the start of the interview that they did not have to answer any questions they did not wish to. In addition, an invitational approach to answering sensitive, difficult, or probing questions was adopted in order to ensure that participants were aware that they did not have to answer any questions that they were uncomfortable answering. If participants became upset during the interview but wished to continue with the study, they were given the opportunity to pause the interview and seek support from either the researcher, Designated Safeguarding Lead or gatekeeper within the charity or organisation. In addition, the gatekeeper offered to be present during the interview if participants wished. During the interview, I encountered a situation in which a young person was finding it difficult to discuss HIV at length as they felt that this was the most they had spoken about HIV in a significant amount of time. However, we paused the interview, discussed the fact that they could opt out, avoid answering any questions they did not want to, and seek support from either the Designated Safeguarding Lead or gatekeeper. In this case, the young person wished to continue the interview and was happy to proceed with the remaining questions.

Participants were offered an opportunity for a debrief once the interview was completed and were invited to receive a copy of a research briefing, detailing the outcomes of the study. Findings will also be disseminated to the organisation upon completion of the research study.

Chapter 5: Findings from the in-depth semi-structured interviews with young people living with HIV

This chapter will present the analysis of the seven in-depth semi-structured interviews carried out with each young person. As discussed in the previous chapter, Thematic Analysis (TA) was used to analyse the interviews, which focused on addressing the following research questions:

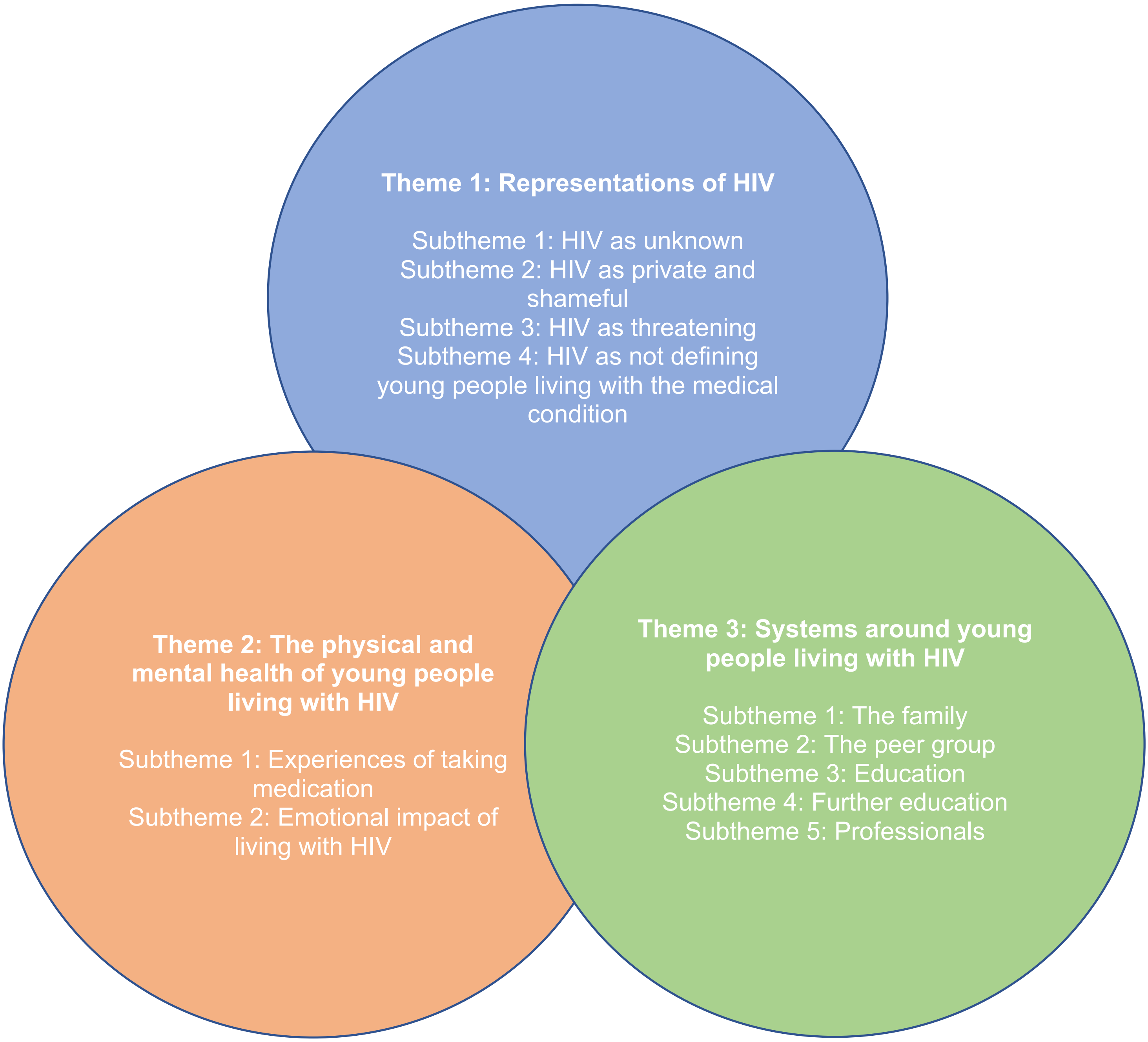
1. What are the lived experiences of children and young people living with HIV?
2. What are some of the protective factors that have supported children and young people living with HIV?
3. What are the educational experiences of children and young people living with HIV?

Throughout this chapter, the results of each theme will be presented alongside separate subthemes. I will also draw on theory and relevant literature to explore the significance of the themes and to support the arguments that I have presented in the analysis. Quotes from the interviews will be used to illustrate and explain themes.

Three themes and eleven subthemes were generated through the TA, with several of the subthemes cutting across themes (see Figure 4).

Figure 4

Thematic Map outlining the three themes and eleven subthemes generated from the data collected through the in-depth semi-structured interviews with young people living with HIV.



5.1 Theme 1: Representations of HIV

Theme 1, ‘Representations of HIV’, explores the range of different representations that emerged from the interviews, and aimed to address research question 1. Subtheme 1 explores young people’s initial representation of HIV as unknown. This initial representation was formed when young people received their diagnosis of HIV, which was predominantly delivered by a healthcare professional, such as a nurse or doctor. Young people’s initial interactions with family shed light on the importance of concealment, secrecy, and non-disclosure. For most participants, HIV was an unspoken topic and young people living with HIV frequently viewed the medical condition as ‘shameful’, which led to the concealment of their HIV status, ensuring that HIV was kept ‘private’. Further to this, experiences in the peer group, the education system, and wider society, led to young people forming representations of other people’s representations around HIV, which are predominantly around HIV as ‘threatening’. However, participants’ opportunities to interact with other young people living with HIV was supportive in helping them to develop a positive mindset and form a representation that HIV does not define them.

5.1.1 Subtheme 1: HIV as unknown

Subtheme 1 revolves around participants’ initial experiences of being diagnosed with HIV and having little understanding about this diagnosis. This stage was the catalyst for the meaning-making process participants undertook in order to explore more about their diagnosis and their new identity as a young person living with HIV.

The young people’s understanding of HIV as a medical condition appeared to vary significantly in relation to whether they were born in the UK or migrated to the UK. Young people born in the UK frequently reported that when they were diagnosed with HIV, they were unaware of what the medical condition was and how it affected them. Therefore, at this stage, the majority of the young people did not appear to hold a representation of HIV as a medical condition, with one participant, Josh, sharing that he:

“… didn’t really understand what was like… going on… I just took it as OK and I didn’t really like… I guess at that age I didn’t understand properly what it was”.

However, Sarah and Caroline, who both migrated to the UK from Southern Africa, appeared to have an existing representation of HIV as a medical condition prior to their diagnosis, with Sarah stating that she:

“…read the leaflets and we had done it in school… I learned about it in school… So I was like oh my god, this is the same things like me…”.

The meaning-making process for young people initially took place through self-education. The process of self-education involved further research, questioning, and a general approach of curiosity around HIV and their HIV status in an attempt to learn more. In addition, the media was initially used as a form of learning more about HIV. Sarah stated that her general curiosity led her to seek out more information about HIV through various means:

“we had just learned about it in school… I would go back on the notes that I had to write and be like… OK, it’s starting to make sense… And after reading a textbook”.

Sarah’s initial understanding of HIV and clear access to information around HIV had allowed her to explore her diagnosis further through this process of self-education, which contributed towards her initial representation of HIV and of herself as a young person living with HIV.

Other young people spoke about using the internet and information online to search for more information about HIV, however, this appeared to have both positive and negative effects for the young people. Josh stated he *"…looked towards* [organisation]*… and then also did search up a lot of information"*, i.e., he used the website of the organisation he was associated with to find out more about HIV. In addition, Caroline stated that she utilised *"different websites online and even the* [organisation] *website"*. However, Ellie reflected on the negative impact unofficial sources of information had on her, stating that:

> *"… I regret looking online because online… Sometimes the information is misled… So many stuff comes up online, but just… It's like Googling your symptoms when you're sick, and then it says that you're dying."*

5.1.2 Subtheme 2: HIV as private and shameful

Subtheme 2 focuses on young people's initial representations of HIV as private and shameful. This resulted in many participants concealing their HIV status from wider society due to shame and as a way of protecting themselves from stigma, prejudice, and discrimination.

Participants' experiences of HIV as private were related to the fact that during the initial stages of receiving their HIV diagnosis, young people reported that HIV was an unspoken topic within the home and therefore rarely discussed with close family members. Sarah stated that *"…in my house we never spoke about it… my mum never spoke about it… she never tried to explain it like what's going on…"*. Sarah's experience mirrors that of Eva, who shared that *"we didn't even speak about it in our house…".*

As well as being a topic that is considered to be private within the home, Ellie also reflected on the fact that HIV is not spoken about in school or wider society, leading to many misconceptions around HIV, stigma, prejudice and discrimination, and miseducation around HIV. Ellie reflected on her experiences of this:

"… the chance to actually meet someone living with this condition is quite… very low… and if they do they just would have no idea because it's just not spoken about… and like they wouldn't know what to do."

One of the key findings was related to the fact that many of the young people rarely discussed the topic of HIV with their closest family members.

Secrecy and Non-Disclosure was also a key theme that arose from the interviews with young people, as they discussed their experiences of concealing their HIV-status from wider society. In addition, this concealment process appeared to also come from young people's parents, with Caroline stating that:

"a lot of people actually scared of talking about HIV… 'cause if I talk too much, people are gonna know that I have HIV and obviously, my mum told me not to tell anyone about it…"

Caroline's experience was shared by a number of participants who reported that they had been told to conceal their HIV status. In addition, all young people spoke about their own experiences of concealing their HIV status from wider society, including educational settings, to varying degrees. Eva told me that:

"No, no, no, no, no, no, no… Um… school... I didn't talk with... I don't think… I feel that if I'm able to talk to them about it, I don't trust them enough that they will keep it a secret or that they would see it the way I see it…"

The concept of trust posited here by Eva was an experience shared by another participant, Amelia, who also stated that she was *"…kind of scared… I didn't really trust anyone, so I didn't really tell anyone for a really long time."*

Throughout the interviews with young people, secrecy and concealment were seemingly becoming part of their identity, as they spoke about being shy, reserved, and isolated at times. This notion came across throughout the interviews with the majority of the young people, with Georgia stating that she *"was a very, very quiet person…".*

5.1.3 Subtheme 3: HIV as threatening

Participants in this study frequently reported experiencing both direct and indirect forms of stigma, prejudice, and discrimination in relation to their HIV-status. Georgia shared that *"… the stigma that goes around like… ugh"*. In addition, Ellie shed light on the role a lack of education around HIV has on people's views around the medical condition, stating that *"I don't think a lot of people actually know what it is and when they do it's like hugely stigmatised…"*

Amelia discussed her perceptions around other people's representations of HIV in wider society, thinking that she will be viewed as *"sort of like a walking disease... That if I touch them, um… They would be diseased as well…"* Other people's lack of knowledge and understanding of HIV seemingly led to the formation of representations of HIV as threatening.

5.1.4 Subtheme 4: HIV as not defining young people living with the medical condition

Through social interactions and the social support afforded by being part of organisations supporting children and young people living with HIV, young people discussed their change in mindset and how their representations of their identity as a young person living with HIV developed over time. Georgia spoke about HIV and the way in which she was supported to view herself as a young person living with HIV, sharing that she was helped to *"build… self-confidence... to live with it and not let it* *rule your life…”*. Similarly, Caroline spoke about her experiences of attending camp and meeting other young people living with HIV and how this helped to change her perspective:

“…camp that was the first time I actually met other young people who are my age who were living with HIV and obviously being in that atmosphere again changed my perspective…. From negative to understanding that you know HIV is not something that defines me… It’s something that I live with, but it’s not something that I am and it’s about trying to understand myself now and trying to say… OK HIV doesn’t define me then what actually defines me...”

The protective factors and coping mechanisms shared by the young people clearly play a range of different functions for them. The opportunity to develop close relationships with other peers living with HIV clearly provided the young people with social support and interactions that have helped them to thrive.

5.2 Theme 2: The physical and mental health of young people living with HIV

Theme 2 focuses on both the physical and mental health of young people living with HIV. Most of the young people in this study commented on the impact of living with HIV on their physical health, mental health, and emotional wellbeing. In addition, young people spoke about the emotional impact of having to conceal their HIV-status and being silenced by others when expressing some knowledge or understanding about HIV.

5.2.1 Subtheme 1: Experiences of taking medication

Subtheme 1 outlines young people’s experiences of taking medication and medication adherence and the impact this can have on their physical and mental health. Young people provided both positive and negative examples of taking medication and how it impacted on them. These experiences of taking medication feed into their overall lived experience as a young person living with HIV.

Caroline, despite having a positive relationship with her medication, stated that she already had a representation of what the experience of taking medication may be through discussions with her peers within the organisation she is associated with. This demonstrates the significant influence of social interaction and communication on developing social representations around a new phenomenon. Caroline stated that:

"To be quite honest when I first started I was nervous 'cause having lived all my life taking any medication and you know hearing other people's experiences with taking medication… It seemed horrific… and I was like I don't think I'm going to manage and I kept pushing it back like no I'm not ready to start… but so far it's been alright… I take medicine every day without it affecting anything…"

Despite the positive experiences highlighted by Caroline, many young people reflected on difficulties or negative relationships with medication. Ellie spoke to the psychological difficulties she experienced in relation to taking her medication. She said that:

"From like year… to year … Completely fine… But then I think it was like more year… It just started to take a toll on me and I just stopped taking them sort of thing… So like no reason and stuff like that like I don't know what reason it was… But then that's where things started getting complicated and my meds actually became a problem to me… Just more like in the back of your head of why am I doing this every day… It's more like… subconscious… Is a bit conflicted, like the relationship with your medication because… it's like they make one part of you better, but then they make one part of you worse sometimes…"

In addition to the psychological difficulties associated with medication adherence, the physical implications of taking medication were discussed by some young people. Georgia appeared to experience significant physical difficulties in relation to her medication, stating that:

"… for so long [it] *was just me suffering… So before I used to like every time I take them... Um… paralyse [me] like I just feel so dizzy, nauseous, like I just feel like my body should just… freeze… so like that can happen immediately as I take them… then I can have the feeling for like the next… That's literally my body… I can't move like if I move it gets worse so I just lie in my bed and... Not being able to move…"*

The young people who reported negative experiences with medication predominantly focused on the physical side effects. Ellie found it difficult to articulate the reasons behind the negative experiences of taking medication.

5.2.2 Subtheme 2: Emotional impact of living with HIV

Most young people referred to HIV being associated with difficulties with mental health and emotional wellbeing, with some young people reflecting on personal experiences. These experiences have been characterised by the internalisation of the stigmatising views of society, having to conceal their HIV-status, and experiences of self-stigma. In addition, young people shared experiencing low self-esteem and self-worth. Caroline spoke about the experiences of being a young person living with HIV and the impact that this can have on mental health and emotional wellbeing. She shared that:

"… it is quite challenging... I feel like sometimes HIV can affect… Um, your mental state but it all just depends… with the issue of self-stigma… you end up isolating yourself… it can cause anxiety, it can cause you feeling low about yourself

like low self-esteem... Um just sad… depression… You just crying, you just sad you don’t even know why, but you just… you’re just sad… you’re just sad sometimes…”

Some of the young people recounted the emotional impact of experiencing stigma, prejudice, and discrimination. These experiences frequently occur during interactions with the peer group, in educational settings and in wider society. Georgia spoke about the emotional impact of a specific experience with her peers, stating that *“it comes real… like people actually think this way... you know.”* She later stated that it is important for her to ignore these interactions as she *“would just crumble”* if she let the comments affect her.

Caroline reflected on the impact of self-stigma, a concept that appears to be related to the ways in which people living with HIV anticipate the stigmatising beliefs held by society and protect themselves by concealing their status. She described the fact that this process of concealment, secrecy and non-disclosure leads to self-stigma. Caroline gave a detailed account of self-stigma:

“there’s that self-stigma that’s there ’cause you know, like let’s say when… I got told about my HIV and my sister was like, you know, don’t tell anybody about it… Now this was as a young person... It kind of killed that young person in me who was, you know, jovial happy trying to make friends trying to talk ’cause I was always in my head like I’ve just found out this information... And obviously it’s definitely changed who I am… I can’t be the same person, but then I can’t really talk about it, so I was always in my head... So if you ask a lot of people that were in my high school, they think I’m a quiet person and I don’t talk much… But it was only because I was always in my head and obviously it was something that I couldn’t discuss with them so I was always just thinking in my head… The stigma on the outside is not as much as it was let’s say in the 1980... But now obviously it's the idea of, you know you can't tell

anyone about this and then you keeping this big secret it's like... why can't I tell somebody about it? Or like why would someone think I'm dirty but you know it's not my fault that I have it... I got it from birth and I didn't choose to be like that... I didn't choose to have to have this virus and it's like... you know it's like... it makes you feel alienated and it... sometimes it makes you feel different like why do I... Why does it have to be me, you know?"

Caroline appears to describe self-stigma as the questioning of the self and identity as a young person living with HIV, which has come about as a result of the wider stigmatising views held by society which has forced people living with HIV to conceal their HIV status. She clearly references the isolation that this can cause which may have a detrimental impact on the mental health and wellbeing of people living with HIV.

Some participants discussed the emotional impact of having to explain *"when you're going through something"* to other people who don't have HIV, such as teachers. This appeared to be due to the young people's representations of others having a lack of education around HIV and thus not understanding what they're going through. Eva told me that:

"It's hard, it's hard to sit there and describe what you been feeling, 'cause it's not really… can't really put a word to it… 'cause sometimes what happens to me… I would be so tired of explaining what's been happening… that I'll just be like I'm fine… like let's move on… because I know it'll be so hard for them to understand…"

5.3 Theme 3: Systems around young people living with HIV

Theme 3 outlines the most influential systems around young people living with HIV. These systems include the family, the peer group, education, and professionals supporting young people living with HIV. This theme will cover the ways in which these systems are both supportive, i.e., protective factors for participants, and unsupportive, i.e., having a negative influence, in relation to their lived experiences as young people living with HIV.

5.3.1 Subtheme 1: The family

Some young people spoke about the important role their family played in supporting them during the initial stages of receiving their HIV diagnosis and throughout their lives, with particular attention paid to the caregiver-child relationship. However, for some young people, this relationship was one that developed and evolved over time as both the parent and child became more comfortable and confident to talk about HIV-related issues. This also appeared to be helped by the young person becoming educated more about HIV through the support of outside agencies and organisations. Sarah spoke about how her relationship with her mother, who also has a diagnosis of HIV, developed over time so that they were able to have more open conversations about HIV. She said that:

"… she wasn't really open about it, but like as time went on, she was now more open to talking about it… Now she talks about it and it's like so different…"

As discussed previously, many young people conceal their HIV-status in order to protect them from the stigmatising views of society, and therefore the family may be one of the most significant protective factors for young people living with HIV. However, one young person shared the tragic loss of her parent, stating *"she died of HIV"*. In this young person's case, she was diagnosed with HIV by healthcare professionals in the UK after her mother passed away and was therefore unable to receive the important forms of support from a caregiver that other young people have reflected on. In addition, another participant, Georgia, shared that her relationship with her mother was difficult in that she didn't want her mother to ever feel blamed and thus rarely discussed HIV at home. She told me that:

> *"… it's personal to her like it is… it's hard for her because she feels like it was her fault that she gave it... She gave it to me... So for me to talk to her about it, um... I don't want her to feel like I'm blaming her..."*

Georgia's experience here clearly references the ways in which she protected her mother's mental health by choosing not to discuss HIV with her, and therefore seemed to internalise her feelings. Some young people stated that their caregiver's mental health also played a role in managing their own stress, mental health, and emotional wellbeing. Caregivers' worries and concerns about their child's wellbeing appeared to influence parent-child relationships and abilities to communicate and interact about HIV. Sarah stated that her mother *"didn't have anybody she'd speak to…"*.

5.3.2 Subtheme 2: The peer group

Social support appeared to be a significant protective factor for young people living with HIV, who reflected on the support they have received through developing relationships with their peers also living with HIV through a range of different organisations. Many of the young people reflected on the fact that meeting people living with HIV increased their support network, with Sarah reflecting on her time at a camp for young people living with HIV, stating that she *"now had a whole… bunch of support and it was so great…"*

For many participants, having the opportunity to meet other young people living with HIV appeared to normalise their own experiences. Josh told me that *"you never really like, really think of it as… Someone's got the same thing as you, but living normally… like you are."* In addition, the social support appeared to alleviate some of the feelings of alienation and isolation discussed in previous sections, with Caroline sharing that:

"Obviously coming to [organisation]*… I then understood that, you know, I'm not alone in this I'm not the only young person that has HIV and it's OK… like it's OK it's not the end of the world, you know… and yeah so* [organisation] *just provided me with knowledge and obviously the confidence to speak about your story…"*

The social support, sense of belonging, and sense of security afforded by having a safe space and supportive network of peers living with HIV appeared to allow the young people the opportunity to develop relationships and normalise the medical condition for them. In addition, young people spoke to the ways in which these social interactions influenced their representations of themselves and allowing themselves to not be "defined" by the medical condition.

The majority of young people reported that they concealed their HIV status from their peers outside of the social group they had formed through attending camps and groups for children and young people living with HIV. However, some young people discussed their experiences of disclosure to friends, school, and others through their own volition. Amelia reflected on their experiences of disclosing to a close friend:

"I felt it a bit relieving… like now that my best friend knew and I… she's very trustworthy so I knew that she wasn't gonna tell anyone."

In this instance, Amelia reflected on the positive experience of disclosing her HIV status to her friend, as this led to increased social support from her closest friend in school. However, this experience appeared to be relatively rare in relation to the experiences of other young people involved in this study. Some young people spoke to the difficult experiences of disclosing to peers, shedding light on the anticipation that they may be feared or rejected due to the representation of HIV as threatening and being rejected. One participant, Georgia, discussed her experiences of disclosing her HIV status to close friends. However, this experience appeared to be negative, as they recounted:

“When I told them… I think I just wanted to know how they would react… and I felt like they were my friends I could like trust… with it… but after I told… they were like… they grew distant.”

The concept of trust has emerged again through Georgia’s experiences of disclosing her HIV status to her close friends. Establishing trust appears to of significant importance of many of the young people and appears to impact on whether they choose to disclose. For Georgia, she felt that she had established trust with close friends, and this was seemingly broken as they grew distant.

Caroline spoke about the fear of being ostracised when considering disclosing to others. She commented that *“You don’t know how they’re going to react... You don’t know whether they’re gonna leave you… they’re gonna reject you…”*. A key factor for Caroline appeared to be whether the individual had prior knowledge or understanding about HIV. She stated that *“obviously you don’t know how much information they know about HIV…”*.

Many young people outlined directly experiencing a range of misconceptions around HIV. These misconceptions appear to be related to young people’s experiences of HIV being a topic that is seen as private and shameful in wider society, as discussed in the previous section. The lack of discussion around HIV has seemingly led to a lack of education around the medical condition. In addition, stigmatising views around HIV have led to a range of misconceptions that some of the young people reflected on. Georgia shared her peers’ reaction when she disclosed her HIV status, stating that *"…The way they* [treated] *it was like 'Oh my Gosh'… like they felt sorry for me and it came across like there's like… very sick person who was gonna die soon…".* Georgia's peers held a representation around people living with HIV as presenting as "sick" and had little understanding around the ways in which advances in HIV treatment can lead to people living with HIV living significantly longer lives.

Some young people described the fact that positive experiences of educating others can serve as a protective function for them, in that they are able to provide people with accurate sources of information. Ellie spoke about educating her friend who she disclosed her HIV status to, and the benefits of being able to provide accurate sources of information:

"Again, I don't think it's that very much a big of a deal 'cause I had to do some explaining, like it would be different if she had her own perspective on it, but she had no idea what it was, so it's easy for me to explain to her it is what it is and that and that and that… But let's say if she had actually known from like some misled information… or something like that, I feel like it could have gone a different way… But the fact that she had no idea what it was, she was totally understood… Understanding... and like I fully explained like this is how I got it… like that… this is how it doesn't actually affect me... It's the meds… this and that like I feel like… it would be 100% different if she had a different interpretation of it, but she didn't."

Caroline also reflected on the importance of educating others, describing the process as:

"…empowering... because to be honest I love educating people on… so right now I'm actually educating people in their basic human right… so it's just that ability of being able to talk to people on a conver... like just having a conversation and the

dialogue and you know just understanding where they're coming from and then helping them understand where we are coming from… and then… it's just… for me it's an enjoyable process… I love talking (laughs)…"

However, alongside – and despite – their peers' lack of knowledge, participants discussed experiences of both being silenced and feeling silenced during social interactions with peers around HIV. Some young people discussed their experiences of being silenced by their peers when trying to educate them around HIV or address any misconceptions that they had heard. This appears to be closely related to the concept of secrecy and non-disclosure as discussed in Chapter 3.4.4. Amelia paid particular attention to this, sharing a situation in which she was forced to manage her expert knowledge alongside concealing her HIV status:

"And when I try and educate them, they kind of just shut me off… saying like it's not why you don't have the right information…like now young people obviously they go to parties and stuff… I'm not really that person that goes to parties, but when you're the next day and people talk about it in class and then they keep on saying, oh, I think this person might have caught HIV... I try and tell them that might not be possible 'cause there's like ways to prevent it, but they're always like... Do you have HIV? How would you know? And… I would have to be like I… I don't I just know…"

A similar experience was shared by Josh, who alluded to his experiences of feeling silenced, as opposed to actively being silenced by peers. Josh referred to the fact that it was difficult to be involved in some peer interactions and speak up due to the fact that he was concealing his HIV status:

"as you get older in secondary school, certain jokes come out and you do the laughing and all of that, then it becomes a bit more relevant and... Certain ones like

sting, more than others, but you can't really say anything about it because… Yeah it's a private matter really yeah."

Many young people reflected on both direct and indirect forms of HIV-related stigma, prejudice, and discrimination experienced through interactions with peers. Josh spoke about situations in secondary school, in which he described HIV as increasingly coming up in conversation. He said that:

"…like secondary school... Obviously you get like those jokes and... like some uneducated teachers really like try and do the whole sexual talk... They give up like certain stigmas that... From being at [organisation] *I know weren't true"*

Josh's experience suggests that the teaching around HIV revolved solely around HIV as being sexually transmitted. This appears to relate to the representation of HIV as threatening, as discussed in Chapter 5.1.3, and the teaching clearly didn't reference the other ways in which HIV can be transmitted and therefore did not reflect the information Josh had received through trusted sources. Education will be further discussed in the Chapter 5.3.3.

In addition to the stigma, prejudice, and discrimination experienced as a result of HIV-status, Caroline also reflected on her experiences as a young black African woman, and the additional prejudice and discrimination she experienced in school. She shared that:

"… we were experiencing so much racism at the time in [country]*… so we moved… I still did get like semi bullied…"*

5.3.3 Subtheme 3: Education

Educational experiences were widely discussed by young people living with HIV. Young people reflected on their experiences of attending primary school, secondary school, sixth form colleges, and university. They discussed the impact of being a young person living with HIV in the educational system, reflecting on some of their negative, and thus unsupportive, experiences.

Young people expressed concerns in relation to inaccurate education around HIV in school and how this miseducation was leading to people having a lack of understanding about HIV. Ellie reflected on experiences of being taught about HIV in school in which she received inaccurate teaching:

“If that makes sense like there’s not really that much education to it… Like if you fully don’t know, like… The ins and your outs of biology like sometimes some biology teachers do teach it wrong… You honestly have no idea what it is. At all. And yeah.”

Participants shared the multiple worries experienced by children and young people living with HIV and how this has the potential to impact on educational experiences. Participants’ experiences of taking medication were widely explored in Chapter 5.2.1, with young people sharing the impact of this process on their physical and mental health. Josh reflected on his experience of attending school and taking medication, sharing that:

“you got so much more in your mind… you got so much more in your mind... Like I do remember like some days when I had exams there were like days where I would like skip meds just because I’d been revising or just gone to bed late or… just not felt like taking the meds because I need to do this work and get this off my mind first.”

Josh clearly shared the impact worries around work were having on his medication adherence, as he was unable to take his medication during particularly stressful times, such as during exam periods. Amelia also reflected on her experiences of taking medication and attending educational settings, sharing that a key barrier for her was her liquid medication. She reflected on difficulties experienced in primary school:

"When I had my liquid medication, I found it really hard to take the meds 'cause I would need to take it morning and evening… and when I took it in the morning I would feel sick when I go to school… but I couldn't tell anyone that I felt sick because they would wonder why and I didn't want to tell anyone what meds I was taking… So I just had to live at school just with that sickness."

Amelia appeared to experience a multitude of difficulties during this time. Her medication was clearly having an impact on her physical health, as she reports that her medication led to her feeling "sick". However, the psychological impact of concealing her HIV status and not being able to express the reasons for her sickness clearly appeared to be having an emotional bearing on her.

A key discussion point throughout the interviews was young people's decisions as to whether they disclosed their HIV status to school. Some young people spoke about their experiences of disclosing their HIV status to key members of staff and receiving a lack of support and experiencing an unsupportive environment. Georgia stated that she felt like the school were *"just terrified of me, really"*. She continued by sharing her negative experiences in relation to the school staff's approach to supporting her:

"Some of them were like OK? So? That's not my concern… and it just came across that you just here for like a short time after that I don't really care about you kinda... So I feel like if it comes to supporting kids… I think just need to… Schools need to educate... themselves really… Because I want the kids, I don't want them to feel like they have to teach them…"

An additional pattern that emerged from the data was the notion that a disclosure was forced or taken out of the control of the young person. This forced disclosure appeared to take place in educational settings. Amelia reflected on an experience, in which her disclosure to school was seemingly forced, and the resulting power imbalances between herself and a Teaching Assistant. She stated that *“some of my TAs* [Teaching Assistants] *found out that I had HIV… we decided to tell them because I started going on a lot of school trips.”* Amelia’s experience of disclosing appeared to be somewhat out of her control as she did not appear to disclose her status out of her own volition. The feelings she felt after clearly had an impact on her that mirrors the feelings of being silenced and feeling silenced. Amelia stated that:

“one of my TAs… started saying really random things that weren't true but if I corrected her then she could have the power to put me in detention or isolation just for back talking…”

Despite the clear difficulties experienced by many of the participants, some young people reflected on the positive support they received from specific teachers and Special Educational Needs Coordinators (SENCos) in school, highlighting the “understanding” nature of teachers and SENCos which led to them having positive experiences of disclosing their status. Ellie stated that her school was:

“…very understanding… they put like a support thing like in place for me and her... So like obviously we had our history teacher to talk about… There were some days where I say obviously sometimes your medication could cause you fatigue and all of that like if we miss a lesson… There’s a reason to our absence… like just don’t… like for other teachers to not question it like… their doors were always open like even if we wanted to cry or you know just going through it or anything like that… And obviously one of our favourite teachers who we also told she was just amazing

and always there for us... So we were very, very lucky in that sense that in… we had a good school who we could disclose our status to who were very, very understanding, and they actually put support measures in place…"

As well as putting a support plan in place for some young people, the experience of disclosing to school appeared to play a significant role for Amelia, who was able to discuss her concerns with a key teacher. She told me that:

"She [SENCo] *kind of like if I said that I needed to talk to her she would at let me cancel my lesson... And just sit down in an office and just drink a cup of tea and just talk to her… I felt like like a weight has come off me... Like I could finally have someone in school if this if I was having any problems… it felt like… I'd woken up from a nightmare."*

For Amelia, disclosing her HIV status clearly had a positive impact on her mental health and emotional wellbeing, as she describes waking up "from a nightmare".

5.3.4 Subtheme 4: Further education

Subtheme 4 highlights the supportive role further education has played for a number of the participants. Young people appeared to be more likely to disclose their HIV status to further educational settings, such as University, in order to receive additional support. Josh, who hadn't disclosed to his primary or secondary school, chose to disclose to his university so that he could receive additional support. In addition, Caroline chose to disclose to her university due to knowing about the beneficial support she would receive. She told me that:

"…when I was going to university, I actually received support from the DSA, which is the disability support allowance… You know I got given a new laptop like it was just amazing and to help me... um to make sure that I have the same quality of

education as other people who don't have this disability and for me that was very empowering for me…"

However, she also stated that, despite there being a significant amount of support on offer, young people living with HIV *"just need to know where the support is... And reach out and ask them to support us."*

Ellie, who disclosed her status to their secondary school and sixth form college, found the process easier and could see the benefits of receiving additional support. She said that:

"So like I might as well do that for Uni and I thought I had to go through my support plan and all of that... So now I have a support plan in place... give me reasons let's say... If it was a normal academic year and there was actual lectures and going on campus… I'd be able to... Sometimes if I overslept due to meds, I would be able to get the recording of the lecture to me, or like a dedicated reading list... So I'm not overloading myself with work…"

5.3.5 Subtheme 5: Professionals

Subtheme 5 focuses on the support received from a range of different professionals, such as doctors, nurses, and social workers, in supporting participants during the initial meaning-making phases. The role of medical professionals was highlighted by several young people in helping them to learn more about HIV, signposting them to HIV-related groups, supporting them with medication and providing emotional support where possible. Ellie alluded to the support she receives from her nurse, sharing that:

"Now, like when I go to my appointments… Like we're able to talk… Like if we have any time there we're able to talk about… Like my medication… We've been able to talk about… my life and that everything that's going on…"

In addition to the support received from medical professionals, Sarah spoke to the role of their social worker who she frequently met, stating that:

"… She would [ask me]*… how are you feeling? … I wanna know how* ***you're*** *feeling… I was like that's the first time anybody's asked me that, and it feels weird…"*

A further supportive factor for some young people was the existence of external programs, such as camps organised through charities and organisations. This camp allowed many participants to come together with other young people living with HIV in order to learn more about HIV and gain a significant amount of social support from both their peers, key workers, and volunteers. All young people who attended the camp spoke of the important role in shaping their experiences as a young person living with HIV. Sarah reflected on the experience, stating that she *"learned a whole lot at* [organisation]*… then I came back and I was like… I know so many things"*.

The quotations detailed above demonstrate the important role of different individuals and systems in supporting young people living with HIV not just during the initial meaning-making process, but also post-diagnosis in helping to shape their representations of HIV and how this may relate to their experiences and identity as a young person.

Chapter 6: Findings from the qualitative content analysis of the websites of three key charities and organisations who support people living with HIV

This chapter will present the qualitative content analysis of the textual information, images, and both audio and video files available on the websites of three of the largest charities and organisations that support children, young people and families living with and affected by HIV in the UK: Organisation 1, Organisation 2, and Organisation 3. The information on websites was chosen as opposed to perusing policy documents, as it was felt that an exploration of the actual content being accessed by children and young people living with HIV was the most useful approach to adopt. The websites generally contained information about the support offered to children, young people and families, information about HIV for children and young people, information for parents and carers, information around work with other professionals, and information for professionals around HIV. This information was written for a range of different audiences, which was broken down into different sections on each website, e.g., for children, young people, and adults living with HIV, for parents, and for professionals. Although there were many similarities in the information on the websites, there were also some clear differences in the websites' presentation of information. Organisation 2 focused on supporting the development of understanding expert information through the use of videos. However, the majority of information on the website of Organisation 1 revolved around text that was supported by some images. This differed further from Organisation 3, which included audio files of the experiences of people living with HIV, reflected on similar, seemingly shared experiences of being diagnosed with HIV. In general, Organisation

1 appeared to share the most amount of HIV-related information on their website and appeared to seek to support young people who were perhaps making sense of their diagnosis before meeting with their peers living with HIV, whereas Organisation 2 and 3 appeared to have less information present on their websites. This may be due to the fact that the majority of support is delivered through attending groups face to face.

The majority of the text, images, videos, and audio files available on the websites was analysed, with the main focus revolving around the content associated with the key findings from the literature review of Chapter 3, i.e., stigma, disclosure, secrecy, non-disclosure, medication, medication adherence, mental health, emotional wellbeing, and education. The qualitative content analysis was carried out to address research question 4:

> To what extent does the information, advice and guidance provided by charities and organisations align with the views of children and young people in relation to their lived and educational experiences?

The ways in which the charities and organisations presented the information was noteworthy throughout this qualitative content analysis, as they attempted to support the development of understanding the expert knowledge related to HIV as a medical condition. Three themes were generated through the qualitative content analysis, 1) Being part of a collective, 2) Supporting the development of understanding expert knowledge, and 3) Supporting the development of understanding psychosocial difficulties.

6.1 Theme 1: Being part of a collective

Theme 1 focuses on the ways in which the websites promote being part of a collective, which was predominantly achieved through the normalisation and discussion of shared experiences of people living with HIV. By normalisation, I mean the ways in which the websites seemingly describe some of the experiences of people living with HIV as shared. A key finding from the interview data presented in Chapter 5 was young people's experiences of isolation and alienation. During the initial meaning-making process for young people, many participants found it difficult to make sense of their diagnosis before meeting other young people living with HIV. In the present analysis, it was found that some of the key charities and organisations supporting people living with HIV aimed to promote the normalisation of the experiences of people living with HIV. This was achieved through the careful use of language throughout the charities and organisations' website material.

6.1.1 Taking medication

The three organisations being studied seemed to recognise that many young people had difficult experiences of taking medicine (this was also in line with what the young people discussed with me during the interviews). As a result, they attempted to normalise this by referring to common experiences around medication.

Organisation 1	*"Anyone who is living with HIV may get some of these unwanted effects of taking medicine. It is quite usual for this to happen…"*
Organisation 2	*"…with good adherence and many different anti-retroviral drugs… it means that people with HIV are living long and healthy lives"*

From these extracts, it appeared that the normalisation of the process sought to support young people to feel less isolated and alienated (i.e., as in fact experiencing “quite usual”) if they were to have a similar experience of taking medication.

6.1.2 Disclosure, secrecy, and non-disclosure

As described in both the literature review of Chapter 3 and in the findings of Chapter 5, disclosure, secrecy, and non-disclosure are key issues facing young people living with HIV, with many experiencing difficulties around whether to disclose their HIV status to others, e.g., friends, family, and schools. Findings from Organisation 1 suggest that the websites present clear support and guidance around disclosure, in the below alluding, for instance, to communicating with peers as a supportive mechanism for young people considering disclosing their HIV status:

“If you are not sure that you are ready to tell yet, please speak to other young people you know who have told others about their HIV. Listen to their experiences, and also ask them what worked for them. You might be surprised by how many people have had positive reactions.”

Normalising the process of disclosure and making reference to the fact that many young people living with HIV have had a positive experience in disclosing their status to others is further evidence of the presentation of young people as not alone in their experiences of living with HIV in organisational material. However, these messages are in contrast to some of the feelings expressed by participants in the interview study.

6.1.3 Group membership

The provision of information around taking medication and disclosure sought to provide young people living with HIV with safety and security. This notion was especially found to be true of the website material of Organisation 2, who explained that *“A feeling of community or social connectedness can be highly protective when our lives become challenging”*. As discussed in Chapter 5, the presence of a group membership appeared to provide young people with a sense of belonging and identity. Through this normalisation process, the websites appeared to seek to provide young people with a further sense of group membership, and thus supporting them to develop a positive identity and representation of themselves as a young person living with HIV.

6.2 Theme 2: Supporting the development of understanding expert knowledge

Theme 2 highlights the ways in which the three leading charities and organisations provided a wide range of information for young people living with HIV. The way in which this information is presented is of particular interest, as the expert knowledge delivered by doctors and nurses is seemingly translated into common sense understandings through the use of simple language that is accessible for children and young people. As established in the interview study, the majority of young people living with HIV are required to make sense of the expert information around HIV that is delivered by healthcare professionals, such as doctors and nurses. This can lead to representations of HIV as unknown, as highlighted in Chapter 5. On the contrary, the website of Organisation 1 was found to have provided a significant amount of information about what HIV is, helpfully highlighting how young people can explain this to others:

“[HIV] is a virus that makes my immune system weak so I cannot fight off infections as easily as other people without HIV. So I take medication which makes my immune system strong…”

The information provided by this organisation clearly may support young people's understanding of HIV, particularly through the use of accessible terms such as *"fight off"* and *"makes my immune system strong"*, which appears to simplify the expert information that the young people may have received from healthcare professionals. In this extract, the use of the first narrative, i.e. *"I"* and *"my"*, is a powerful way of helping young people to feel like an active participant when perusing the information available on the website. In addition, the information presented may further support young people to come up with a 'script' to use when disclosing their HIV status to others. Increasing young people's understanding of what HIV is may also support them during the meaning-making process discussed in Chapter 4, in which young people initially hold a representation of HIV as 'unknown'.

Further to the information around taking medication, information about transmission was incorporated into the website of Organisation 1, and was arguably another means by which expert knowledge was translated into common sense understandings:

"To pass on HIV, first of all you must have a detectable viral load, so if you are undetectable there is NO WAY you can pass it on. Even if you have a detectable viral load, there must be a direct way for the virus to get into another person's blood stream – a bit like going through a door."

The use of accessible language to convey information, in this case about the transmission of HIV, appears to seek to further support young people to move away from this representation of HIV as 'unknown', as they develop their knowledge and understanding of the medical condition. This information may also be related to understanding stigma and misunderstandings of HIV, as many people fail to understand how HIV is transmitted.

As highlighted in the literature review of Chapter 3, and in the findings of Chapter 5, managing medication and medication adherence has been widely explored as an issue for young people living with HIV. In addition to the information provided on HIV as a medical condition and the transmission of HIV, the experiences of taking medication and the potential side effects were highlighted on the organisation websites analysed.

Organisation 1	*“A ‘side effect’ is the name for when taking a particular medicine makes you feel unwell… Side effects can be any symptom that is different to your normal state of bring. Any medicine – even Paracetamol or Ibuprofen– have a long list of possible side effects.”*
Organisation 2	*“HIV treatment involves taking anti-HIV drugs everyday… the best way to make sure treatment works is through adherence… [which] means following the doctors plan exactly for how you are supposed to take your medication…”*

6.3 Theme 3: Supporting the development of understanding psychosocial difficulties

As highlighted throughout the literature review of Chapter 3, and emerging from the findings in Chapter 5, people living with HIV are likely to experience a multitude of psychosocial difficulties, such as stigma, negative experiences related to disclosure, and mental health difficulties. This study focuses on children and young people's experiences of education, and therefore this was a key area explored in the analysis of the websites of supporting charities and organisations.

6.3.1 Stigma

Organisation 1 was found to foreground the psychosocial experience of stigma, providing clear definitions of both stigma: *"… when a person is seen or treated in a negative way, because of something they experience… or because of something that makes up their identity…"* and self-stigma, which *"happens when a person from a stigmatised group… internalises negative public attitudes and believes them to be true…"*, highlighting the fact that these attitudes can lead to *"high levels of discrimination"* and impact on an individual's mental health and lived experiences. Through the analysis of content included on the three websites, it was clear that charities and organisations sought in general to explain the significant issue of stigma and its impact on people's experiences of secrecy and non-disclosure.

6.3.2 Disclosure, secrecy, and non-disclosure

In terms of disclosure, non-disclosure, and secrecy, Organisation 1 was found to state that *"Professionals have a responsibility to uphold the level of confidentiality the child or family require and support them within this context."* A key context in which confidentiality may be required is the education system. On this topic, Organisation 1 further included that *"Families often do not share their children's HIV status with schools due to real fears that the information will not be managed well"*, with the implication stated that *"…additional educational support goes unrecognised or intervention is delayed."* This information revolved around more professional and expert language and may not have been aimed at professionals and parents or carers supporting children and young people living with HIV.

6.3.3 Disclosure, secrecy, and non-disclosure in schools

As we know from the interviews with young people living with HIV, some participants chose to disclose their HIV status to their school in order to receive further support. Organisation 1 was found to provide a significant amount of advice and guidance around the ways in which school systems should be supportive and meet the needs of children and young people living with HIV, stating that *"School needs to be a place where it is safe to be living with HIV and where families feel safe to share this information"*. In addition, this organisation's material was found to include messages such as, *"An HIV-friendly school can be achieved through a holistic approach that promotes a caring, supportive and inclusive environment"*. The use of language that focuses on safety, care, and inclusion, provides very clear and specific guidance with which professionals can adopt to effectively support children and young people in schools. Furthermore, the notion of confidentiality was found to be made explicit here, arguably so that young people are aware of the fact that it is the responsibility of professionals to ensure that information about a young person living with HIV is not shared, with Organisation 1 making refence to the fact that it is a school's duty to *"reassure* [a child who discloses their HIV status] *that… information will be kept confidentially amongst specific staff in the school"*. The remaining two organisations explored in the qualitative content analysis did not make reference to education.

Change at a systemic level through educating school staff about HIV was found to be described as an effective approach, so that it can be ensured that *"…staff's HIV knowledge is up-to-date"* and to *"firmly establish the need for confidentiality"*. These findings echo the strategies identified as important by the young people living with HIV in Chapter 5. Participants felt that there was a significant need for people, including school staff, to be educated about HIV so as to avoid the presence of stigmatising views around HIV, misconceptions about HIV, and miseducation in schools.

6.3.4 Mental health

Findings in Chapter 4 additionally made clear the impact of living with HIV on both the physical and mental wellbeing of participants, who described that difficulties with mental health could arise from negative experiences within unsupportive systems, e.g. experiences with peers and in school, a finding that is also well-documented in the literature. In the present analysis, the mental health of people living with HIV was recognised by charities and organisations through the inclusion of resources and information to support young people's mental health and emotional wellbeing. For instance, Organisation 2 was found to have established a *"… digital resource for young people to improve mental health and wellbeing…"*, while Organisation 3 alludes to *"courses that support your mental wellbeing"* on their website. Therefore, it is clear that the charities and organisations involved in this qualitative content analysis are mindful of the mental health and emotional wellbeing of young people living with HIV.

Chapter 7: Discussion

There is a lack of research that explores the lived and educational experiences of children and young people living with HIV in the UK. This research study sought to address the paucity of research by carrying out in-depth semi-structured interviews with young people aged 12-25 years old, living with HIV. In addition, a qualitative content analysis was carried out in order to explore the information and guidance available on the websites of three charities and organisations for people living with and affected by HIV. The research questions to be addressed were:

1. What are the lived experiences of children and young people living with HIV?
2. What are some of the protective factors that have supported children and young people living with HIV?
3. What are the educational experiences of children and young people living with HIV?
4. To what extent does the information, advice and guidance provided by charities and organisations align with the views of children and young people in relation to their lived and educational experiences?

This chapter will outline how the findings across the semi-structured interviews and qualitative content analysis, as presented in Chapter 5 and 6 respectively, answer the studies' research questions. This will be achieved through addressing the relevant literature and with a clear focus on the role of Social Representations Theory (Moscovici, 1961) and Bronfenbrenner's (2005) PPCT model. In addition to answering the research questions, the strengths and limitations of the present study will be presented, as well as potential implications for

Educational Psychologists and schools to consider in order to effectively and appropriately support children and young people living with HIV.

7.1 Research Question 1: What are the lived experiences of children and young people living with HIV?

All of the young people involved in the present research study provided a rich description of their lived experience of living with HIV. Throughout the interviews, participants reflected on seemingly shared experiences, which were presented in Chapter 5.1 as young people's representations of HIV. These representations were related to both young people's representations of HIV and the representations of HIV that the participants perceived other people to hold. Despite sharing many similarities, there were some key differences between young people's lived experiences. The representations of HIV outlined in Theme 1 of Chapter 5 were 'HIV as unknown', 'HIV as private and shameful', 'HIV as threatening' and 'HIV as not defining young people living with the medical condition'. A key consideration here is the notion of representations as a process. Young people's representations were not fixed and therefore developed over time. This is in line with Bauer and Gaskell's (1999) Toblerone model, in which the authors allude to the development of representations over time, which was of particular importance for the young people involved in this study. In addition, considering the time element of Bronfenbrenner's (2005) PPCT model was an important way of shedding light on the significance of considering the relationship between an individual and their environment as fluid, thus changing over time.

As discussed previously, the point of being diagnosed with HIV appeared to elicit a meaning-making process for participants, who sought to understand their diagnosis and identity as a young person living with HIV. The narratives shared by the young people during the early stage of receiving a diagnosis of HIV appears to suggest that HIV was to the young people what Social Representations Theory scholars would consider an unfamiliar concept that thus required familiarisation (Moscovici, 1961). Particularly relevant here is the distinction between expert and lay knowledges (Joffe, 1996). The young people were expected to interpret expert knowledge around an unfamiliar concept, HIV, shared predominantly by doctors and nurses. At this point, it appeared that a meaning-making process was initiated for the young people, as they were forced to learn more about HIV and what it meant for them. Therefore, participants initially appeared to hold a representation of HIV as ‘unknown’, in that they had little understanding of HIV as a medical condition. However, this was dependent on whether participants were born in the UK or migrated to the UK. The young people who migrated to the UK appeared to have a greater understanding of HIV as a medical condition, as this was something that was covered in school in their country of origin. This may have been due to the fact that the prevalence of HIV was higher in these countries and therefore there was a clearer focus on education around HIV in schools. This appeared to facilitate these particular young people’s understanding of HIV. Conversely, the majority of children in the UK learnt about HIV and their diagnosis through healthcare professionals, such as doctors, nurses, and social workers.

Through a qualitative content analysis, it was found that the websites of three of the largest charities and organisations that work with people living with HIV contained a significant amount of information that appeared to support the development of understanding the expert knowledge that was associated with the unfamiliar concept of HIV. Some of the young people alluded to the ways in which trustworthy sources of information, like these websites, supported them to gain a greater understanding of HIV and thus move away from this representation of HIV as unknown. This was of significant importance, as Jaspal and Nerlich (2017) highlight the significant role of the media in providing information around scientific, technological, and medical developments. However, the authors allude to the polarised nature of the media, stating that it is either highly positive or highly negative. When commenting on emerging and re-emerging infectious diseases, such as HIV, Joffe (2011) states that the media can create a sense of catastrophe. Therefore, the trustworthy sources of information available on the aforementioned websites supported many of the young people to avoid the potential risk of being exposed to untrustworthy sources of information and potentially threatening representations of HIV during this process of self-education. In addition, attending support groups and for some young people, discussions with family members, also supported participants to develop their representations around HIV. However, experiences in the family and wider society that revolved around HIV as an unspoken topic led to representations of HIV as private and shameful.

Young people's representations of HIV as private and shameful appeared to be closely related to the fact that HIV is a highly stigmatised medical condition. These representations led to secrecy and non-disclosure, which has been widely explored in the literature as an approach adopted by people who experience stigma in order to conceal their identity (Liamputtong, 2016) and avoid engaging with people who are outside of their group (Goffman, 1963). In addition, research by Liamputtong (2016) established that parents frequently attempt to conceal their children's HIV status due to worries around the impact of stigma on their mental health and emotional wellbeing. For many participants, HIV was not a topic spoken about in the home, which further contributed towards representations of HIV as private and shameful. Therefore, young people appeared to conceal their status due to fears of isolation and rejection, which have been widely explored in the literature (Persson et al., 2016). This process of concealment may have contributed towards the initial difficulties of young people forming a positive representation of themselves living with HIV, since it appeared to be something shameful. In addition, the lack of communication and interaction with significant others during this fundamental meaning-making phase may have an impact on young people's ability to develop a sense of personal orientation, i.e., identity, and engage in interpersonal communication, which are key functions that Moscovici (1973) argues are related to forming social representations.

Throughout the interviews, both supportive and unsupportive systems were explored. It appeared that experiences within unsupportive systems led to young people perceiving that members of wider society hold representations of HIV as threatening. As highlighted in Earnshaw and Chaudoir's (2009) HIV Stigma Framework, people living with HIV are likely to experience stigma in a range of different ways, i.e., anticipated, internalised, and enacted. Anticipated stigma is closely related to young people attempting to conceal their HIV-status in order to protect themselves from the stigmatising views of society. Young people frequently discussed both direct and indirect experiences of prejudice and discrimination in relation to HIV, i.e., enacted stigma, and how this has either impacted themselves or others. In addition, stigma was found to be present in a range of different settings, such as in school and on social media. This appears to be related to the brief history of HIV/AIDS in the UK highlighted in Chapter 2.1, in which public information campaigns warning people about the medical condition created a sense of fear and led to stigmatising views. In addition, these experiences are closely related to the findings in the study carried out by the National AIDS Trust (NAT) (2014), in which a considerable number of people had little understanding about HIV, specifically how HIV can be transmitted. In addition, experiences in the peer group and education systems exposed participants to inappropriate jokes, stigma, discrimination, isolation, miseducation, and a range of different misconceptions related to HIV. For some participants, it was also important to consider lived experiences in the context of Intersectionality (Crenshaw, 1989, 1991) as they were members of minority ethnic groups. Intersectionality explores the impact of oppression, inequality, and stigma across multiple levels within society on diverse groups of people. It is important to consider the impact of experiencing multiple levels of discrimination, as Rosenthal (2016) argues that these experiences can have a range of adverse outcomes, such as mental health difficulties. Participants also reflected on negative experiences with professionals working in schools which appeared to be related to the concept of emotional anchoring and objectification (Höijer, 2010), as one young person was viewed as terrifying. Young people felt that a lack of education around HIV may lead to these stigmatised views and misconceptions.

Despite the experiences highlighted that led to representations of HIV as threatening, many young people discussed positive experiences within supportive systems as shaping their development of a positive mindset and representation of HIV as not defining them. In relation to Bronfenbrenner’s (2005) PPCT model, this process allowed the young people to develop key supportive relationships at the ‘microsystem’ level. This, in turn, appeared to help the young people to develop positive representations of themselves as young people living with HIV, adopting a positive mindset revolving around not being defined by the medical condition. Opportunities to develop positive peer relationships through attending camps and groups with other young people living with HIV offered a sense of belonging and group membership, a key protective factor illustrated in previous research (Rueda et al., 2016). This has also been widely explored by a range of different researchers, who report that increased opportunities for social interactions, social support, learning about HIV-specific issues, and developing a positive self-image and self-confidence are afforded by attending these camps. In relation to Bronfenbrenner's (2005) PPCT model, this finding shed light on the importance of the 'microsystem' in supporting young people living with HIV to develop a positive identity and sense of self, but also the 'exosystem', in which organisations support young people by facilitating the development of these peer relationships.

Positive experiences within the education system, such as having positive teachers, SENCos, and Heads of Year, also appeared to support participants' inclusion within the school setting, which may have also had a positive impact on the positive representation of HIV illustrated above. Campbell et al. (2014) highlight the importance of having a sense of a positive identity in school was a key form of support for children living with HIV in Zimbabwe.

The physical and mental health of young people living with HIV was widely explored as issues associated with participants' experiences of being a young person living with HIV. Young people alluded to difficulties that they experienced with medication and medication adherence, mental health, and emotional wellbeing. The young people who reported negative experiences with medication predominantly focused on the physical side effects. The debilitating side effects reported by young people around taking medication, such as feeling nauseous and finding it difficult to function, clearly had an impact on their physical wellbeing and ability to engage in learning. Medication adherence has been widely explored within the HIV literature, and Sweeney and Vanable (2016) posit that HIV-related stigma can have a detrimental impact on medication adherence for people living with HIV. Ellie found it difficult to articulate the reasons behind the negative experiences of taking medication, but the extant literature highlights stigma as a potential reason behind challenges with medication adherence. Nanni et al. (2015) report that difficulties with medication adherence can be associated with experiencing mental health difficulties, such as depression. The associations between medication adherence and mental health difficulties are concerning. The findings demonstrated here clearly emphasise the importance of supporting young people through medication adherence so that they are not at further risk of experiencing mental health difficulties.

The frequency with which young people discussed and opened up about difficulties with mental health and emotional wellbeing suggested that this is a significant part of their lived experiences as a young person living with HIV. This is reflected in the literature, which suggests that young people living with and affected by HIV are likely to experience a multitude of psychosocial difficulties, such as mental health difficulties. As discussed in Chapter 3.3, Malee et al. (2011) made reference to the fact that children and young people living with and affected by HIV are likely to experience mental health difficulties at a higher rate than the general population in the US. Such findings were replicated by the authors in subsequent research (Mellins & Malee, 2013). In addition, researchers have found that children and young people living with HIV are at risk of experiencing anxiety, depression, and low self-esteem (Le Prevost et al., 2018). Given this, it is clear that young people must have access to appropriate support in this area.

Parental mental health was explored in this study, with some young people reflecting on the fact that they had to be mindful of their parents' mental health and emotional wellbeing when discussing HIV. Mellins and Malee (2013) refer to the fact that parents' experiences of mental health difficulties and adverse life events can potentially lead to children and young people living with HIV experiencing mental health difficulties themselves. Bronfenbrenner's (2005) PPCT model posits that the caregiver-child relationship falls within the microsystem, i.e., the system that holds the most significant influence over a child or young person's development. As the caregiver-child relationship is reported to be a significant form of support, young people's lived experiences are likely to be strongly influenced by parents' experiences with mental health difficulties.

These findings were clearly associated with the range of studies that explore the mental health, physical health, quality of life, and health-related quality of life of people living with HIV (e.g., Malee et al., 2011; Mellins & Malee, 2013; Le Prevost et al., 2018), as discussed in Chapter 3.3.

7.2 Research Question 2: What are some of the protective factors that have supported children and young people living with HIV?

The protective factors that have supported the participants in the present study were widely explored in Chapter 5.3, 'Systems around young people living with HIV'. The findings suggested that a range of different systems had a positive impact on the young people's lived experiences. These systems were explored in the context of the inter-related systems associated with Bronfenbrenner's (2005) PPCT model. Throughout this study, the microsystem and exosystem appeared to be the most influential systems impacting on participants' lived experiences and supporting the development of positive representations of themselves and their identity as young people living with HIV. First, the family was explored, who some participants stated played a significant role in supporting them through the early meaning-making process, with other young people reflecting on how the supportive role of the family developed as their knowledge and understanding of HIV developed so that they were confident in discussing HIV-related issues within the family.

The peer group was found to be a significant protective factor for participants involved in the present study. The social support, sense of belonging, and sense of security afforded by having a safe space and supportive network of peers living with HIV appeared to allow the young people the opportunity to develop relationships and normalise the medical condition for them. In addition, young people spoke to the ways in which these social interactions influenced their representations of themselves and allowing themselves to not be “defined” by the medical condition. Rueda et al. (2016), in their series of meta-analyses focusing on the associations between HIV-related stigma and health outcomes, found that forming social and interpersonal relationships with others has been found to be a protective factor for people living with HIV and can play a role in alleviating the experience of mental health difficulties, such as depression. In addition, some young people’s positive experiences of disclosing their status to friends and partners further increase their social support and appeared to be in line with findings reported by Das et al. (2016).

Being exposed to an inclusive environment in educational settings was found to be a protective factor for some participants who disclosed their status to schools, who reported that talking to teachers about HIV-related issues and receiving support around workloads supported them during their school experiences. In addition, other community settings, such as camps providing support for people living with HIV, were found to be significantly supportive systems for participants. These systems consistently allowed for the previously mentioned increased levels of social support. These findings have also been widely reported in the HIV literature, with previous research indicating that attending camps provided young people with increased opportunities for social interactions, social support, learning about HIV-specific issues, and developing a positive self-image and self-confidence (Evangeli et al., 2019; Gillard et al., 2011; Lut et al., 2017).

Participants' positive experiences within the context of their microsystem suggest that the family, peer group, and school can be key protective factors for young people living with HIV. This support appears to be important not just during the initial meaning-making process, but also post-diagnosis in helping to shape their representations of HIV and how this may relate to their experiences and identity as a young person. Further to this, support at the exosystem level in the form of charities and organisations were also key sources of support for young people living with HIV.

7.3 Research Question 3: What are the educational experiences of children and young people living with HIV?

During the interviews, participants widely discussed the issues experienced when attending school settings, which were both positive and negative. For some young people, a lack of education around some professionals within schools led to challenging experiences, such as feelings of power imbalances with some members of staff, hearing misconceptions around HIV, receiving little support, and experiencing miseducation, i.e., the wrong or limited information about HIV. These experiences led to young people's perceptions that other people have representations of HIV as threatening, and it was through this that young people appeared to perceive that a lack of education for staff may be associated with these views. For young people living with HIV, receiving inaccurate teaching from those that are meant to provide trustworthy sources of information appeared to negatively impact upon the participants in this study. Participants' experiences of being taught about HIV in the UK suggests that we are failing to appropriately educate children and young people about the medical condition. These experiences highlight a need for teachers themselves to be educated around HIV in order to support them to deliver this teaching in schools and to ensure that accurate information is being delivered to children and young people.

The concept of forced disclosure also arose through the interviews, in which young people were forced to disclose their HIV status through means that were out of their control, e.g., to attend school trips. This appeared to take the power and control away from the young person and through the qualitative content analysis, it was found that the guidance states that young people living with HIV are not legally required to disclose their status to school.

Further to experiences with professionals working in schools, participants discussed the fact that difficulties with both physical and mental health, which were widely explored in Chapter 5.2, had the potential to have an impact on their educational experiences, e.g., engagement in learning due to taking medicine. The emotional and physical factors associated with living with HIV clearly had an impact on some of the young people’s educational experiences. Some of the young people living with HIV chose to not disclose their status, and therefore, despite experiencing both emotional and physical difficulties, would not have been able to receive any support in school. Findings from previous research indicate that children are likely to experience a multitude of physical, emotional, and social challenges in school, such as social neglect, physical ill-health, social isolation, bullying, and experiencing HIV-related stigma, as reported by the peers of children living with HIV in Zimbabwe (Campbell et al., 2014). Therefore, the detrimental role of stigma, as discussed in previous sections, has a significant bearing over young people’s decisions to disclose to their school in the first place. Anchoring and objectification, as discussed by Höijer (2010), are techniques used to transform unfamiliar concepts into lay knowledge. Höijer (2010) argues that emotions are often used within these two concepts in order to shape our representations. As findings in Chapter 5 suggest, representations of HIV, such as in the media, are often threatening. The ways in which these representations target people's emotions may lead to them holding negative views of people living with HIV. The views of others, and the fear of isolation and alienation, appeared to have an impact on an individual's decision to disclose their HIV status.

Despite the difficulties surrounding disclosure, school also appeared to have a positive influence. Campbell et al. (2014), in a study of children's representations of school support for HIV-affected peers in rural Zimbabwe, found that teachers, peers, and a sense of positive identity within school were key forms of support for children living with HIV. Therefore, it appears that within the HIV literature, disclosing to school can have positive outcomes. These findings were mirrored for some young people in this study, in that some teachers played a significant role in supporting some of the young people living with HIV. Settings that were seemingly more inclusive appeared to be very supportive for young people living with HIV, who discussed advantages of discussing HIV-related issues with a range of different teachers, such as subject teachers, SENCos, and Heads of Year.

Findings from the interviews with young people suggested that participants were more likely to disclose their status to further education settings, such as university. At this point, young people were more likely to have developed a representation of HIV as not defining them, and therefore adopted a positive mindset in relation to the medical condition. This may have contributed towards these decisions to disclose their status. However, it was also clear from the interviews that knowing (or not knowing) the support, e.g., through the Disability Support Allowance, that was available appeared to play a role in young people's decisions to disclose. Therefore, it may be important to consider how we can support young people to understand resources that may be available through disclosing their status to school settings so that they will be able to receive appropriate support.

7.4 Research Question 4: To what extent does the information, advice and guidance provided by charities and organisations align with the views of children and young people in relation to their lived and educational experiences?

The qualitative content analysis demonstrated that many of the views and experiences shared by young people living with HIV, as detailed in Chapter 5, are reflected in the information and guidance available on the websites of three key charities and organisations that support people living with HIV. Through this analysis, some of the key guidance, advice and information that was provided for young people living with HIV appeared to centre around some of the key issues discussed by participants during the interviews, i.e., stigma, disclosure, and mental health. The information available appeared to clearly align with the lived and educational experiences shared by participants in the present study. The charities and organisations appeared to support the development of understanding both psychosocial issues and the expert knowledge associated with HIV through processes such as anchoring. Providing this trusted information appears to be of great importance to young people living with HIV who are required to make sense of their new diagnosis and identity as a young person living with HIV.

During the initial process of holding a representation of HIV as unknown, as explored in Chapter 5, the content available on these websites appear to have a positive impact in shaping young people's understanding of the medical condition, and it is essential that these websites are signposted to young people. Through the qualitative content analysis, it was clear that the charities and organisations aimed to normalise the experiences of people living with HIV in order to alleviate feelings of isolation and alienation and promote a sense of group membership. In addition, a key function explored through the qualitative content analysis was the supportive role charities and organisations endeavour to play in simplifying the expert information around HIV to support the development of common-sense understandings through their careful use of language, thus facilitating the meaning-making process for young people. Some of the information was made intelligible through the use of anchoring objects through the use of more familiar, well-known concepts, such as Paracetamol and Ibuprofen. Ostensibly used as examples to explain the notion of side effects, anchoring HIV medication in these well-known medicines served to normalise the experiences of taking HIV medication overall.

Through the qualitative content analysis, it was found that only one of the three websites provided clear guidance around the experiences of children and young people living with HIV in schools. This guidance, and the promotion of HIV-friendly schools, appears to align with the views and experiences of young people living with HIV as explored in this study. This finding shed light on the importance of further disseminating clear information around such young people's experiences so that they are able to access appropriate support in school settings. It is also important that schools have access to such information so that they are able to best support children and young people living with HIV in their settings.

7.5 Limitations

One of the main limitations of the present study was the recruitment of participants. A purposive sampling method was employed, in which the gatekeeper at the organisation selected the young people that they felt would be most appropriate to take part in the interview. Therefore, it is important to consider that there were not opportunities for a range of different children and young people to have their voices heard. Further research may seek to adopt a random sample of participants in order to ensure that the sample is more diverse. However, considering the ethical issues involved in recruiting participants during the Covid-19 pandemic as discussed in Chapter 4.4.1, the opportunity sample meant that the gatekeeper was able to select participants that were best suited to being involved in the study at the time of data collection.

A further limitation of the present study was the sample size. The small sample of seven participants, who were all associated with the same organisation, brings into question the transferability of the present study. First, the small sample size makes it difficult to transfer the findings to the wider context of young people living with HIV. In addition, the fact that all of the participants were associated with the same organisation, who are a significant protective factor for young people living with HIV, suggests that this has supported them to have increasingly positive experiences. Further research may wish to focus on a bigger sample with a larger number of participants. However, the small sample size of this study allowed for a thorough, detailed exploration of young people’s experiences through in-depth semi-structured interviews.

When undertaking this research study, it was hoped that interviews would be carried out within the young person’s environment in order to fully engage with the group of young people and to establish a community level understanding in line with the work of Howarth et al. (2004). The main hope for the interviews to be carried out face to face was the opportunities to build rapport over a period of time so that a trusting relationship with the participants could be formed. However, it was required that interviews took place remotely due to the Covid-19 pandemic. In order to attempt to overcome some of the concerns related to rapport building, time and space was allocated to build rapport with the participants, with cameras turned on, and facilitated by the gatekeeper on some occasions and at the request of the participant. Musselwhite et al. (2007) state that a limitation of remote interviews is the fact that they can cause difficulties with engaging participants and limits the amount of non-verbal communication that is gathered within regular face-to-face interactions. During the remote interviews in the present study, cameras were turned off due to the sensitive nature of the research and therefore any non-verbal communication was lost. However, it was felt that the participants found a sense of safety in the fact that they did not have to take part in the face-to-face interview and each young person appeared to share a significant amount of information during each interview.

7.6 Implications for educational psychology practice

EPs work closely with schools and other educational settings, such as colleges, to support children and young people to ensure that they are able to receive appropriate support and provision to meet their needs. EPs work in line with legislation, such as the Equality Act (2010) and the Special Educational Needs and Disability (SEND) Code of Practice (2015) in order to ensure that children and young people have access to services and opportunities regardless of their age, disability, gender, ethnicity, religion, beliefs, and sexual identity. EPs consult with children, young people, and families so that they can plan, commission and review services, as well as working closely with schools to support them to promote the inclusion of all pupils in accordance with the previously mentioned legislation. In order to achieve this, EPs work with schools at the individual level, group level, and organisational level (Curran et al., 2003). The ways in which EPs are potentially best placed to support schools around HIV appears to be at the individual and organisational levels, the reasons for which will be detailed below.

EPs are able to form close, trusting relationships with children, young people and their families so that they can be advocates and can act as a bridge between the home and school settings. Therefore, EPs are well-placed to working alongside children and young people living with HIV in order to both support them to share their views around the forms of support they feel they need to receive in school settings and to be a strong advocate. EPs will therefore be able to work with the school system to consider the most appropriate ways of supporting individuals who are impacted by this condition and promoting their inclusion within the school environment. EPs often work with children and young people with medical conditions and have the skills and expertise to enable schools to consider appropriate forms of support and provision to meet their needs. The present study has shed light on the impact of taking medication on a young person’s school experience, with participants reflecting on the difficulties that this can cause them in school. These difficulties can have a significant impact on learning, and it is important that EPs help schools to understand these issues and consider the most appropriate and sensitive ways of meeting their needs and enabling them to access learning. In addition, young people living with HIV are vulnerable to experiencing mental health difficulties, which has been widely documented in the literature to date. Again, this has the potential to have a detrimental impact on the educational experiences and wellbeing of such young people and it is important that professionals, such as EPs, are able to facilitate discussions with schools to consider the most appropriate forms of support.

EPs hold frequent planning meetings within schools, predominantly with SENCos, in order to plan work. During these planning meetings, it may be important for EPs to question whether schools are aware of any children or young people with specific medical needs in order to emphasise the school’s and EPs’ role in supporting such individuals. However, many children and young people may not always share information about their diagnosis, and this should be borne in mind when children present with the difficulties associated with regularly taking medication (e.g., fatigue, nausea). Schools predominantly commission EP services and therefore EPs will be reliant on children, young people, and families disclosing their HIV status to school staff. Hopefully, through the work between schools and EPs, creating an open, inclusive school culture could lead to a reduction in non-disclosure. A way in which this issue may be overcome, could be through EPs delivering training to parents of children and young people living with HIV in collaboration with charities and organisations who support such affected individuals. This would aim to increase parents’ awareness of the role of EPs and how they may be able to support a child or young person living with HIV should they decide to disclose their status to school.

In addition to the support that can be potentially offered at the individual level, training, and support at a wider, organisational level, may also be within the remit of an EP. It is clear through the literature review of Chapter 3 and the findings from the in-depth semi-structured interviews of Chapter 5 that there is a learning need for teachers and school staff supporting young people living with HIV. Participants reflected on challenging experiences in school that related to the lack of knowledge of both their peers and school staff. EPs frequently deliver training to schools across a range of different themes. Therefore, it may be that EPs can facilitate training around HIV and supporting such children and young people in school settings, potentially alongside healthcare professionals that provide medical support. This would also promote the concept of HIV-friendly schools. EPs have vast experience in working holistically and collaboratively in order to promote a caring, supportive, and inclusive environment. Therefore, EPs may be well-placed to work within a multi-disciplinary team to support schools to become HIV-friendly. An approach like this would call for continuing professional development among EPs so that they can increase their knowledge around HIV-related issues and how best to support schools to become HIV-friendly.

EPs may also have the opportunity to support children and young people living with HIV in a range of different settings, such as in the community settings discussed throughout this study, e.g., camps. Supporting young people in more informal settings may involve working with professionals to co-construct educational programmes within community settings for children and young people living with HIV in order to ensure that information is accessible. Further to this, EPs could support with the presentation of information and material available on websites so that they are further supporting with the accessibility of trustworthy sources of information. EPs may also support professionals to include young people in the educational programmes, ensure that their views are being considered and listened to in order to further develop these programmes. In addition, given the fact that people living with HIV are at risk of experiencing difficulties with mental health and wellbeing, EPs may have a more direct role in supporting young people within community settings. EPs, with expertise in mental health and wellbeing, may have a role in facilitating discussions around these areas with children and young people living with HIV through developing their understanding of coping strategies.

7.7 Reflective statement

Through the process of carrying out this research study, some key findings appear to have influenced my current practice as a Trainee EP working in an inner-London borough. Throughout planning meetings with SENCos, in which an exploration of the work to be completed on a termly basis is carried out, I have ensured that I highlight the importance of working with children and young people living with medical conditions and the scope of support that can be offered by EPs. In addition, a key finding from this research study around the potential physical and mental health impact of taking medication has allowed me to support school staff with working effectively with children and young people with medical conditions. I have drawn upon knowledge of the ways in which young people can be adversely affected by taking medication in order to open up discussions with staff around appropriate support and ways of working with such individuals.

This research study has prompted me to consider the ways in which I can disseminate these findings, through providing a research briefing to the organisation I worked with, through presenting my findings to Educational Psychology Services, and through seeking a future publication.

7.8 Conclusion

This research study has provided a rich, detailed understanding of the lived experiences of children and young people living with HIV in the UK. There has been limited qualitative research in the UK exploring young people’s experiences, especially related to educational settings. Therefore, this study provides a unique exploration of the lived and educational experiences of young people living with HIV.

Those involved in this study reflected on a range of supportive systems that led to positive experiences for them. Some of these positive experiences stemmed from the young people disclosing their HIV status to others, such as their peers and teachers in schools. However, as the young people reflected on throughout this study, a range of psychosocial factors, such as stigma, and the fear of rejection and isolation, led to many young people forming representations of HIV as private, shameful, and threatening, and therefore found it difficult to disclose their status to those who did not also have HIV. A key finding from this research study was the impact of taking medication on both physical and mental health, and the affect that this can have on children and young people attending school settings. Young people living with HIV who did choose to disclose their status alluded to increased social support, experiences in an inclusive school environment, and opportunities to discuss HIV-related issues within school in order to receive both emotional and educational support as positive experiences. Being exposed to positive experiences appeared to be linked to young people having a positive identity and representations of themselves as not being defined by the medical condition.

School staff and EPs may be able to influence young people’s positive identities and representations of themselves as young people living with HIV through creating inclusive, supportive environments in school to ensure that school systems are a protective factor.

References

Alderson, P. (University C. L. (2021). *Critical Realism for Health and Illness Research: A Practical Introduction*. Policy Press. https://go.openathens.net/redirector/umoncton.ca?url=https%3A%2F%2Febookcentral.proquest.com%2Flib%2Fumoncton-ebooks%2Fdetail.action%3FdocID%3D6463232

Andersen, L., Nyamukapa, C., Gregson, S., Pufall, E., Madanhire, C., Mutsikiwa, A., Gawa, R., Skovdal, M., & Campbell, C. (2014). The Role of Schools in Supporting Children Affected by Hiv: Stakeholder Report 2014. *Biomedical Research and Training Institute, Harare, Zimbabwe*.

Balayan, T., & Sudfeld, C. R. (2020). Health-related quality of life among adults living with HIV: A cross-sectional survey in Armenia. *AIDS Care*, 1–11. https://doi.org/10.1080/09540121.2019.1709615

Bauer, M. W., & Gaskell, G. (1999). Towards a Paradigm for Research on Social Representations. *Journal for the Theory of Social Behaviour*, *29*(2), 163–186. https://doi.org/10.1111/1468-5914.00096

Bauer, M. W., & Gaskell, G. (2008). Social Representations Theory: A Progressive Research Programme for Social Psychology. *Journal for the Theory of Social Behaviour*, *38*(4), 335–353. https://doi.org/10.1111/j.1468-5914.2008.00374.x

Booker, R. (2021). A psychological perspective of agency and structure within critical realist theory: A specific application to the construct of self-efficacy. *Journal of Critical Realism*, *20*(3), 239–256. https://doi.org/10.1080/14767430.2021.1958281

Brandt, C., Zvolensky, M. J., Woods, S. P., Gonzalez, A., Safren, S. A., & O'Cleirigh, C. M. (2017). Anxiety symptoms and disorders among adults living with HIV and AIDS: A critical review and integrative synthesis of the empirical literature. *Clinical Psychology Review*, *51*, 164–184. https://doi.org/10.1016/j.cpr.2016.11.005

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Harvard University Press.

Bronfenbrenner, U. (1989). Ecological systems theory. *Annals of Child Development*, *6*, 187–249.

Bronfenbrenner, U. (Ed.). (2005). *Making human beings human: Bioecological perspectives on human development*. Sage Publications.

Brown, M. T., & Bussell, J. K. (2011). Medication Adherence: WHO Cares? *Mayo Clinic Proceedings*, *86*(4), 304–314. https://doi.org/10.4065/mcp.2010.0575

Bucek, A., Mellins, C. A., Leu, C.-S., Dolezal, C., Wiznia, A., & Abrams, E. J. (2020). Psychiatric disorders and young adult milestones in HIV-exposed, uninfected youth. *AIDS CARE*, *32*(4), 10.

Burr, V. (2003). Social Constructionism. In *International Encyclopedia of the Social & Behavioral Sciences* (pp. 222–227). Elsevier. https://doi.org/10.1016/B978-0-08-097086-8.24049-X

Campbell, C., Andersen, L., Mutsikiwa, A., Madanhire, C., Nyamukapa, C., & Gregson, S. (2016). Can Schools Support HIV/AIDS-Affected Children?

Exploring the ‘Ethic of Care’ amongst Rural Zimbabwean Teachers. *PLoS ONE*, *11*(1). https://doi.org/10.1371/journal.pone.0146322

Campbell, C., Andersen, L., Mutsikiwa, A., Madanhire, C., Skovdal, M., Nyamukapa, C., & Gregson, S. (2014). Children’s representations of school support for HIV-affected peers in rural Zimbabwe. *BMC Public Health*, *14*(1). https://doi.org/10.1186/1471-2458-14-402

Carr, A. J., & Higginson, I. (2001). Measuring quality of life: Are quality of life measures patient centred? *BMJ*, *322*(7298), 1357–1360. https://doi.org/10.1136/bmj.322.7298.1357

Chapman Lambert, C., Westfall, A., Modi, R., Amico, R. K., Golin, C., Keruly, J., Quinlivan, E. B., Crane, H. M., Zinski, A., Turan, B., Turan, J. M., & Mugavero, M. J. (2020). HIV-related stigma, depression, and social support are associated with health-related quality of life among patients newly entering HIV care. *AIDS Care*, *32*(6), 681–688. https://doi.org/10.1080/09540121.2019.1622635

Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychologist*, *26*(2), 120–123.

Copelyn, J., Thompson, L. C., Le Prevost, M., Castro, H., Sturgeon, K., Rowson, K., Brice, S., Foster, C., Gibb, D. M., & Judd, A. (2019). Self-harm in young people with perinatal HIV and HIV negative young people in England: Cross sectional analysis. *BMC Public Health*, *19*(1), 1165. https://doi.org/10.1186/s12889-019-7424-7

Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics. *University of Chicago Legal Forum*, 31.

Crenshaw, K. (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review*, *43*(6), 1241–1299. https://doi.org/10.2307/1229039

Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th edition, international student edition). SAGE.

Crockett, K. B., Kalichman, S. C., Kalichman, M. O., Cruess, D. G., & Katner, H. P. (2019). Experiences of HIV-related discrimination and consequences for internalised stigma, depression and a. *Psychology & Health*, *34*(7), 796–810.

Curran, P., Gersch, I., & Wolfendale, S. (2003). Educational Psychology. In R. Bayne & I. Horton, *Applied Psychology: Current Issues and New Directions* (pp. 23–37). SAGE Publications Ltd. https://doi.org/10.4135/9781446279151.n2

Das, A., Detels, R., Javanbakht, M., & Panda, S. (2016). Issues around childhood disclosure of HIV status – findings from a qualitative study in West Bengal, India. *Child: Care, Health and Development*, *42*(4), 553–564. https://doi.org/10.1111/cch.12338

Duveen, G. (2001). Social representations. In B. Fraser, B. Burchell, D. Hay, & G. Duveen (Eds.), *Introducing Social Psychology* (pp. 268–288).

Duveen, G., & Lloyd, B. (Eds.). (1990). *Social Representations and the Development of Knowledge* (1st ed.). Cambridge University Press. https://doi.org/10.1017/CBO9780511659874

Earnshaw, V. A., & Chaudoir, S. R. (2009). From Conceptualizing to Measuring HIV Stigma: A Review of HIV Stigma Mechanism Measures. *AIDS and Behavior*, *13*(6), 1160–1177. https://doi.org/10.1007/s10461-009-9593-3

Earnshaw, V. A., Smith, L. R., Chaudoir, S. R., Amico, K. R., & Copenhaver, M. M. (2013). HIV Stigma Mechanisms and Well-Being Among PLWH: A Test of the HIV Stigma Framework. *AIDS and Behavior*, *17*(5), 1785–1795. https://doi.org/10.1007/s10461-013-0437-9

Eriksson, M., Ghazinour, M., & Hammarström, A. (2018). Different uses of Bronfenbrenner's ecological theory in public mental health research: What is their value for guiding public mental health policy and practice? *Social Theory & Health*, *16*(4), 414–433. https://doi.org/10.1057/s41285-018-0065-6

Evangeli, M., Lut, I., & Ely, A. (2019). A longitudinal evaluation of an intensive residential intervention (camp) for 12–16 year olds living. *AIDS Care*, *31*(1), 85–89.

Faircloth, C., Twamley, K., & Iqbal, H. (2021). 'Er, not the best time': Methodological and ethical challenges of researching family life during a pandemic. *Families, Relationships and Societies*. https://doi.org/10.1332/204674320X16073443900591

Farr, R. M. (1996). *The Roots of Modern Social Psychology*. Oxford: Blackwell.

Fielden, S. J., Sheckter, L., Chapman, G. E., Alimenti, A., Forbes, J. C., Sheps, S., Cadell, S., & Frankish, J. C. (2006). Growing up: Perspectives of children, families and service providers regarding the needs of older children with perinatally-acquired HIV. *AIDS Care*, *18*(8), 1050–1053. https://doi.org/10.1080/09540120600581460

Flick, U. (2018). *An introduction to qualitative research* (6th edition). SAGE Publications.

Flick, U., & Foster, J. L. H. (2008). Social representations. In C. Willig & W. Stainton-Rogers (Eds.), *The SAGE Handbook of Qualitative Research in Psychology* (pp. 195–214). London: SAGE.

Gadow, K. D., Angelidou, K., Chernoff, M., Williams, P. L., Heston, J., Hodge, J., & Nachman, S. (2012). Longitudinal Study of Emerging Mental Health Concerns in Youth Perinatally Infected With HIV and Peer Comparisons. *Journal of Developmental and Behavioral Pediatrics : JDBP*, *33*(6), 456–468. https://doi.org/10.1097/DBP.0b013e31825b8482

Gillard, A., Witt, P. A., & Watts, C. E. (2011). Outcomes and Processes at a Camp for Youth With HIV/AIDS. *Qualitative Health Research*, *21*(11), 1508–1526. https://doi.org/10.1177/1049732311413907

Given, L. (2008). *The SAGE Encyclopedia of Qualitative Research Methods*. SAGE Publications, Inc. https://doi.org/10.4135/9781412963909

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Penguin.

Hayes, S. W. (2021). Commentary: Deepening understanding of refugee children and adolescents using Bronfenbrenner's bioecological and PPCT models – A Commentary on Arakelyan and Ager (2020). *Journal of Child Psychology and Psychiatry*, *62*(5), 510–513. https://doi.org/10.1111/jcpp.13403

Herzlich, C. (1973). *Health and illness: A social psychological analysis*. European Association of Experimental Social Psychology by Academic Press.

Hibbert, M., Crenna-Jennings, W., Kirwan, P., Benton, L., Lut, I., Okala, S., Asboe, D., Jeffries, J., Kunda, C., Mbewe, R., Morris, S., Morton, J., Nelson, M., Thorley, L., Paterson, H., Ross, M., Reeves, I., Sharp, L., Sseruma, W., …

Delpech, V. (2018). The people living with HIV stigma survey UK 2015: HIV-related sexual rejection and other experiences of stigma and discrimination among gay and heterosexual men. *AIDS Care*, *30*(9), 1189–1196. https://doi.org/10.1080/09540121.2018.1479027

Höijer, B. (2010). Emotional anchoring and objectification in the media reporting on climate change. *Public Understanding of Science*, *19*(6), 717–731. https://doi.org/10.1177/0963662509348863

Howarth, C. (2002). Identity in Whose Eyes? The Role of Representations in Identity Construction. *Journal for the Theory of Social Behaviour*, *32*(2), 145–162. https://doi.org/10.1111/1468-5914.00181

Howarth, C., Foster, J., & Dorrer, N. (2004). Exploring the Potential of the Theory of Social Representations in Community-Based Health Research—And Vice Versa? *Journal of Health Psychology*, *9*(2), 229–243. https://doi.org/10.1177/1359105304040889

Howarth, C. S. (2001). Towards a Social Psychology of Community: A Social Representations Perspective. *Journal for the Theory of Social Behaviour*, *31*(2), 223–238. https://doi.org/10.1111/1468-5914.00155

Ipsos Healthcare. (2014). *HIV in Schools: Uncovering the Unmet Needs in Management of Children Affected by HIV*. https://www.chiva.org.uk/files/8614/3808/7012/14-060786-01_HIV_in_Schools_23Jul15_revisions_2.pdf

Jaspal, R., & Nerlich, B. (2017). Polarised press reporting about HIV prevention: Social representations of pre-exposure prophylaxis in the UK press. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, *21*(5), 478–497. https://doi.org/10.1177/1363459316649763

Joffe, H. (1996). AIDS research and prevention: A social representational approach. *British Journal of Medical Psychology*, *69*(3), 169–190. https://doi.org/10.1111/j.2044-8341.1996.tb01863.x

Joffe, H. (2011). Public apprehension of emerging infectious diseases: Are changes afoot? *Public Understanding of Science*, *20*(4), 446–460. https://doi.org/10.1177/0963662510391604

Le Prevost, M., Arenas-Pinto, A., Melvin, D., Parrott, F., Foster, C., Ford, D., Evangeli, M., Winston, A., Sturgeon, K., Rowson, K., Gibb, D. M., Judd, A., & on behalf of the Adolescents and Adults Living with Perinatal HIV (AALPHI) Steering Committee. (2018). Anxiety and depression symptoms in young people with perinatally acquired HIV and HIV affected young people in England. *AIDS Care*, *30*(8), 1040–1049. https://doi.org/10.1080/09540121.2018.1441972

Liamputtong, P. (Ed.). (2016). *Children and Young People Living with HIV/AIDS: A Cross-Cultural Perspective* (2016th ed.). Springer International Publishing : Imprint: Springer. https://doi.org/10.1007/978-3-319-29936-5

Liamputtong, P. (2019). *Handbook of research methods in health social sciences*. Springer Berlin Heidelberg.

Liamputtong, P., & Haritavorn, N. (2014). To tell or not to tell: Disclosure to children and family amongst Thai women living with HIV/AIDS: Table 1: *Health Promotion International*, *31*(1), 23–32. https://doi.org/10.1093/heapro/dau057

Lut, I., Evangeli, M., & Ely, A. (2017). “When I went to camp, it made me free”: A longitudinal qualitative study of a residential intervention for adolescents living with HIV in the UK. *Children and Youth Services Review*, *79*, 426–431. https://doi.org/10.1016/j.childyouth.2017.07.002

Macnamara, J. (2005). Media Content Analysis: Its Uses; Benefits and Best Practice Methodology. *Asia Pacific Public Relations Journal*, *6*(1), 1–34.

Major, B., & O’Brien, L. T. (2005). The Social Psychology of Stigma. *Annual Review of Psychology*, *56*(1), 393–421. https://doi.org/10.1146/annurev.psych.56.091103.070137

Malee, K. M., Tassiopoulos, K., Huo, Y., Siberry, G., Williams, P. L., Hazra, R., Smith, R. A., Allison, S. M., Garvie, P. A., Kammerer, B., Kapetanovic, S., Nichols, S., Van Dyke, R., Seage, G. R., Mellins, C. A., & for the Pediatric HIV/AIDS Cohort S. (2011). Mental health functioning among children and adolescents with perinatal HIV infection and perinatal HIV exposure. *AIDS Care*, *23*(12), 1533–1544. https://doi.org/10.1080/09540121.2011.575120

Mellins, C. A., & Malee, K. M. (2013). Understanding the mental health of youth living with perinatal HIV infection: Lessons learned and current challenges. *Journal of the International AIDS Society*, *16*(1), 18593. https://doi.org/10.7448/IAS.16.1.18593

Moscovici, S. (1961). *La psychanalyse, son image et son public* (3. éd). Presses Univ. de France.

Moscovici, S. (1972). Theory and society in social psychology. In J. Israel & H. Tajfel (Eds.), *The Context of Social Psychology* (pp. 17–68). London: Academic Press.

Moscovici, S. (1973). Preface. In C. Herzlich (Ed.), *Health and Illness: A Social Psychological Analysis* (p. V–VII). London: Academic Press.

Moscovici, S. (1984). The phenomenon of social representations. In R. M. Farr & S. Moscovici (Eds.), *Social Representations* (pp. 3–69). Cambridge: Cambridge University Press.

Moscovici, S. (1988). Notes towards a description of Social Representations. *European Journal of Social Psychology*, *18*(3), 211–250. https://doi.org/10.1002/ejsp.2420180303

Moscovici, S. (2000). Society and theory in social psychology. In S. Moscovici & G. Duveen (Eds.), *Social Representations: Explorations in social psychology*. Cambridge: Polity.

Musselwhite, K., Cuff, L., McGregor, L., & King, K. M. (2007). The telephone interview is an effective method of data collection in clinical nursing research: A discussion paper. *International Journal of Nursing Studies*, *44*(6), 1064–1070. https://doi.org/10.1016/j.ijnurstu.2006.05.014

Nanni, M. G., Caruso, R., Mitchell, A. J., Meggiolaro, E., & Grassi, L. (2015). Depression in HIV Infected Patients: A Review. *Current Psychiatry Reports*, *17*(1), 530. https://doi.org/10.1007/s11920-014-0530-4

National AIDS Trust. (2014). *HIV Public Knowledge and Attitudes*.

National Health Service. (2018). *HIV and AIDS*. https://www.nhs.uk/conditions/hiv-and-aids/

National Health Service. (2021). *HIV and AIDS*. https://www.nhs.uk/conditions/hiv-and-aids/treatment/

Neal, M. R. (2013). *Media Content Analysis: Qualitative Methods*. Oxford University Press. https://doi.org/10.1093/oxfordhb/9780195398809.013.0029

Neuendorf, K. A. (2017). *The Content Analysis Guidebook*. SAGE Publications, Inc. https://doi.org/10.4135/9781071802878

Nightingale, D. J., & Cromby, J. (2002). Social Constructionism as Ontology: Exposition and Example. *Theory & Psychology*, *12*(5), 701–713. https://doi.org/10.1177/0959354302012005901

Nobre, N., Pereira, M., Roine, R. P., Sintonen, H., & Sutinen, J. (2017). Factors associated with the quality of life of people living with HIV in Finland. *AIDS Care*, *29*(8), 1074–1078. https://doi.org/10.1080/09540121.2017.1281879

Persson, A., Newman, C. E., & Miller, A. (2016). "There's More to You Than Just This Virus": Young People Growing Up with Perinatally-Acquired HIV in Australia. In P. Liamputtong (Ed.), *Children and Young People Living with HIV/AIDS: A Cross-Cultural Perspective* (pp. 107–124). Springer International Publishing. https://doi.org/10.1007/978-3-319-29936-5_6

Petersen, I., Bhana, A., Myeza, N., Alicea, S., John, S., Holst, H., & McKay, M. (2010). Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in. *AIDS Care*, *22*(8), 970–978.

Philogene, G. (1994). 'African American' as a new Social Representation. *Journal for the Theory of Social Behaviour*, *24*(2), 89–109. https://doi.org/10.1111/j.1468-5914.1994.tb00248.x

Pilgrim, D. (2020). *Critical realism for psychologists*.

Public Health England. (2019). *Prevalence of HIV infection in the UK in 2018*.

Robson, C., & McCartan, K. (2016). *Real world research: A resource for users of social research methods in applied settings* (Fourth Edition). Wiley.

Rosenthal, L. (2016). Incorporating intersectionality into psychology: An opportunity to promote social justice and equity. *American Psychologist*, *71*(6), 474–485. https://doi.org/10.1037/a0040323

Rueda, S., Mitra, S., Chen, S., Gogolishvili, D., Globerman, J., Chambers, L., Wilson, M., Logie, C. H., Shi, Q., Morassaei, S., & Rourke, S. B. (2016). Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: A series of meta-analyses. *BMJ Open*, *6*(7), e011453. https://doi.org/10.1136/bmjopen-2016-011453

Sweeney, S. M., & Vanable, P. A. (2016). The Association of HIV-Related Stigma to HIV Medication Adherence: A Systematic Review and Synthesis of the Literature. *AIDS and Behavior*, *20*(1), 29–50. https://doi.org/10.1007/s10461-015-1164-1

The Children's Society. (2018). *The Good Childhood Report 2018*.

Tudge, J., Freitas, L., & F Doucet. (2012). The Transition to School: Reflections from a Contextualist Perspective. In *Educational Theories, Cultures and Learning: A Critical Perspective* (pp. 117–133). Taylor and Francis.

Tudge, J. R. H., Mokrova, I., Hatfield, B. E., & Karnik, R. B. (2009). Uses and Misuses of Bronfenbrenner's Bioecological Theory of Human Development. *Journal of Family Theory & Review*, *1*(4), 198–210. https://doi.org/10.1111/j.1756-2589.2009.00026.x

Turan, B., Budhwani, H., Fazeli, P. L., Browning, W. R., Raper, J. L., Mugavero, M. J., & Turan, J. M. (2017). How Does Stigma Affect People Living with HIV? The Mediating Roles of Internalized and Anticipated HIV Stigma in the Effects of Perceived Community Stigma on Health and Psychosocial Outcomes. *AIDS and Behavior*, *21*(1), 283–291. https://doi.org/10.1007/s10461-016-1451-5

Wagner, W., Duveen, G., Farr, R., Jovchelovitch, S., Lorenzi-Cioldi, F., Marková, I., & Rose, D. (1999). Theory and Method of Social Representations. *Asian Journal of Social Psychology*, *2*(1), 95–125. https://doi.org/10.1111/1467-839X.00028

Willig, C. (2008). *Introducing qualitative research in psychology: Adventures in theory and method* (2nd ed). Open University Press.

Willig, C. (2013). *Introducing qualitative research in psychology* (3. ed). Open Univ. Press.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, *15*(2), 215–228. https://doi.org/10.1080/08870440008400302

Appendices

Appendix A: Research Advert

The lived experiences of young people living with HIV

Doctoral research project, Theo Ogbonna-Marks UCL Institute of Education

Who I am

My name is Theo Ogbonna-Marks and I am currently studying the Professional Doctorate in Educational, Child and Adolescent Psychology. As part of the course, we are required to carry out a research project. I am interested in learning more about the lived and educational experiences of children and young people who are living with HIV.

About my research

Since leaving my voluntary role supporting young people with HIV to undertake the doctoral course, I have been eager to carry out a research project that focuses on eliciting the narratives of children and young people who are living with HIV. My research project will involve a 45-60 minute interview with interested participants. Participants will receive a £10 reward for participation.

Aims of the research

- To explore the lived experiences of children and young people living with HIV;
- To explore the educational experiences of children and young people living with HIV;
- To explore the views of children and young people living with HIV about the support they would like to receive in educational settings.

Overall purpose of my research

I am hoping that this project will help to raise awareness of some of the issues experienced by children and young people living with HIV, and to inform professionals of how to appropriately support children and young people in school and community settings.

Contact Details:

Please contact me via email @ucl.ac.uk if you are interested in taking part in the research.

Appendix B: Information sheet and consent form (child/young person)

What it's like to be young and living with HIV in the UK

You have been invited to be involved in a resarch project. Before you decide that you want to be involved in this project, it is important that you read the following information so that you understand what the research is about and what taking part will involve.

Who am I?

My name is Theo Ogbonna-Marks and I am currently carrying out a research project at the UCL Institute of Education as part of my course. Before starting this course, I worked with young people living with and affected by HIV at a charity in London.

Research project aims:

I am carrying out a research project to look at what it is like to be a young person living with HIV in the UK. I am interested in looking at educational experiences and how we can best support children and young people living with HIV in school.

Why have you been chosen?

I am asking you to take part as you are a member at [organisation].

Do I have to take part?

No. It is your decision whether or not you want to take part in the research project. If you decide you do want to take part, you can say no at any point and withdraw from the project at any time. You do not have to give a reason for your decision. Any unprocessed data will be destroyed.

What do I have to do if I take part?

The research project will involve a 60-minute interview via a telephone call or secure video conferencing platform (Microsoft Teams). This is due to the current Covid-19 pandemic, which means that we will be unable to meet face-to-face.

All the information I will collect will be confidential. Your personal details will not be included when I write up my research project.

The interview

During the interview, I will be asking some questions about what it is like to be young and living with HIV. I will also be asking some questions about your experiences in school and how these could be made better.

During the interview, if you become upset, you will be able to speak to someone from [organisation]. You will also be able to speak to someone after the interview if you need to.

Everything you tell me in the interview will be kept private and will be stored safely and securely. The only time I will have to tell someone what you told me is if I am worried about your safety. In this situation, I will need to speak to the Safeguarding Lead at [organisation].

What are the benefits of taking part?

I am hoping that this research project will help to raise awareness of some of the issues that you may experience in school and offer support and recommendations for some of the ways we can better support kids living with HIV in schools in the UK.

What do I do now?

If you would like to take part, please read the data protection privacy notice and fill in the consent form below. Please return the completed form to the email address below.

If you have any queries, please do not hesitate to contact me via email. If you would like to discuss anything in more detail, I am very happy to arrange a telephone call.

Researcher:

Theo Ogbonna-Marks

Email address: @ucl.ac.uk

Thank you for reading this information sheet and for thinking about taking part in the resarch project.

Data Protection Privacy Notice

Some of the things that will be asked during the research project will be sensitive, e.g., information such as age, gender, and ethnicity, however, we will collect only the minimum amount of personal data required to carry out the research. We will follow the rules of Data Protection Law.

Who will see your data?

- All personal information (data) will be kept safe, protected and locked. Data will be stored on UCL servers, and a password-protected mobile phone and laptop in the UK.
- Only the researchers will see this data.
- At the end of the research, the results will be shared with you.
- Original recordings are stored securely and will be deleted within 10 years after the completion of the study.
- Interviews will be recorded, written up, and analysed. When this happens, all personal data will be removed so that you will not be identified.
- No one outside the research team will be able to identify you.

How we use your information and what will happen after the research?

- We will give you the results of the research.
- We will write about what you tell us in a report, and this may be disseminated to academics and policy makers. We will use a pretend name for you, and no one would be able to tell you took part.

- Sometimes these reports and presentations can be read by anyone on the internet, but this will not include any personal details.

If you have any questions about this Privacy Notice, want further information, or want to complain, then please contact our Data Protection Officer using the following details:

Data Protection & Freedom of Information Officer

data-protection@ucl.ac.uk

If you are concerned about how your personal data is being processed, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

What it's like to be young and living with HIV in the UK

Consent for Young People

Please complete this form after you have read the information sheet and/or listened to an explanation about the research project.

Thank you for considering taking part in this research project. If you have any questions about the information sheet, please ask the researcher before you decide whether you want to give your full consent.

I confirm that I understand that by ticking each box below I am consenting to the part of the research project.

I understand that unticked boxes means that I do NOT consent to the part of the study.

I understand that by not giving consent for any one part of the research project means that I may be unable to take part in the whole study.

	Please tick
I have read and understood the information sheet about the research, or it has been explained to me.	☐
I agree to take part in an interview for the purpose of this research project.	☐
I agree that my words may be used in reports, but my name will not be used, and will not be written in any lists or papers	☐
I understand that I can leave the research project at any time, and if I choose to do this, any data I have contributed will not be used.	☐
I know that I can refuse to answer any or all of the questions during the interview.	☐
I agree to my interview being audio/video recorded and understand that the recordings will be stored anonymously, using password-protected software.	☐
I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	☐
I voluntarily agree to take part in this study.	☐

I understand that if I have any questions or complaints I can talk to the researcher using the details on the information sheet, or I can ask someone else to talk to them on my behalf ☐

Name ………………………… Signed …………………………

Date …………………………

Please print, sign, and photograph this page. If you are unable to print this page, I will be able to send a paper copy to you.

This photograph can be sent to the below email address. I will then be in contact with you to arrange an interview.

Theo Ogbonna-Marks

@ucl.ac.uk

Appendix C: Information sheet and consent form (parent)

What it's like to be young and living with HIV in the UK

Who am I?

Hello. My name is Theo Ogbonna-Marks and I am currently studying the Professional Doctorate in Educational, Child and Adolescent Psychology at the UCL Institute of Education. As part of the Professional Doctorate, we are required to carry out a research project. I have chosen to learn more about what it's like to be young and live with HIV in the UK. This is a topic very important to me. Before starting my studies, I spent two years working with children and young people living with and affected by HIV and this experience left me feeling that there is still much to learn in this area, especially around education.

What is the research about?

This research project will explore the lived experiences of children and young people who are living with HIV. I am especially interested in focusing on educational experiences in order to consider some of the ways in which children and young people living with HIV can be further supported in school and community settings.

What will the research involve?

The research will involve a 60-minute interview with your child via a telephone call or secure video conferencing platform (Microsoft Teams). All interviews will be online due to the current Covid-19 pandemic. I will also be speaking to other children and young people living with HIV about their lived and educational experiences. The children and young people will also choose whether or not they want to be involved in the research project and will receive an information sheet and consent form similar to this one.

What will the benefit be?

This research project will aim to raise awareness and understanding of the lived and educational experiences of children and young people living with HIV. The focus on educational experiences will help to raise awareness of some of the issues faced in school settings. This will help us to consider the ways in which children and young people living with HIV feel that they want to be supported in school in order to explore how we can better support young people in the future.

What happens next?

If you are happy for your child to take part in this research project, please read the data protection privacy notice and fill in the consent form below. Please return the completed form to the email address below. If you would like to discuss anything further, I am very happy to arrange a telephone call.

Additional information

- All the interviews will be confidential and the names of all children and young people involved will NOT be included when I write up the research project.
- I have received training to work with young people as part of my course and am already familiar with some of the challenges young people living with HIV experience.
- Your child will be able to refuse or withdraw from the research project at any time. Your child will not have to give a reason if they do not want to be involved in the project any longer.
- Everything your child says will be kept private and will be stored safely and securely.
- The only time I will tell someone about what your child tells me, is if I am worried about their safety. I will need to report this to the Safeguarding Lead at [organisation].

- Your child will have the opportunity to speak to someone from [organisation] during and after the interview if they become upset or distressed.

Contact details

Email address: @ucl.ac.uk

Many thanks for your time.

Data Protection Privacy Notice

Some of the things that will be asked during the research project will be sensitive, e.g., information such as age, gender, and ethnicity, however, we will collect only the minimum amount of personal data required to carry out the research. We will follow the rules of Data Protection Law.

Who will see your child's data?

- All personal information (data) will be kept safe, protected and locked. Data will be stored on UCL servers, and a password-protected mobile phone and laptop in the UK.
- Only the researchers will see this data.
- At the end of the research, the results will be shared with you and your child.
- Original recordings are stored securely and will be deleted within 10 years after the completion of the study.
- Interviews will be recorded, written up, and analysed. When this happens, all personal data will be removed so that your child cannot be identified.
- No one outside the research team will be able to identify your child.

How we use your child's information and what will happen after the research?

- You will receive the results of the research.

- A report will be sent to academics and policy makers. Pretend names will be used so that no one would be able to tell who took part.
- Sometimes these reports and presentations can be read by anyone on the internet, but this will not include any personal details.

If you have any questions about this Privacy Notice, want further information, or want to complain, then please contact our Data Protection Officer using the following details:

Data Protection & Freedom of Information Officer

data-protection@ucl.ac.uk

If you are concerned about how your personal data is being processed, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

What it's like to be young and living with HIV in the UK

If you are happy for your child to take part in this research project, please sign below. I will check with your child if they still want to be involved in the project on the day of the interview and inform them that they can refuse or withdraw at any point.

Please tick to indicate consent:

I am happy for my child to take part in this research project. This will include:

Participation in interview ☐

Child name ………………………………………………………

Parent name ………………………………………………………

Parent signature ………………………………………………………

Date ……………………………

Thank you for participating in this research project. If you have any queries about this form, please do not hesitate to contact me via email.

Please print, sign, and photograph this page. If you are unable to print this page, I will be able to send a paper copy to you.

This photograph can be sent to the below email address. I will then be in contact with you to arrange an interview.

Theo Ogbonna-Marks

@ucl.ac.uk

Appendix D: Signed ethics application form

Departmental use		
If a project raises particularly challenging ethics issues, or a more detailed review would be appropriate, the supervisor must refer the application to the Research Development Administrator via email so that it can be submitted to the IOE Research Ethics Committee for consideration. A departmental research ethics coordinator or representative can advise you, either to support your review process, or help decide whether an application should be referred to the REC. If unsure please refer to the guidelines explaining when to refer the ethics application to the IOE Research Ethics Committee, posted on the committee's website.		
Student name	Theo Ogbonna-Marks	
Student department	Psychology & Human Development	
Course	DEdPsy	
Project title	An exploration of the lived and educational experiences of children and young people living with HIV.	
Reviewer 1		
Supervisor/first reviewer name	Humera Iqbal	
Do you foresee any ethical difficulties with this research?	This final document has been developed following a number of drafts and iterations in which different aspects of the research were considered. Given this extensive process, I am confident that the research will not encounter ethical difficulties.	
Supervisor/first reviewer signature	[redacted]	
Date	02/10/2020	
Reviewer 2		
Second reviewer name	Karen Majors	
Do you foresee any ethical difficulties with this research?	Potential ethical issues have been considered and addressed.	
Supervisor/second reviewer signature	[redacted]	
Date		
Decision on behalf of reviews		
Decision	Approved	☒
	Approved subject to the following additional measures	☐

	Not approved for the reasons given below	☐
	Referred to REC for review	☐
Points to be noted by other reviewers and in report to REC		
Comments from reviewers for the applicant		
Once it is approved by both reviewers, students should submit their ethics application form to the Centre for Doctoral Education team: IOE.CDE@ucl.ac.uk.		

Appendix E: Interview schedule

A) Opening

1. My name is Theo Ogbonna-Marks and I am a Trainee Educational Psychologist. Thank you for agreeing to take part in the interview today. It will be about what it is like to be young and living with HIV. The interview will be based on a few topics, such as life experiences, school, outside support, and attitudes of others.
2. I hope that I will use the information from these interviews to think about the ways in which CYP living with HIV can be better supported in educational and other community settings.
3. This interview will be completely anonymous and should take around an hour to an hour and a half.
4. If at any point you feel that you don’t want to answer a question, then please don’t feel like you have to – we can move on at any point. Also, if you feel like you would like to have a break from the interview, please let me know and we can pause and return at any point. You are also able to withdraw from the interview at any point and do not have to provide a reason.
5. Are there any questions you want to ask before we begin?
6. I know that you have agreed on the consent form for this interview to be recorded but before I press record and we start the interview; would it be possible to just confirm again that you are happy for this interview to be recorded? I think it will be best if we turn our cameras off for recording purposes, just so it has our voice.

B) Introduction/Rapport Building

1. Before we start, it would be great if you could tell me a bit about yourself.
2. Prompts: name, are you currently attending an educational setting, interests, talents, skills, something proud of.

C) Early experiences

1. Can you tell me about when you first found out that you had HIV?
    a) Who told you?
    b) How did you feel at first when you were told about HIV?
    c) How did you initially feel others would perceive you?
    d) Did you know much about HIV before you found out?
2. What steps did you take to learn more about HIV? (where did you get your information)
3. Did you get any support from [X]? Who supported you with understanding more about HIV? (GP?)
4. Can you tell me about some of your early experiences of living with HIV? (Medication)

D) Wider Social Support & Coping

1. Who were some of the key people who supported you when you were told that you had HIV?
2. What/who else supported you? Tell me about the main people who support you now.
3. Do your friends/wider family know you are living with HIV (Disclosure)
4. Have you experienced any intolerance/discrimination around living with HIV (what are some of the common misconceptions of HIV you think people still have; do you feel like others perceive you differently; how would you like them to perceive you?)

5. Any important forms of coping that you have? (faith, friends, sport, media)

E) XXX

1. When did you first become involved with XXX? How have they supported you? (Topics they cover, what activities you do, do you focus on HIV or is it more general)
2. How has camp supported you?

F) Education

6. What were your school experiences like as a young person living with HIV?
7. Were you able to speak to any teachers about HIV? Any other key adults?
8. Were there any areas of the curriculum that you would say were supportive for you?
9. What was it like when you moved from primary school to secondary school? Secondary school to college?
10. Did you receive any additional support in secondary school?

G) Support in Education

1. Can you tell me about a time when you felt well supported in school? Who helped you? How did this make you feel? Is there any other setting(s) where you have felt well supported?
2. What support would you have liked to receive in school during times that may have been challenging?
3. Can you tell me about some of the ways you think young people with HIV should be supported in school?
4. Are there any other kinds of support you can think of?

H) Future

   1. Moving forward, what are your plans for the future?
   2. Can you think about what has helped you to be in your current position?

I) Closing

   1. Thank you very much for your time. I appreciate you taking time out of your day for this interview. Is there anything that you thought I’d ask today but I haven’t covered?
   2. Just to let you know, I will be collecting all the data, which will be completely anonymised, when I finish interviewing all the participants. The data will then be used to produce a doctoral thesis, for which you will have a copy of the research briefing (which will be a summary of the research and its relevance to practice).
   3. Thank you again for your time today and I hopefully look forward to seeing you in the future.

Appendix F: List of codes in alphabetical order

Being shutdown

Camp

Community

Coping

Curiosity

Disclosure

Educating others

Educational impact

Educational support

Emotional impact

Fear

Forced disclosure

Hopes

Internalising behaviours

Isolated

Lack of support

Lack of understanding

Learning

Media

Medication

Misconceptions

Miseducation

Not being defined

Parental mental health

Parental support

People’s perceptions

Positive experiences

Power imbalance

Prejudice and discrimination

Professional support

Secrecy and non-disclosure

Self-education

Self-esteem or self-worth

Shy, reserved

Social care

Social support

Stigma

Support for family

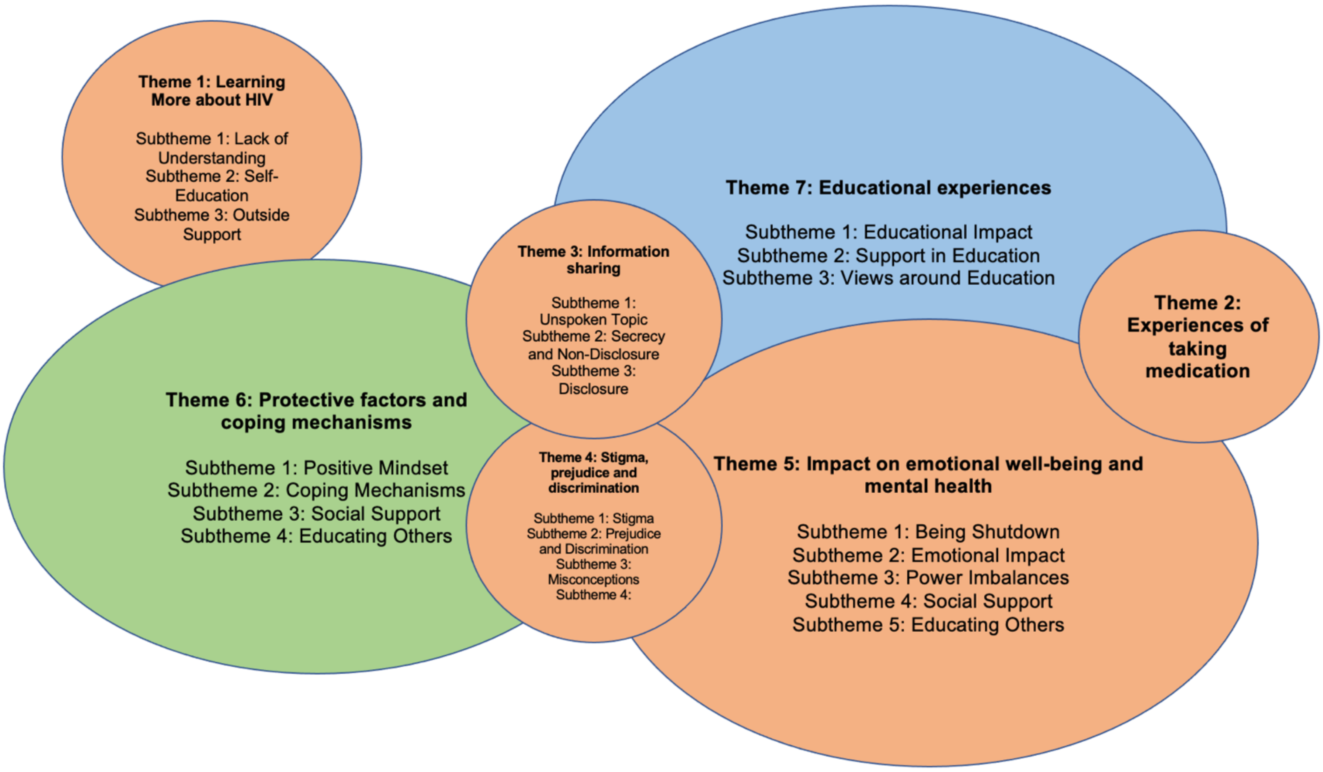
Support

Supporting others

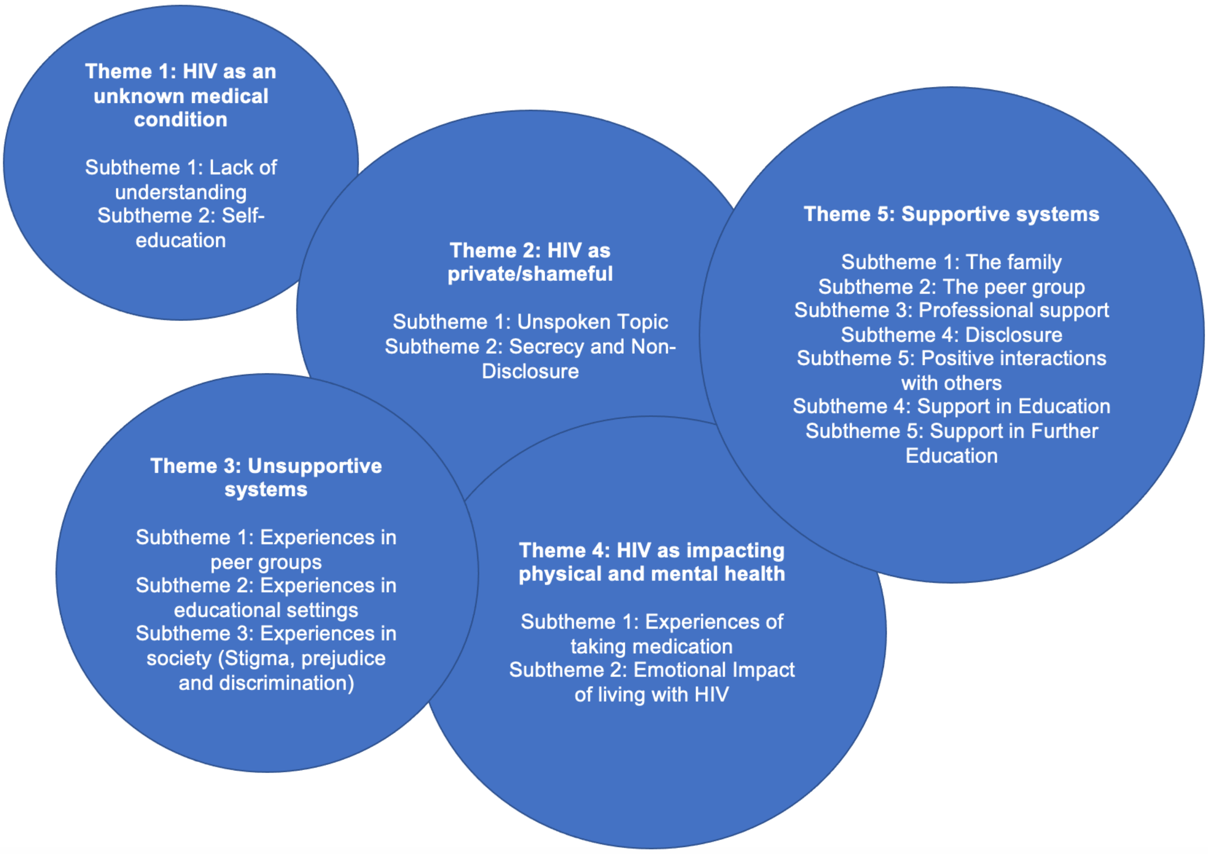
Trauma

Unspoken topic

Appendix G: Thematic map 1



Appendix H: Thematic map 2



Appendix I: Final thematic map