Thesis Submitted for the Award of PhD at Lancaster University

Stigmatised transitions into adulthood: Understanding the experiences of black African youth with prenatally acquired HIV in the UK.

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Abstract

Young black African migrants living with prenatally acquired HIV in the UK experience an intersection of racism and HIV stigma. Their parents play a role in socialising them into their status as stigmatised. This makes transition into adulthood difficult in specific ways that could be better supported if we had a good understanding of them, but no-one has looked at this. Despite the knowledge that the population of young people with prenatally acquired HIV in the UK is mainly comprised of black Africans, no research has explored how the intersection of race and HIV related stigma may potentially exacerbate transition challenges of this group.

The aim of this qualitative study was to address this gap by reporting on the experiences and impact of intersecting stigmatised identities as well as being socialised into stigma by parents, on the transition to adulthood of the black African young people with prenatally acquired HIV living in the United Kingdom (UK). Using semi-structured interviews with 13 male and female participants between the ages of 16-25 years, the study explored the young people's experiences of being socialised into stigma by parents, ethnic and HIV-related stigma with particular reference to employment, peer and romantic relationships and the ways in which these experiences shaped their transition into adulthood.

The findings revealed that the transition to adulthood of prenatally infected HIV positive black African youth in the UK is not only affected by ethnic and HIV related stigma but also by the covert and overt messages from their parents that HIV is a stigmatised disease therefore it has to be kept private. The privacy orientation from parents and society's negative attitudes toward Africans and HIV, restrict the young people's ability to disclose their status consequently, limiting their social support networks and delaying or preventing their opportunities to form families of their own or fulfil their employment and career aspirations. There is need for stigma reduction interventions that include the parents and are also ethnic-sensitive so to challenge the racist stereotypes towards the black African youth with prenatally acquired HIV living in the UK in order to promote a successful transition into adulthood.

Declaration

I confirm that this thesis is entirely my own work and has not been submitted or presented elsewhere.

Signed: S. Muchena Date:22 March 2021

Salome Muchena

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Chapter 1

Introduction

It was in high school, at the end of my GCE ‘O’ Levels in Zimbabwe some 34 years ago that I first heard about Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) from my then English teacher. I remember the whole class distancing ourselves from the disease and ignorantly taking a stigmatising stance making judgemental statements such as: “If you are promiscuous, well, you will reap what you sow.” Little did I know that a decade down the line, the disease would have ravaged my family and wiped out all of my older siblings; I would be the adoptive mother to two nephews both born with HIV. It was a time of heartache as I hopelessly watched my “two children” and was constantly overwhelmed by the fear of losing them to the disease one day. Fortunately, due to the advances in HIV treatment and the subsequent introduction of highly active antiretroviral therapy (HAART), for many people, including my two children, HIV is no longer a terminal illness. Instead, it has been transformed into a treatable chronic illness (Fielden et al., 2006; Gibb et al., 2003).

Even though, in recent years there has been a dramatic improvement in the life expectancy of young people born with HIV, who are now living healthier lives, the language of stigma has not yet changed. Society continues to hold the same prejudiced attitudes toward people living with HIV; stigma related to HIV continues to be a challenge (Mburu et al., 2014). Despite relentless efforts to lobby for the eradication of HIV stigma by many organisations such as The National Aids Trust (NAT) in the United Kingdom (UK), the unchanging prejudices and discrimination against people living with HIV inevitably left me concerned about how this may be impacting on my children and other young black people in the UK born with HIV now that they are transitioning into adulthood and, in particular, whether living in a foreign country has an impact on their experiences. In addition, the unyielding and tenacious nature of the stigma also led me to be interested in the role of parents in stigma and how that affects the transition into adulthood of young people with HIV, especially where the parents too are of an ethnic minority. Research with HIV positive adults has shown that those from ethnic minority groups are less likely to disclose their HIV status (Korner, 2007; Petrak et al., 2001). Based upon this evidence, it is reasonable to assume that the parents of such young people may have passed on a fear of disclosure to their children, perhaps related, in part, to ethnicity. It is these concerns and anxieties that led me to this research to try and understand the parents' role in socialising young people into stigma, the young people's experiences of ethnic-related stigma and how both might be acting in tandem with HIV stigma to impact on young people in various areas of their lives as they transition into adulthood as HIV positive immigrants in the UK. I hope that this understanding may be used to inform policy and ethnically sensitive HIV stigma reduction interventions.

The UK has a small but significant number of young people of Black and Minority Ethnic (BME) background living with HIV since birth (Gibb et al., 2003). Although not very large in terms of numbers, this population is an important group whose needs can easily be ignored due to the small population (Dorrell and Katz, 2013a). UNICEF statistics suggest that, in 2019, there were around 1.7 million cases of young people between the age of 10- and 19-years old living with HIV worldwide and about 1.5 million of these lived in sub-Saharan Africa (UNICEF, 2020). In recent decades, we have seen some of this population migrate to developed countries such as the UK with their parents/guardians for various reasons including educational purposes, family reunion, political and economic instability in their countries of origin (Poppe et al., 2014). Research by the Collaborative HIV Paediatric Study (CHIPS)[1] has indicated that, by early 2014, there were 1039 children and young people living with prenatally acquired HIV in the UK (CHIPS, 2014). The study revealed that 820 out of the 1039 young people were of black African ethnicity and nearly 96% of them were infected through mother-to-child transmission; the majority were born abroad (CHIPS, 2014). HIV infection is no longer a terminal disease because of the increased access to antiretroviral medications worldwide, including in the UK. As a result, there is now a cohort of prenatally HIV infected young people living in the UK who are predominantly of BME background and transitioning into adulthood (CHIPS, 2014).

This thesis is framed around the concern that immigrants have always been stigmatised and associated with diseases, in particular HIV in recent decades (Harper and Raman, 2008; Markel and Stern, 2002). Likewise, the National Aids Trust (NAT, 2003) states:

> “Stigmatisation and discrimination are not new to migrant communities and the AIDS epidemic has played into and reinforced existing racism… because of HIV stigma and pre-existing negative assumptions, people from ethnic minorities experience a double discrimination… on the grounds of race and on the basis of HIV status” (NAT, 2003: 1).

Against such a backdrop, this thesis is concerned with investigating how young black African migrants in the UK born with HIV are navigating their way into adulthood. Research suggests

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[1] CHIPS is a collaboration between UK and Ireland centres that care for HIV infected children, members of the Institute of Child Health and the Medical Research Council Clinical Trials Unit.

that young people, in general, face significant challenges in the transition to adulthood, due, for example, to reduced employment prospects (Heinz, 2009; Furlong and Cartmel, 1997). Furthermore, evidence show that growing up with a stigmatised identity can hinder successful transition into adulthood (Halverson, 2005; Furlong and Cartmel, 2007). However, we know very little about how the added burden of HIV and race-related stigma coupled with stigma socialisation from parents may affect young people with prenatally acquired HIV in the UK as they navigate their way into adulthood. Despite the knowledge that the population of young people living with HIV in the UK is predominantly of BME background, no research has yet explored how intersectional stigma in addition to coaching from parents may potentially exacerbate transition challenges for this group. It is important to understand more about the combination of the parents' role, HIV- and ethnic-related stigma to ensure that these young people are properly supported and that interventions to tackle HIV stigma are tailor-made and holistically designed (Hogwood et al., 2013; Time to Change, 2007)[2].

The UK government has gone some way towards addressing HIV-related stigma and discrimination by including HIV as a disability under the Equality Act (2010). The aim of the legal framework is to protect people living or associated with HIV and certain other illnesses from discrimination. The Act also protects people from discrimination on the grounds of their race/ethnicity (Equality Act, 2010; NAT, 2016). Whilst the policy is relevant to all people living with HIV in general and also to black African people living with or affected by HIV, it does not exclusively address issues pertaining to young black people born with HIV as they transition into adulthood in the context of the layers of stigma referred to above. These young people continue to have distinct HIV-related issues compared to those who acquire the disease

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[2] Time to change is a programme run by Mind and Rethink mental health charities. The programme is aimed at ending stigma and discrimination against the mentally ill.

later in life. These issues include having to learn to live and grow up with a stigmatised identity in a foreign country and trying to foster intimate relationships and fulfil career aspirations whilst learning how to navigate the issues of secrecy and disclosure with various significant others in that foreign context (NAT, 2014).

Although HIV stigma in the UK is alluded to in various strategies for sexual health, the National Aids Trust has criticised the UK for not having a clear strategic plan to address HIV stigma (NAT, 2016). For instance, the Framework for Sexual Health Improvement in England (Health, 2013) identifies the need for continued efforts to fight the stigma, discrimination and prejudice often associated with sexual health matters. Accordingly, the national HIV prevention programme managed by The Terrence Higgins Trust and funded by the Department of Health England has included tackling HIV stigma within the black African population as one of its components. However, similarly to the Equality Act (2010) this programme fails to specifically include issues of transition relating to young black African people born with HIV despite evidence that transition into adulthood can be more challenging for those with a stigmatised identity and more so for those who are doubly marginalised (Halverson, 2005; Furlong and Cartmel, 2007).

Nonetheless, the People Living with HIV Stigma Index (2015) in the UK has been built on the above observations by identifying the different layers of stigma experienced by migrants living with HIV in the UK, including ethnicity and migration. A report based on the study findings for the Stigma Index recommends efforts to fight HIV stigma that take into account discourses emanating from the multiple layers that interface with HIV stigma among the black African population in the UK (Chinouya et al., 2017). Against such recommendations, the National Aids Trust endorsed research into exploring the experiences of multiple stigma amongst the black African community in the UK in order to inform policy makers, funders and intervention planners (NAT, 2014). There has been a growing literature concerning the issues of layers of stigma among black African people living with HIV in the UK (Chinouya et al., 2017; Doyal, 2009) . However, these studies have been carried out with adults whose experiences of stigma might be different from the young people in this study whose lives have been fraught with stigma since birth and who are now trying to navigate into adulthood heavily burdened with stigma.

In spite of this specific gap in the literature, a limited number of UK-based studies have sought to explore the experiences of growing up with HIV (Dorrell et al., 2008; Hamblin, 2011; Hogwood et al., 2013). Although these studies have explored the issues of stigma in relation to the challenges young people face regarding disclosure of their status, they have focused only on HIV as a reason why the young people struggled to disclose their status. They did not go beyond the HIV and explore other factors such as ethnicity and the role of parents in initiating their children into stigma; such factors may be exacerbating disclosure issues and consequently impacting on their transition into adulthood (Goffman, 1963; Petronio, 2002; Flair and Albright, 2012). There is no study exploring the added impact of ethnicity and the role of parents in stigma among the young black African people living in the UK born with HIV as they transition into adulthood; this is a significant gap given the population of young people with prenatally acquired HIV living in the UK. This thesis therefore seeks to address this gap by exploring the intersection of ethnicity, HIV and parents’ role in stigma among the black African young people in the UK born with HIV and the impact of these factors on the young people’s transition into adulthood.

The core objectives of this thesis are thus to explore and understand:

i) The experiences of race/ethnic- and HIV-related stigma and stigma socialisation by parents, among black African young people in the UK born with HIV

ii) The impact of these experiences on the young people's transition into adulthood

1.1. Overview of Chapters

This chapter has provided the context for the study; subsequent chapters will address the following: an exploration of the theoretical underpinnings of youth transition, stigma as well as the literature surrounding ethnicity and HIV-related stigma; and a description of the methodology used and the results derived from qualitative interviews. Finally, a discussion section reviewing the findings of the study will be presented.

Chapter 2 begins by providing a conceptual framework for youth transition by Erikson (1968). The section then shifts attention to the frameworks of stigma, illustrating how stigma may manifest in young people with prenatally acquired HIV and how this might complicate their transition into adulthood along the lines of disclosure. Having established the role of parents in socialising young people into stigma and consequent disclosure dilemmas, the next section will then focus on ethnicity and how this too might complicate their transition into adulthood. The communication privacy model and how this might help us understand more fully the dilemmas the young people might face in disclosing their HIV status will be the focus of the next section. Finally, the chapter will provide a discussion on employment and transitioning in the context of ethnicity.

Chapter 3 begins by justifying the decision to use a qualitative approach and the use of interviews to collect data and the challenges faced. The methodology is discussed further in light of the challenges met in recruiting participants and arranging interviews in both clinical and home environments. The data analysis is explored alongside a consideration of the key themes which were derived. The chapter concludes with an examination of my impact and role as a researcher on the research process.

Chapter 4 is the first of three chapters presenting the findings of the study which are derived directly from the young people's narratives and then related to the relevant literature. Drawing from the young people's narratives, this chapter explores their lives prior to and after learning of their HIV status with particular focus on the contexts in which the young people were brought up. The chapter explores these contexts and the role they played in making the young people aware of the stigma attached to their HIV status.

Exploring the young people's experiences of forming peer and romantic relationships as they try to attain markers of adulthood in the context of HIV and ethnicity is the focus of Chapter 5. It begins with an exploration of the young people's narratives on their social networking with peers before focusing on their romantic relationships. Chapter 6 then explores the young people's career and employment trajectories in the face of ethnic-related stigma.

Finally, Chapter 7 pulls together the contributions of this under three themes emerging from the findings and these will be discussed with reference to the theoretical frameworks underpinning this study. The first theme focuses on the origins of stigma awareness in the young people's lives, with particular reference to the role of parents and professionals. The second theme demonstrates how ethnicity exacerbates HIV stigma and how this affects the young people in terms of the formation of relationships with peers and romantic partners. Finally, the impact of ethnic and HIV stigma on career choices and aspirations is central to the last theme. The chapter will end with some methodological reflections on the study as well as suggestions for future areas of research.

Chapter 2

Literature Review

2.0. Introduction

This chapter will briefly describe the relevant literature in this field before exploring the theoretical debates around youth transition and stigma in order to give a better understanding of young people's experiences of growing into adulthood in the face of layers of stigma. The chapter will then move on to explore literature relating to the dilemmas of disclosure before examining how communication privacy theory might offer insights into these dilemmas.

2.1. Literature Search

The following Social Sciences related databases were searched for relevant studies throughout the study from its commencement to April 2020: Child Development and Adolescent Studies (CDAS), SocIndex, PsyInfor and Medline. Terms indicative of transition were combined and entered into the Child Development and Adolescent Studies database in order to capture the concept of youth transition (see Appendix 1 for terms used and number of retrieved articles). The other three databases, SocIndex, PsyInfor and Medline were searched in order to capture concepts of ethnicity, stigma and HIV (see table Appendix 1 for the terms used and number of retrieved articles). All the articles and books identified as potentially relevant were then assessed by reference to the abstracts and summaries to ascertain how each piece of work would contribute to the study. Those with little or no relevance were discarded.

2.2. Youth Transition Frameworks

The concept of youth transition is at the very core of the focus for this study. Youth transition is a very critical period when young people move from adolescence to adulthood. European sociology has adopted the metaphor “transition” to try and understand the experiences of young people in this liminal state as they sit on the border between childhood and adulthood (Furlong and Cartmel, 2007; Bradford and Clark, 2011). A number of perspectives have been developed to try and explain how young people experience the transition into adulthood with some early work on the developmental perspective pioneered by the American psychologist Stanley-Hall (1904). He argued that youth or adolescence is the most perilous stage of human development which involves transitioning from childhood to adulthood (Stanley-Hall, 1904). This conceptualisation of youth making the perilous journey from childhood to adulthood then became popular with other psychologists such as Erikson (1968).

Erikson proposed an eight-stage model of psychosocial development. However, only two stages – identity and intimacy – are relevant to this study since these are the stages which characterise adolescence and early adulthood (Erikson, 1968). Erikson conceptualises that for each psychosocial development stage, there is an opposing potential outcome; for example, during the identity formation stage, the young person may also be confronted with role confusion, and during intimacy formation, the adolescent may be faced with potential isolation (Erikson, 1968; Vogel-Scibilia et al., 2004; Beyers and Seiffge-Krenke, 2010; Pittman et al., 2011). According to the psychosocial model, the task for the individual is to resolve the dialectical tension between these opposing aspects in order to successfully reach adulthood (Erikson, 1968; Pittman et al., 2011).

The psychosocial developmental model posits that the process of resolving these opposing aspects as the young people try and develop identity and intimacy is shaped by the historical and cultural contexts in which the identity and intimacy are taking place (Pittman et al., 2011).

Thus, Erikson emphasises that the developmental and self-relevant information regarding identity and intimacy is influenced by the young person's significant relationships in their lives (Erikson, 1968; Vogel-Scibilia et al., 2009). Some writers have observed that the parent-child relationship can have an impact on identity formation in a young person; for instance, individuals whose parents are overprotective during the identity formation period, may yield to an identity characterised by insecurity (Vogel-Scibilia et al., 2009).

However, as the young person actively explores and engages with the world as they navigate through the identity and intimacy phases, their radius of significant relationships expands from the sphere of parents to peers and romantic partners (Erikson, 1968). Peers and romantic partners become highly important; the young person begins to spend more time in exploration with peers and romantic partners and these people become important sources of interaction and support (Erikson, 1968; Steinberg and Morris, 2009; Pittman and Richmond, 2008; Worth, 2009; Huynh and Fuligni, 2010; Pittman et al., 2011). Stable social networks with peers contribute to the young people's sense of well-being and connectedness and these will, in turn, provide the young people with the confidence and support needed to face the challenges of transitioning into adulthood (Masten et al., 2004; Schoen et al., 2007; Hagell et al., 2018). Nevertheless, Erikson (1968) maintains that even as the young people's social worlds expand, their parents continue to be key figures in their identity and intimacy formation processes; they continue to offer oversight and assistance as the young person encounters challenges during the transition.

Whilst during the identity/role confusion phase young people establish who they are (their identity), during the intimacy/isolation stage, the individual determines with whom they want to share their identity (Erikson, 1968; Lenz, 2001; Zimmer-Gembeck and Petherick, 2006). During the intimacy phase, adolescent romance starts to manifest and romantic partners become important (Erikson, 1968; Furman and Shaver, 2003; Gomez-Lopez et al., 2009). Romantic relationships play a key role in the development of the young person. They provide the young person with the opportunity to define their identity further by projecting their image on the partner; those with a clearer sense of identity are more willing to share intimacy and the opposite is also true (Montgomery, 2005; Pittman et al., 2011). Romantic relationships also provide company, emotional security, intimacy, positive self-concept, personal happiness, and greater social integration (Erikson, 1968; Montgomery, 2005; Meler and Allen, 2008; Adamczyk and Segrin, 2015; Blanca et al., 2018). Some writers have argued that successful formation and maintenance of romantic relationships can contribute to young people's well-being (Arnett et al., 2014; Davila et al., 2017; Gomez-Lopez et al., 2019).

However, threats to one's identity may negatively impact on development and attainment of adulthood markers. For instance, negative treatment during this period, when young people are pursuing their identity and intimacy goals, may affect their long-term adjustment (Erikson, 1968; Kerpelman et al., 2004; Blank et al., 2004). Young black African youth with prenatally acquired HIV in the UK may be especially vulnerable to identity threats as they may face stigma and be treated differently both on the basis of their ethnicity and their HIV status (Blank et al., 2004). In their quest for social connectedness and peer acceptance, their sphere of relationships may expand; hence, they may start to recognise and perceive discrimination more as they become increasingly exposed to negative stereotypes and how society views their ethnic group as inferior (Brown et al., 2011; Gee and Walsemann, 2009; Huynh and Fuligni 2012). Huynh and Fuligni (2010) have argued that stigma shapes the developmental trajectories of ethnic minority groups. As black African youth with prenatally acquired HIV in the UK become sensitised to stigma, they may begin to struggle with their identity, trying to separate their personal identity from the implications of and emotions related to ethnic and HIV stigma (Seaton et al., 2008; Vogel- Scibilia et al., 2009). In an attempt to separate their personal identity from the stigmatised identity, they may try to hide their stigmatised identity by avoiding and isolating themselves from society (Vogel-Scibilia et al., 2009; Brown and Larson, 2009; Huynh and Fuligni, 2010). Although the young people may be successful in hiding their stigmatised identity (particularly HIV) from peers and employers, dating and establishing intimacy with romantic partners may cause intense feelings of anxiety. This may mean that such young people struggle to establish an intimate relationship (Montgomery, 2005; Vogel-Scibilia et al., 2009; Beyers and Seiffge-Krenke, 2010).

Although Erikson's perspective informs our understanding of the challenges that may be faced by black African youth with prenatally acquired HIV in the UK as they transition into adulthood, it has been criticised for inferring that transition to adulthood takes place in a chronological and predictable manner (Worth, 2009; Clark, 2012). More contemporary developmental theories, such as that of emerging adulthood developed by Arnett (2000), have offered a slightly different perspective on youth transition. Emerging adulthood postulates that contemporary youth transitions have become individualised and protracted with the acquisition of jobs and family formation being delayed until later as young people explore and acquire human capital which becomes a precursor to a successful adulthood (Arnett, 2000; Lee and Waithaka, 2017). Nonetheless, similarly to Erikson, Arnett defines transition as a distinctive developmental stage characterised by identity explorations in employment, romantic and social relationships (Arnett, 2000). However, emerging adulthood is not suited to this study as it infers that the delay in achieving adulthood markers is voluntary; it fails to articulate structural barriers such as stigma that might be an impediment to young people's identity explorations, making their transition complex and difficult to negotiate (Cieslik and Pollock, 2002; Lee and Waithaka, 2017). Erikson's conceptualisation of youth transition will be used in this current study since it contributes to our understanding of the influence of parents and society on young people's perception of their stigmatised identities. In addition, Erikson's conceptualisation is most suited to this study as it provides a framework through which we can understand how HIV- and ethnic-related stigma can pose threats to young people's identity explorations in the areas of employment, romantic and peer relationships.

It is generally agreed that youth transitions, particularly for the marginalised, have become more complex and difficult to negotiate over time (Furlong and Cartmel, 2007; Catan, 2004; Clark, 2012). Increasingly, many young people are experiencing fractured transitions and are faced with long struggles to obtain reliable work and secure independence (Cieslik and Pollock, 2002; Furlong and Cartmel, 2007). Whilst a growing body of literature suggests that transitions to adulthood differ and are made more difficult by the presence of stigma (Berlin et al., 2010; Berzin and De Marco, 2010; Jackson and Berkowitz, 2005), no study has ever simultaneously considered the impact of intersecting multiple layers of marginalised identities on the transition to adulthood of young black people born with HIV living in the UK. Some writers maintain that the intersection of multiple layers of marginalised identities may have a larger effect than that of a single stigmatised status (Shanahan, 2000b; Mahaffy, 2003; Lee and Waithaka, 2017). However, the focus of this study is not simply to examine how the intersection of HIV stigma and ethnicity might be influencing the attainment of adulthood status for black African youth with prenatally acquired HIV in the UK. To ensure a holistic approach, the study simultaneously explores how the parents' role in stigma, which may also be fuelled by ethnic-related stigma, could be an added factor in the transitioning challenges faced by African youth with prenatally acquired HIV living in the UK.

In order to fully understand how stigma socialisation/teaching by parents in addition to ethnic- and HIV-related stigma might be affecting the transition to adulthood for this population, it is important, firstly, to have an in depth understanding of how stigma manifests and how it weaves its way into every aspect of the everyday lives of individuals. The following section will now focus on the conceptualisation of stigma.

2.3. Conceptualising Stigma

Goffman defines stigma as an "undesirable attribute that deeply discredits" an individual (Goffman, 1963: 3). The individual with the socially undesirable attribute is perceived by society as diverging from group norms; thus, he/she acquires a "spoiled identity" leading to social devaluation and discrimination (Goffman, 1963). Stigma is experienced when the individual with the spoiled identity anticipates and senses disapproval (felt or perceived stigma) or experiences exclusion, isolation or disgust (enacted stigma) from those who do not possess the undesirable attribute (Scambler, 2009; Goffman, 1963).

Goffman claims that, when an individual is assigned the spoiled identity (the stigma), their significant others take responsibility for socialising the individual into an awareness of their perceived deviance, resulting in what Goffman refers to as a "moral career" (Goffman, 1963). He identified four types of moral careers of which three are relevant to the population in this study and these are described below. Goffman asserts that for those born with a stigma, socialisation to stigma takes place through the settings or circumstances they are brought up in; that is, they are raised in contexts that make them aware of their differences (Goffman, 1963; Tyler and Slater, 2018). For instance, some young people in a UK study by Dorrell et al. (2008), despite their parents keeping their HIV status a secret, reported picking up clues about HIV from the HIV clinics they regularly attended and also observing and listening to doctors' conversations. These individuals soon learned that whatever disease they had, it was not a good thing and it had to be concealed. Equally, families can socialise individuals by acting as what Goffman terms "protective capsules" through their efforts to protect the individuals from stigma. For example, findings from studies on young people with HIV have revealed how some parents instruct the young people to conceal their HIV status so as to protect them from being treated differently; in doing this, the young people became aware that having HIV is not socially accepted (Fielden et al., 2011; Hogwood et al., 2013).

Another pattern of socialisation occurs when the stigmatised individual grows out of their protective environment and must now learn to adapt and conform to the socially accepted norms of their new environment (Goffman, 1963). For instance, parents/guardians of HIV positive children can protect their children's HIV status within a protective capsule for so long until they are grown-ups and are developing new social networks (Dorrell et al., 2008). However, within these broader social networks, they experience the stigmatising attitudes of society towards HIV (Dorrell et al., 2008). Consequently, they may internalise the stigma leading to more feelings of shame as they start to believe in the negative attitudes of society towards their disease (Scambler, 2004).

In addition to the socialisation of stigma and “moral careers”, visibility of the undesirable attribute is also central to Goffman’s work. He described “discredited” individuals as those whose stigma is immediately visible, for instance through skin colour or that which others have previous knowledge of (Goffman, 1963). On the other hand, he also identified “discreditable” as individuals whose stigma is not outwardly visible and can be concealed, such as HIV. The term “discreditable” points to the looming possibility of the undesirable attribute being found out and the subsequent vulnerabilities associated with it (Goffman, 1963).

Goffman claims that socialisation to stigma makes one aware of the stigma identities individuals’ carry with them in their everyday lives and that those identities are imbued with social information which can be the basis of judgement from society (Goffman, 1963; Attell, 2013). Goffman affirms that “discreditable” individuals can choose to be in control of the social information they present to society in a number of ways (Goffman, 1963; Tyler and Slater, 2018). One such way is to dissociate from the people who may be the cause of the stigmatisation. Goffman refers to such people as “biographical others” (Goffman, 1963: 65). The whole purpose of distancing the self from the context of “biographical others” is to try to form a new identity which subsequently escapes from the consequences of stigma (Goffman 1963: 67). Furthermore, Goffman points out that those with a concealable stigma such as HIV have the option of “passing” as normal in order to avoid the devastating effects of being stigmatised (Goffman, 1963; Tyler and Slater, 2018). Passing may involve hiding any reference to the stigmatised disease or fabricating alternative stories to explain one’s differentness (Dorrell et al., 2008). Such a scenario has been evident in a number of studies involving young people with concealable diseases such as epilepsy as well as HIV (Fielden et al., 2011; Scambler, 2004). Findings from a study by Fielden et al. (2011) suggest that some young people resort to silence; not disclosing their HIV status represents a way to try and pass as normal. Although passing may help to avoid potential negative responses, managing a secret and concealing a stigma can be distressing (Scambler, 2009).

2.4. Felt and Enacted Stigma

Goffman's concept of socialisation to stigma was further developed by Scambler and Hopkins in their study of adults with epilepsy (Scambler and Hopkins, 1986; Scambler, 2004). They attempted to identify the primary source of stigma by countering the arguments of the orthodox viewpoint of the time which stated that discrimination is the principal source of distress or stigma among people with stigmatised identities (Deacon, 2005). In contrast, Scambler and Hopkins (1986), in their study of people with epilepsy, argue that one does not have to experience discrimination to feel stigmatised and the shame associated with the stigmatised disease. They maintain that the fear of being stigmatised can trigger the same feelings of shame associated with their disease. Scambler and Hopkins (1986), therefore, formulated an alternative model (Hidden Distress Model) to the orthodox viewpoint. The Hidden Distress Model makes a distinction between felt and enacted stigma (Scambler and Hopkins, 1986). Enacted stigma is described as the actual instances or experiences of stigma whilst felt stigma refers to the fear of enacted stigma and it also incorporates feelings of shame associated with the disease (Scambler and Hopkins, 1986).

Whilst work such as the Hidden Distress Model is relevant to this study in enhancing an understanding of how stigma can be experienced, such conceptualisation has remained confined within Goffman's understanding of stigma which has been criticised for being limited in scope (Link and Phelan, 2001; Parker and Aggleton, 2003; Tyler and Slater, 2018). Goffman's conceptualisation of stigma neglects the function of stigma as a form of power. Consequently, this has led to stigma being perceived only as a problem with social norms

(Tyler and Slater, 2018). Such understanding limits the focus of addressing stigma to educating society about stigmatised identities and teaching the stigmatised how to manage their differentness. However, the stigmatised might lack the power to protect themselves from society's stigmatising attitudes (Tyler and Slater, 2018; Link and Phelan, 2001).

Nevertheless, Goffman provides a powerful analytical framework for understanding stigma and his framework is relevant to this study as it meshes well with Erikson's developmental phases of identity and intimacy formation and how the social contexts play a significant role in shaping the young people's identities. Goffman's model therefore enhances our understanding of how the young people's stigma is a perspective generated in social settings in which the young people's stigmatised identities are formed as they transition into adulthood (Goffman, 1963; Erikson, 1968). Goffman's understanding of stigma will further assist in understanding how the young people manage the information imbued in their stigmatised identities (Goffman, 1963). Although in his initial claims, Goffman had postulated that stigma is historically specific and serves as a means of formal social power, he neglected these insights in his final conceptualisation of stigma (Goffman, 1963; Link and Phelan, 2001; Parker and Aggleton, 2003, Tyler and Slater, 2018).

Given the ethnic background of the participants in this study and the existing inequalities of race, understanding stigma whilst neglecting the issues of power inherent in stigmatisation will not offer a deeper understanding of the nature of stigma affecting the young black African youth with prenatally HIV in the UK (Parker and Aggleton, 2003; Tyler and Slater, 2018). To augment Goffman's conceptualisation of stigma, this study will employ another conceptualisation of stigma that takes into account the functions of stigma as a form of power that is exercised to keep certain groups of people down (Link and Phelan, 2001; Parker and

Aggleton, 2003; Hannem, 2012; Tyler and Slater, 2018). However, conceptualising stigma as a form of power will be discussed in a later section. The next section focuses again on understanding stigma based on Goffman's conceptualisation in order to explore the role of parents and social context in shaping the young people's perspectives of their stigmatised identities (Goffman, 1963).

2.5. Parents as Stigma Coaches

Guided by Goffman's understanding of stigma, Scambler argues that those born with stigmatised identities develop a special view of the world (Goffman, 1963; Scambler and Hopkins, 1986; Scambler, 2004). This is described as a way in which an individual interprets events associated with their undesirable identity. Scambler (2004) argues that this special view mainly stems from the teachings/coaching of parents. Data from a study of children with epilepsy indicated that parents of children acted as "stigma coaches"; the more they conveyed epilepsy as something bad and the less they were willing to talk about the disease with their children, the more the children viewed it as something undesirable, hence leaving the children with the impression that it had to be concealed (Schneider and Conrad, 1980). The parents and professionals coached the children on how to conceal their illness and how to be discreditable by lying or partially disclosing their disease and by giving non-stigmatising names to their epilepsy such as "passing out" or metaphors such as "dreams" (Scambler and Hopkins 1986; Scambler, 2004). Similar patterns of partial disclosure by parents and professionals were also observed in studies with HIV positive young people (Dorrell et al., 2008; Lesch et al., 2007; Kallem et al., 2011). Data from these studies reveal that children were not told the real name of their disease and, instead, non-stigmatising conditions such as asthma were given to the child to explain their ill-health.

Due to parents' stigma coaching/teaching, an individual's interpretation of their disease, for example HIV, is confined within the parameters of stigma; thus, their special view of the world is the sense of their disease as stigma (Scambler and Hopkins, 1986; Scambler, 2004). Scambler and Hopkins (1986) further theorised that whenever the special view of the world is activated by a situational stimulus, for example meeting a new friend, the individual's "special view of the world" predisposes them to secrecy or concealment. Consequently, according to Scambler (2004), a policy of concealment/non-disclosure is developed and firmly rooted in the individuals' lives. Scambler and Hopkins (1986) argue that felt stigma among the discreditable is rarely triggered by incidents of enacted stigma but it is often the result of the stigma coaching engaged in by parents and the subsequent policy of non-disclosure to try and manage their discreditable information so they can "pass" as normal. However, this approach is not without challenges. Scambler (2004) stresses that although the policy of non-disclosure originates in benevolence towards discreditable individuals, it renders decisions about disclosure of an illness particularly difficult. When the children outgrow the protective capsules of the parents and are then transitioning into adulthood and trying to foster intimacy in new social networks, they are faced with a dilemma: whether to break the rules of the concealing policy or not (Goffman 1963; Scambler, 2004).

2.6. Stigma Coaching and Disclosure

Young people with a concealable stigmatised disease such as HIV may need to disclose their status in order to establish emotionally close relationships in the hope of fostering intimacy which is critical to a successful transition into adulthood; however, they might find themselves constrained by the policy of non-disclosure instilled in them by their parents (Scambler and Hopkins, 1986; Greene and Faulkner, 2002; Greene et al., 2003).

Within the literature, there is evidence of the non-concealment/disclosure policy being reinforced by parents during this transition period. For instance, some young people born with HIV reported being reminded repeatedly by their parents to keep their HIV positive status a secret from anyone outside the nucleus family (Swendeman et al., 2006; Michaud et al., 2009; Fielden et al., 2011; Blake et al., 2012; Fair and Albright, 2012; Hogwood et al., 2013; Philbin, 2014; Dorrell et al., 2008; Persson and Newman, 2012). Consequently, the young people found it difficult to disclose their HIV status to romantic partners, peers or employers because of the instructions they had received from parents not to do so (Fair and Albright, 2012). This exacerbates the fear of rejection and isolation and is not only relevant to romantic partners but also extends to peers and employers (Michaud et al., 2009; Hogwood et al., 2013). Evidence indicates that young people born with HIV often expect to be stigmatised; they consistently worry about disclosing their status and are apprehensive about maintaining relationships after disclosure (Hogwood et al., 2013; Michaud et al., 2009; Fernet et al., 2011; Fielden et al., 2006; Swendeman et al., 2006; Blake et al., 2012). Given the significance of socialisation in the development of young people, the issue of whether to disclose one’s HIV status can present a huge dilemma (Hogwood et al., 2013; Michaud et al., 2009). Although many may decide not to disclose their status due to the fear of rejection and isolation initiated by parents, they may also fear their relationships and positions will be jeopardised if they fail to disclose and their peers, romantic partners or employers find out later from other sources (Hogwood et al., 2012; Philbin, 2014). Either way, the young person risks potential isolation and rejection (Michaud et al., 2009; Blake et al., 2012; Hogwood et al., 2013).

While a lot has been written about the role of parents in socialising their children into stigma, this role has not been explored in the context of its impact on transition into adulthood among HIV positive youth. There remains a gap in the literature, with no current study exploring the impact of stigma coaching from parents on disclosure of HIV status subsequently impacting on successful transition to adulthood. This study explores this role further, in particular its impact, in addition to ethnicity, on successful transition into adulthood among black African young people living with HIV in the UK, especially in terms of the domains of employment, peer and romantic relationships where disclosure of status may be necessary for a successful transition (Greene et al., 2003).

Whilst the preceding section has discussed the role of parents in socialising young people into stigma, and the challenges of a subsequent policy of non-disclosure, the next section will now focus on ethnicity and HIV with particular focus on how ethnicity may also affect disclosure of HIV status and consequently impact on successful transition into adulthood.

2.7. Ethnic- and HIV-related Stigma

Given the link between ethnicity and every aspect of HIV-related experience, focus will now turn to conceptualisations that regard stigma as a phenomenon purposefully employed in ways that seek to intensify existing inequalities of race (Link and Phelan, 2001, Parker and Aggleton, 2003, Tyler, 2020). Tyler (2020) asserts that it is impossible to separate stigma from power. Similarly, Parker and Aggleton (2003) have pointed out that when understanding the lasting nature of HIV-related stigma, it should be taken into account that stigmatisation is linked to notions of power and powerlessness in every society (Parker and Aggleton, 2003). They illustrated this further by conceptualising stigma as a vehicle by which “symbolic violence” can be exercised; that is, an insidious and invisible way of expressing hostility towards HIV positive people whilst simultaneously legitimising and reproducing existing structures of social inequalities of race (Parker and Aggleton, 2003, Bharat, 2002). Likewise, Castro and Farmer,

(2005) claim that stigma is often a small part of a whole package of social inequalities. They maintain that the way stigma has been conceptualised often pays very little attention to powerful social inequalities of race which come into play, especially in the context of HIV/AIDS.

With HIV remaining a highly stigmatised disease, some writers have pointed out that the challenge in the field of HIV-related stigma is that researchers have ignored the relational nature of the concept of stigma (Link and Phelan, 2001). They argue that much of the literature regards stigma primarily as the outcome of an individual possessing a negative attribute. Instead Link and Phelan recommend a conceptualisation of stigma as the “relationship between attribute and stereotype” (Goffman, 1963: 4, Link and Phelan, 2001). They argue that such a conceptualisation allows for the analysis of both the stereotyper and the stereotyped (Link and Phelan, 2001). The authors further argue that analysing the relational nature of stigma reveals the social inequalities that exist in the distribution of power by exposing who has the social, economic or political power to create and grant stereotypes for “it takes power to stigmatise” Link and Phelan, 2001: 375).

Against such a backdrop, some researchers posit that disease stigma draws heavily on existing lines of prejudices and stereotypes such as ethnicity; however, despite such evidence, work exploring HIV stigma in youth is often dissociated and decontextualised from larger social processes such as conceptualisations of race (Deacon, 2005; Castro and Farmer, 2005). Some writers have argued that ethnicity is a social factor and an identity that is intimately linked to every facet of HIV-related experience (Yep et al., 2002; Flaskerud and Nyamathi, 2000). Deacon (2005) further emphasises that there is a relationship between HIV stigma and other forms of prejudice in the sense that different negative meanings, associated with, for example, ethnicity, are also used to stigmatise HIV positive people of colour in the diaspora. Yet, research on stigma relating to youth living with HIV since birth in the UK has mainly concentrated on one aspect of prejudice, the HIV itself (Dorrell et al., 2008; Swendeman et al., 2006; Hogwood et al., 2013). Given that, currently, the population of young people born with HIV in the UK is mainly comprised of youth of a BME background, a group that is typically already deprived of power due to its ethnic background, it is important to also explore their experiences of stigma through the lens of ethnicity to try and understand how the intersection of ethnic- and HIV-related stigma might be impacting on their transition into adulthood and, in particular, how they are navigating their way into employment, and peer and romantic relationships (Williams and Fredrick, 2015; Chinouya et al., 2017).

Before citing some evidence suggesting the relationship between ethnicity/race and HIV stigma, it is important to give a brief history of the association of diseases with Africans. Such history serves to illuminate the structural inequalities and social prejudices that have long existed and will help explain why people of colour are disproportionately affected by HIV stigma and discrimination (Bharat, 2002).

Africans have long been perceived negatively in relation to disease (Bharat, 2002). Going back to the years of slavery, Wailoo (2006) reminds us how black Americans were blamed for bringing diseases such as hookworm and tuberculosis (TB) to America. Wailoo (2006) sheds more light on the structural inequalities when he points out that the fight against TB among black Americans in the slavery era was not a mere fight against the disease but it was also a fight against moral inferiority, ignorance and filth. In relation to disease and healthcare, black people were depicted as backward, ignorant, inferior and of unsanitary habits which were considered a breeding ground for diseases (Wailoo, 2006). Unfortunately, the stigmatisation of African-Americans in relation to diseases has perpetuated, even to this day, in the context of HIV (Bharat, 2002; Herek, 2002). Racist stereotypes have been engrained within concepts of the genesis of the disease, since its epidemic, with HIV first constructed as a Haitian disease and later an African disease (Gilman, 1988; Farmer, 2001). Given this history, it can be argued that stigma and discrimination linked to HIV is only playing into the already long-standing racial stereotypes and inequalities faced by people of colour (Deacon, 2005; Parker and Aggleton, 2003; Castro and Farmer, 2001). Some writers have maintained that the HIV discourse has endorsed racial stereotypes of ethnic minorities, especially black populations; they have been stereotyped as promiscuous and dangerous, hence a contagion in society (Farmer, 2001).

Data relating to the experiences of ethnic-related stigma in the field of HIV positive youth in the UK and beyond are extremely scarce. Though there is a dearth of data around ethnic- and HIV-related stigma faced by young people with prenatally acquired HIV, there is a growing body of literature on HIV stigma and race-related stereotypes and prejudices that has been derived from studies of HIV positive adults from ethnic minority groups (Green and Sobo, 2000; Petrak et al., 2001; Worth et al., 2001; Lekas et al., 2006; Körner, 2007; Loutfy et al., 2012).

Results from a quantitative study by Loutfy et al. (2012), assessing gender and ethnic differences in the context of HIV-related stigma, revealed that participants of non-white ethnic background were consistently associated with the highest scores for HIV-related stigma, suggesting that HIV-related stigma may be exacerbated by pre-existing social inequalities based on race (Loutfy et al., 2012). The higher scores for HIV-related stigma among ethnic minorities, as reported by Loutfy et al., (2012), are replicated in other studies revealing comparable levels of embeddedness of racial stereotypes in HIV-related stigma (Emlet, 2006; Lekas et al., 2006). Findings from Lekas et al., (2006) underscore the significance of perceived stereotypes in shaping the sense of stigma among HIV positive people from black and ethnic minority groups. The participants in Lekas and colleagues' study discussed extensively the stereotypes associated with HIV and reported that their HIV-related stigma was influenced by their ethnicity. They believed that their HIV-related stigma stemmed partly from society's tendency to look down upon them and blame them more for the disease compared to their white counterparts (Lekas et al., 2006).

Findings from the literature further indicate that people from ethnic minority groups believe that society automatically expects them to be prone to getting HIV, whilst their HIV positive white counterparts are depicted as innocent victims (Lekas et al., 2006). In addition, data from the literature indicate that HIV positive people from ethnic minority groups perceive press adverts relating to HIV to be imbued with racist notions, a position which intensifies their sense of stigma and subsequently impacts on their decisions to disclose their status (Lekas et al., 2006).

Some researchers have also argued that while HIV has resulted in stigma and discrimination for all HIV positive people, for people of ethnic minority backgrounds, the stigma is substantially intensified by virtue of their ethnicity, making disclosure of their status a considerable challenge (Green and Sobo, 2000; Körner, 2007). Findings from a number of studies have revealed that disclosure levels for HIV status are generally lower among people from ethnic minority backgrounds (Körner, 2007; Petrak et al., 2001; Worth et al., 2001). For instance, in a UK study, blacks and Asians had the lowest disclosure rates. Similarly, sub-Saharan refugees in a New Zealand study had kept their status a secret from everyone in their community (Petrak et al., 2001; Worth et al., 2001). Some writers have further validated the notion that ethnicity can affect an individual's disclosure of their HIV diagnosis and can exacerbate the difficulties associated with the disclosure (Flaskerud and Nyamathi, 2000; Yep et al., 2002). On the other hand, data from the literature reveal that in their own racial/ethnic communities where HIV is common and people have a higher exposure to the disease, HIV positive people are likely to disclose their status more freely. They feel they are less likely to be stigmatised compared to in communities where they are numerically in the minority (Lekas et al., 2006). These findings may be true for black African youth with prenatally acquired HIV in the UK. However, this study goes further to explore how this may affect the young people's transition into adulthood.

Having discussed how stigma coaching from parents and ethnicity might influence disclosure of an HIV status, the next section will further explore the dilemmas of disclosure in light of the communication privacy model in order to examine how an individual may try to manage these dilemmas (Petronio, 2002).

2.8. Communication Privacy Management Theory (CPM)

In order to understand how young people may be influenced by ethnicity and stigma coaching from their parents in terms of disclosure of their HIV status, the Communication Privacy Management (CPM) theory by Petronio (2002) contributes some insight. CPM uses a boundary metaphor to demonstrate how individuals formulate borders to surround their private information (Petronio, 2002; Greene et al., 2003). CPM echoes the sentiments of other theorists (Goffman 1963; Erikson, 1968; Scambler and Hopkins, 1986) by proposing that individuals are developed and socialised into privacy rule orientations by their families. The family orientates the individual in terms of privacy boundaries that should not be breached to reveal private information outside the family and this may also be influenced by ethnicity as highlighted in a preceding section (Petronio, 2002; Greene et al., 2003). The privacy rules become very ingrained in the individual through repetitive application of the same rules by the family (Petronio, 2002).

CPM postulates that, although an individual may finally reveal their private information, they may still be controlled by a number of factors such as ethnicity and privacy coaching/orientations from parents (Petronio and Durham, 2015; Petronio, 2002; Flaskerud and Nyamathi, 2000; Yep et al., 2002). Due to ethnic-related stigma and privacy orientations, individuals want to control the flow of their private information, to conceal or disclose it, given that the private information might make them susceptible to vulnerabilities if known (Petronio, 2002) However, retaining ownership and controlling third party disclosure can be difficult. Therefore, the process of disclosing private information involves a dialectical tension between closing and opening the privacy boundaries (Petronio, 2002; Greene et al., 2003). Thus, by disclosing one's HV status, an individual is managing a tension; a conflict between wanting to open the boundary and reveal their status to try and foster intimacy or wanting to close it and conceal their HIV status as coached by parents and also determined by ethnicity; these circumstances potentially lead to isolation (Erikson, 1968; Petronio, 2007; Flaskerud and Nyamathi, 2000; Fair et al., 2018). The tension emanates from the fear of the negative consequences of both. By opening the boundary and disclosing their HIV positive status, individuals are taking themselves out of their "protective capsule" a decision that might make themselves vulnerable to enacted stigma; yet, by closing their privacy boundary and concealing their diagnosis, they risk forfeiting the support they could have had from peers or employers

(Hogwood et al., 2013). Therefore, for the young people, the dilemma is about trying to manage and balance both opening and closing their privacy boundaries without any repercussions.

Nevertheless, an individual can try and manage this dilemma by allowing some boundary permeability and this is achieved by varying degrees of revealing or concealing their private information (Petronio and Reierson, 2009; Petronio, 2002; Greene et al., 2003). Boundary permeability can fluctuate, shifting back and forth from openness to complete denial of access depending on the level of perceived rejection. In such cases, disclosure or concealing of the private information maybe be done in stages (Greene et al., 2003). Greene and Faulkner (2002) maintain that people with highly stigmatised conditions such as HIV may need to test out the reactions of a potential recipient by partially opening the boundary by making hints before opening the boundary fully and revealing their HIV status. There is evidence from the literature showing incremental disclosure among HIV positive young people. For instance, findings from a self-disclosure study of African-American HIV positive adolescent females in the USA reported progressive disclosure to their boyfriends. By progressively revealing their private information, the participants retained control of how much information about their HIV status they could reveal to their boyfriends and when to reveal it (Greene and Faulkner, 2002).

Petronio (2002) maintains that boundaries can be thin walled, meaning that one is highly likely to disclose private information (HIV status) to others, for example, if personal gains such as fostering intimacy are perceived to be a potential consequence. Conversely, despite the desire for intimate relationships, one can build an impermeable boundary due to ethnicity or the privacy rules coached by parents and close access for others to one’s private information, for example, if one fears the confidant might not follow the rules of privacy and may leak the HIV positive status (Petronio, 2002; Hogwood et al., 2013; Körner, 2007; Dodds, 2006). Although the desire to gain intimacy may be strong, ethnic-related stigma, privacy rules from parents and a possibility of third-party leakage may outweigh the desire; hence, some individuals may be motivated to tightly control their privacy boundaries by concealing their HIV status to protect themselves from the consequences of third-party leakage (Greene et al., 2003). The individual becomes concerned that the recipient might misunderstand, breach confidentiality and divulge their HIV diagnosis to unwanted others (Greene and Faulkner, 2002; Petronio, 2000). They may become concerned about the safety of their private information in the hands of a recipient; if the recipient handles the information poorly, the individual might end up being rejected, discriminated against or ostracised (Petronio, 2002; Greene and Faulkner, 2002). However, by keeping their privacy boundaries tightly under control, the young people might forfeit the chance to foster intimacy which may be necessary to form lasting relationships for them to successfully transition into adulthood (Worth, 2009).

Having discussed how ethnicity and privacy orientations from parents may cause an individual to form boundaries to protect their private information, the following section will now focus on transition and employment issues.

2.9. Employment

Transition is an especially critical stage for career exploration and setting career goals and it is during these years that career aspirations can either be established or thwarted (Turmusan 2001; Lloyd 2005; Hopkins 2010; Conkel-Ziebell et al., 2019). As black African youth with HIV transition into adulthood in the face of ethnic-related stigma and privacy/stigma orientations from parents, they must prepare to explore the same normative developmental tasks, including employment opportunities, typical of any young person (Fair et al., 2018). Evidence suggests that achieving the desired transitional outcome into employment can be even more difficult for individuals with stigmatised identities such as HIV and ethnicity (Osgood et al., 2005; Fair et al., 2018; Conkel-Ziebell et al., 2019).

While some youth may successfully integrate into the labour market, others, such as those with stigmatised identities, may find themselves struggling (Furlong and Cartmel, 2007; Sprague et al., 2011). In addition to challenges posed by their HIV status and the stigma coaching/orientations from parents, young black African youth in the UK born with HIV must contend with ethnic-related stigma challenges as well. Thus, their career aspirations may be hindered by a number of factors (Dahlbeck and Lease, 2010).

Some writers posit that work places are important locations in terms of individual economic development (Sprague and Dickinson, 2008). Likewise, for black African young people with prenatally acquired HIV in the UK, workplaces should also be locations that support successful attainment of an adulthood role (Sprague and Dickinson, 2008) but, how do these individuals fair given the layers of stigma they are likely to face?

To date, no study has ever explored the impact of both HIV and ethnicity on employment and career aspirations in black African youth with prenatally acquired HIV living in the UK. Although an earlier USA study by Lightfoot and Healy (2001) attempted to explore career development among youth living with HIV, they were only interested in how the young people’s coping mechanisms and emotional stress influenced career planning and decidedness. Moreover, the sample was comprised of youth with horizontally acquired HIV from varied ethnic groups; therefore, their experiences might not be comparable with the participants in this study. There has only been one American study, by Fair et al. (2018), that has explored the impact of HIV on employment among youth born with HIV. Findings from that study suggest that family members were instrumental in the future career pursuits of the young people; in particular, they were able to identify skills and attributes of the young people and were able to guide them into career pathways best suited to them (Fair et al., 2018). Further findings from the study revealed how the influence of HIV status on the young people's career prospects was varied. While some participants reported HIV did not stop them from pursuing their dream jobs, some participants were apprehensive about pursuing careers such as nursing or in the police force where the risk of accidental transmission of HIV to clients was high (Fair et al., 2018).

Although these findings can be applied to this study, Fair and colleagues focused on the impact of HIV only; moreover, their study does not particularly articulate this impact in the context of transition into adulthood. There remains no study exploring the impact of multiple layers of stigma on the transition of these young people into work. Little is known about how black African young people in the UK born with HIV are transitioning into the world of work in the face of HIV- and ethnic-related stigma. Failure to consider ethnic-related stigma within the context of HIV may deprive policy makers and stigma reduction interventions of a comprehensive understanding of the racial context in which young people's career decisions are made. Given that no study has been conducted exploring the impact of ethnicity and HIV on African youth with prenatally acquired HIV in the UK, the following section will now draw from studies that have been carried out with HIV positive adults.

2.9. 1. Ethnicity and Employment in HIV Positive Immigrants

Some UK-based studies have made some effort to explore the combination of HIV and immigration status of various adults from differing African backgrounds (Doyal, 2009; Dodds et al., 2004). Findings from the studies have revealed that, because of systematic racism, HIV positive African migrants living in the diaspora are faced with varied social and cultural barriers when trying to access resources such as employment (Global Review of Policy, 2010). For instance, findings from the studies indicate that due to the climate of rejection and intolerance fostered by the prejudiced and stereotype representations of HIV positive Africans in the media, the participants felt debilitated and insecure; hence, they would not access certain services in case they had to disclose their HIV status (Dodds et al., 2004). Findings from the studies further revealed that, because of the combination of HIV and their migrant status, some participants' aspirations for the future were challenged since they were prohibited from working because of their immigration status; however, some could not work due to ill-health (Doyal, 2009). Further work has been carried out with HIV positive adults from ethnic minority backgrounds elsewhere and the work confirms the interdependence of HIV-related stigma and racism (Sumari-de Boer et al., 2012; Marsicano et al., 2014; Logie et al., 2011; Monteiro et al., 2013). For instance, one French quantitative study reported high levels of discrimination at work for HIV positive migrant women (Marsicano et al., 2014).

Although the findings might give us some insight into the impact of HIV and ethnicity on employment, these findings may not fully apply to this study since the participants were adults who were past the transition phase; consequently, their experience of ethnic and HIV stigma might be different from the cohort for this study. Given the paucity of literature exploring the impact of ethnic-related stigma on employment among HIV positive young people as they transition into adulthood, the next section will now draw from literature derived from studies on HIV negative youth from ethnic minority backgrounds.

2.9.2. Ethnicity and Career Aspirations Among Youth of Colour

Although not extensive, there is some relevant research which has been conducted elsewhere to examine the influence of race/ethnicity on employment and career aspirations among youth of colour (Evans and Herr, 1994; Brown and Segrist, 2016; Conkel-Ziebell et al., 2019; Tovar-Murray et al., 2012). Evidence from the studies suggests that anticipation of racism is negatively related to career decisions among youth of colour (Conkel-Ziebel et al., 2019). The writers argue that when making career decisions, young people of colour do not just simply consider a vocation but also consider a future pursued in a society marked by racism and discrimination. This then forms the background against which they make their career decisions (Evans and Herr, 1994; Conkel-Ziebel et al., 2019). Thus, the racial climate experienced by the young people is related to how they see the world of work and their future in it (Brown and Segrist, 2016; Conkel-Ziebel et al., 2019). Evans and Herr (1994) maintain that the existence of racial discrimination in modern society is irrefutable; therefore, it is reasonable to assume that such environments have a negative influence on employment and career aspirations. This may be true for the participants in this study who, in addition to their HIV status, may also be faced with ethnic-related stigma as they try to navigate their way into employment. The social context of negative stereotypes towards Africans and HIV may inform their perceptions of the world of work, consequently attenuating their confidence about disclosing their HIV status which will, in turn, stifle their employment and career aspirations (Conkel-Ziebel et al., 2019).

Although some work on the impact of ethnicity and HIV on employment among youth has been undertaken, it has been conducted with the two layers of stigma independent of each other. None has been conducted combining the two layers of stigma to gauge the impact this might have on successful transition into adulthood among black African youth with prenatally acquired HIV living in the UK. There is no research available exploring this impact on black African youth born with HIV living in the UK.

2.9.3 Summary

This chapter has identified and discussed the literature in relation to transitions of the marginalised and the manifestation of stigma awareness in young people born with HIV with reference to the role of parents and professionals in socialising the young people into stigma. Whilst it has been acknowledged in previous studies that parents and professionals play a role in socialising young children into stigma, this has not been explored in relation to its impact on the young people's transition to adulthood. In addition, other prejudices such as ethnicity, that the young people maybe grappling with, have been articulated, though this is an area that research with HIV positive youth has paid very little attention to. This is a very significant gap in the literature on HIV stigma in youth since HIV stigma in youth has been explored independent of other prejudices despite evidence from studies with adults suggesting that HIV stigma draws heavily on existing lines of stigma such as racism (Deacon et al., 2005). The chapter has also identified and explored CPM theory and how this may help in understanding the impact of ethnicity and stigma coaching on individuals as they try and manage their private information. As has been stated above, there is no study exploring the experiences of HIV- and ethnic-related stigma and stigma socialisation among black African youth born with HIV in the UK and how this may affect their transition into adulthood. This study, therefore, seeks to address this gap by focusing on the following questions: 1) What are the experiences of ethnic- and HIV-related stigma and stigma socialisation by parents among African HIV positive youth in the UK born with HIV; 2) How may these experiences affect their transition into adulthood?

The next chapter will focus on the study's methodology, discussing and critiquing the steps taken to address the research questions in this study.

Chapter 3

Methodology

3.0 Introduction

In view of the gaps in the literature identified in the previous section, this research seeks to answer the following two key questions:

1) What are the experiences of the intersection of racism and HIV-related stigma and stigma socialisation by parents among young black African immigrants in the UK born with HIV?

2) How may these experiences affect their transition into adulthood, particularly in terms of relationship formation and employment?

The key aim in this study is to provide insight into the unique experiences and challenges of transitioning into adulthood faced by African young people in the UK born with HIV. This will inform interventions to address stigma that are tailor-made and ethnically sensitive and are developed in collaboration with the young people's parents to ensure successful transitions into adulthood.

This methodology section begins by explaining and justifying the use of a qualitative approach to address the research questions by focusing on the need to capture in-depth data from participants who may never have had the opportunity to talk to someone about their experiences. The next section will outline the process of identifying and recruiting the sample and the challenges faced. This will be followed by a section describing the process of data collection before moving on to a description and critique of the data analysis process with reference to how the data were broken down into codes to make some sense of them before organising the codes into meaningful themes. Validity and reliability are key aspects at every stage of a research project. It is important for a researcher to be able to demonstrate these aspects for the study to be credible. Though these aspects will be articulated and highlighted throughout this methodology chapter by reference to strategies to ensure credibility, a section will be devoted to exploring these issues, particularly those that might not have been explicitly critiqued in the preceding sections of the methodology chapter. Focus will then turn to how the key ethical issues were addressed. Finally, the chapter concludes by exploring and highlighting my role in and impact on the research process.

3.1. Ontological and Epistemological Foundations of the Study

This study adopts a qualitative research approach to explore the lived experiences of multiple stigma among young black African people in the UK born with HIV. The major epistemological argument for choosing a qualitative approach was rooted in the idealist ontological position. Idealism is based on the premise that there is no access to reality independent of our minds and socially constructed meanings (Sale et al., 2002). Therefore, to gain access to the young people's realities of living with layers of stigma, a qualitative approach was deemed suitable as it allowed the researcher to connect interactively with the participants in a mutual construction and understanding of their lived experiences (Guba and Lincoln, 1994; Denzin and Lincoln, 2002; Slevitch, 2011).

Growing into adulthood with layers of stigma is a relatively unexplored phenomenon, particularly among HIV positive African youth in the UK who have lived with HIV since birth.

Furthermore, HIV- and ethnic-related stigma are very sensitive and complex topics that need to be viewed through the eyes of the young people themselves in order to gain in-depth insight into their complexities (Mason, 2002; Bryman, 2012). A qualitative approach is therefore the most appropriate methodology to allow the researcher to explore these issues and gain some insights into and deeper understanding of the challenges and experiences of multiple stigma faced by the young people. Such an exploration would have been difficult to achieve using a quantitative approach with its accompanying realist ontological perspective which would regard the researcher and the researched as independent entities (Sale, 2002). This may have limited the methods by which the phenomenon could be understood to, for example, questionnaires which, in turn would have limited the researcher in terms of the extent to which she could have genuinely listened to the voices of the participants (Denzin and Lincoln, 2002). In her guide to researching sensitive issues, Liamputtong (2006) maintains that a qualitative approach is the only methodology that provides the researcher with the opportunity to uncover people's lived experiences of sensitive issues that may otherwise be hidden, suppressed and inaccessible.

The population of young people who have lived with HIV in the UK is very small; therefore, a qualitative approach was suited to eliciting these experiences. Hammarberg et al. (2016) argue that a qualitative approach is more appropriate when exploring lived experiences with small samples of participants. The same approach has also been shown to be appropriate in exploring the experiences of other groups of HIV positive young people (Dorrell, 2010; Hogwood et al., 2013).

3.2. The Data Collection Tool

Semi-structured interviews with each individual participant were chosen as the data collection tool. Semi-structured interviews are widely used in qualitative research because they allow for an exploration of the participants' subjective viewpoints whilst at the same time helping the researcher to gather in-depth accounts of the participants' experiences (Evans and Lewis, 2018; Sarantakos, 2012). The use of semi-structured interviews in this study allowed the researcher to explore and privilege the voice of the participants and helped the researcher to collect in-depth and detailed narrative experiences of growing up with HIV in the face of ethnic-related stigma (Rubin and Rubin, 2011; Evans and Lewis, 2018). In the context of a clear question guide, semi-structured interviews still allowed both the researcher and participants flexibility. The method's explorative and flexible nature made it appropriate for fully investigating the nature of the young people's experiences of ethnic- and HIV-related stigma. Data could have been generated through focus groups; however, given that being HIV positive is a sensitive issue, the young people might not have felt comfortable about describing their personal experiences and feelings in a group setting (Liamputtong, 2006). Individual interviews afford the interviewees with a more supportive environment to discuss sensitive issues (Liamputtong, 2006; Dickson-Swift et al., 2008; Dempsey et al., 2016).

Having decided on the data gathering tool, the next task was to formulate an interview guide to ensure the focus remained on addressing the research questions (Rubin and Rubin, 2011; Doody and Noonan, 2013) (see Appendix 6 for the guide). However, the interview guide had to be designed in such a way that it would translate the research questions into simple terms. Some writers have emphasised that a researcher should not just ask the study research questions directly of participants as this might be too difficult for them to understand and prevent them from giving meaningful answers (Rubin and Rubin, 2011). Designing an effective interview guide is a crucial component in any qualitative data collection process and, for the schedule to be effective, the main questions need to be developed with reference to the existing literature (McNamara, 2009). Thus, knowledge of the literature around HIV positive young people was fundamental as it afforded me the confidence to know that if I obtained information around how the young people first knew about their HIV diagnosis and their experiences in different areas of their lives, this would help me to answer the research questions (Smith, 2015; Rubin and Rubin, 2011). To design the main questions, it was important to make a note of all the information needed, then work out a main question to elicit each piece of this information. For instance, to elicit how the young people were socialised into stigma, questions were formulated using vocabulary and terms that the young people were familiar with; efforts were made to avoid the word stigma but, instead the questions were framed around how they first knew about their HIV status (Rubin and Rubin, 2011). In spite of this, a few of the participants chose to mention the word stigma in their narratives.

Although the interview schedule ensured that all areas relating to the research questions were explored, the guide was not rigidly but rather emergently designed. It was designed to allow flexibility to allow for adjustments as new lines of inquiry emerged during the interviews, where one participant’s narrative could inform questions for the next interview (Rubin and Rubin, 2011). For example, one participant mentioned that disclosing her HIV status was easier when she was younger. This had not been considered in the initial schedule; however, it was worth exploring this line of enquiry as it could illuminate on the issue of when the awareness of stigma was more profound in the young people’s lives and the impact this had on their transition into adulthood. Questions were open ended to allow the respondents to choose their own terms when answering questions and to help the researcher uncover as much as possible about these young people's experiences (Britten, 2006). The interview guide also incorporated probes to assist the researcher to home in on areas of interest and to allow unexpected data to emerge (Jacob, 2012; Rubin and Rubin, 2011). It was important to ensure that the young people had a full understanding of the questions asked; hence, during the interviews, questions were reframed and refined whenever the researcher sensed the questions had been misunderstood (Creswell and Poth, 2016; Rubin and Rubin, 2011).

Whilst semi-structured interviews are an appropriate method for researching sensitive issues such as HIV- and ethnic-related stigma, care had to be taken to ensure that the methodology did not place the young people in vulnerable positions (Liamputtong, 2006; Hewitt, 2007). Due to the power differentials inherent in qualitative methods, the participants might end up disclosing information even though they were not comfortable to do so (Alderson and Morrow, 2011; Rubin and Rubin, 2011; Hewitt, 2007). For instance, there was a possibility that if the young people had been forced to have interviews in the HIV clinic set up, they might have felt obliged to disclose personal information due to fear that their treatment could be affected. The key to researching sensitive issues is in recognising that the participants may feel apprehensive in different environments (Dempsey et al., 2016). Effectively capturing the true voice of the participants necessitates providing the participant with an opportunity to participate in their own comfortable environments. The young people were therefore given the opportunity to decide on a venue and mode of interview; they had the choice to either have the interview face-to-face at a venue of their choice or via email. Utilising both face-to-face and online methods provided the young people with options and flexibility in terms of how and where they chose to participate (Willis, 2012). Eleven participants chose face-to-face; five chose to be interviewed in their own homes and six were conducted in private rooms at the young people's HIV clinics. Only two participants chose synchronous semi-structured email interviews.

3.3. The Face-to-face Individual Interviews

Face-to-face interviews are a preferable method when researching sensitive issues. They allow the researcher to show empathy making the interviewee feel safe and understood (Mathers et al., 2002; Opdenakker, 2006). The method also allows the researcher to detect social cues such as voice intonation and body language which can enhance verbal answers (Opdenakker, 2006). However, when conducting a conversational relationship with a participant, it is important for a researcher to present themselves in a non-threatening manner so as to minimise the power difference (Dempsey et al., 2016; Rubin and Rubin, 2011). The power imbalance between myself and the participants could have had a profound effect on the interview outcomes; therefore, it was important to adopt an informal, responsive and relaxed interviewing approach so that the participants would likewise feel relaxed, safe and able to talk; this would subsequently generate depths of data (Elmir et al., 2011; Doody and Noonan, 2013). The place of interview made a significant difference; for example, of those interviewed at home, one of the young people was alone. Although it was her choice to be interviewed at home, she was particularly attentive to every sound resembling a door being opened. Early on, she expressed that her partner had been sceptical about her taking part in the study. Consent had to be re-established periodically during the interview. In another case, the young person was home alone and was not expecting anyone to come back home during the interview. However, her mother and younger sister suddenly turned up. The change in her voice tone was evident; she went from talking loudly to speaking in a lowered tone as she asked if we could stop momentarily until she heard them go upstairs. When she signalled that it was alright to carry on, consent was re-affirmed and she was happy to resume the interview. Continuously reaffirming consent is good practice in any qualitative research undertaking as this ensures trust and prevents harm to the participant (Walker, 2007; Aluwihare-Samaranayake, 2012).

Nevertheless, the interviews conducted in the young people's homes seemed to minimise the power difference between the young person and myself in each case. The young people were in familiar surroundings making them more relaxed, thus, giving a different dimension to the interviews as they were held away from hospital (Dickson-Swift et al., 2008; Doody and Noonan, 2013; Ecker, 2016).

Even so, regardless of location, the young people may still have been nervous about being interviewed, a situation not conducive to a thoughtful and rich interview process (Rubin and Rubin, 2011; Ecker, 2016). In handling the potential for such anxieties and building the confidence of the young people, at the beginning of each interview, it was important to take a few moments to chat casually and thank them for agreeing to be interviewed before introducing myself and repeating the purpose of the research. Some of the young people might have seen me at the HIV clinic as a parent with my children, so it was important to make my research role as a student clear. Establishing a meaningful role allowed me to relate honestly to the young people, otherwise they could have been confused and assigned me a role that would have made the interview difficult (Doody and Noonan, 2013; Rubin and Rubin, 2011).

In addition to repeating the purpose of the research, it was important to talk through the information sheet with the participants and reaffirm consent (Kidd and Finlayson, 2006;

Dickson-Swift et al., 2008; Hewitt, 2007). It was further explained to the participants that our conversation would be audio-recorded and that the recorded conversation would be used in the study but anonymised so as to maintain confidentiality (Baez, 2002; Kaiser, 2012; Surmiak, 2018). Participants were reminded that they were free to stop the conversation at any time should they feel distressed or for any other reason. For the purposes of accuracy and clarity, the researcher further discussed with the young people if they wanted the opportunity to view and edit their conversation before the final report (Rubin and Rubin, 2011). Each interview lasted from 45-60 minutes.

3.4. Synchronous Email Interviews

Given the sensitive nature of the study, email interviews were offered as another way to provide the participants with a comfortable and private location of their choice where they would feel safe to share their experiences of living with HIV- and ethnic-related stigma (Bowker and Tuffin, 2004; Deakin and Wakefield, 2014). The email interviews also eliminated restrictions in time and space, thus affording the researcher access to hard-to-reach participants (Burns, 2010; Mann and Stewart, 2000; Dimond et al., 2012). I was able to reach young people who might not have felt so comfortable being in a clinic environment due to the sensitive nature of the study or due to a lack of time and feasibility, as was the case with one participant who migrated to Ireland just before the arranged face-to-face interview. It had been anticipated that online interviews may pose challenges with establishing rapport since it was not possible to observe non-verbal cues (McCoyd and Kerson, 2006). In order to address such challenges, I agreed with individual participants at the beginning of the interview on the use of emoticons and linguistic conventions for instance, laugh out loud (lol) and ☺ to signal smiling or happy moments (Mann and Stewart, 2000). These helped maintain emotional connections and brought a more humanistic element into the interactions (Mann and Stewart, 2000; Willis, 2012).

Although the email interviews were significantly longer than the face-to-face interviews, lasting between three to four hours and held over two days as interviewees and the researcher took a break, they allowed for iterative reflection by both the researcher and participants (Opdenakker, 2006; Ratislavová and Ratislav, 2014). The participants had more time to reflect on the questions before providing thoughtful responses, whilst the researcher had time to iteratively reflect on and interpret the participants' responses before asking additional questions (Ratislavová and Ratislav, 2014; Opdenakker, 2006).

Since the population of the young people interviewed was predominantly of ethnic minority and English was their second language, the evidence suggests that email interviews may be suitable (Kim et al., 2003). I had anticipated that the method would enable young people who could not eloquently express themselves verbally to do so more elaborately in writing. Evidence from a qualitative study with Asian-Americans by Kim et al. (2003) advised that, compared to face-to-face interviews, email interviews can yield more in-depth data from participants when the language used is their second language. However, the quality of data produced by email interviews was essentially the same as that obtained from face-to face interviews, although more succinct (Campbell et al., 2001; Benford and Standen, 2011; Dimond et al., 2012; Abrams et al., 2015; Meho, 2006). Whilst the face-to-face interview participants shared more stories, the email participants provided more concrete examples (Synnot et al., 2014). As has been observed by other researchers, some of the shared stories from the face-to-face interviews were sources of additional data, although not all were relevant to the research questions (Campbell et al., 2001; Bowden and Galindo-Gonzalez, 2015; Synnot et al., 2014).

Although online interviews offered flexibility in terms of the availability of participants, it was extremely time consuming; they took four times longer than the face-to-face interviews due to the time it takes to write text (Willis, 2012). However, the negatives of the additional time taken were outweighed by the advantage of producing immediate transcripts that eliminated transcriber bias (Whitehead, 2007; Ayling and Mewse, 2009).

3.5. The Participants

Given the exploratory nature of the study and small population of black African youth with prenatal HIV in the UK, purposive sampling was deemed appropriate (Hammarberg et al., 2016). The decision to use purposive sampling also ensured that only information-rich participants relevant to the phenomenon of stigma were selected enabling the research question to be addressed (Bryman, 2012). Although purposive sampling can be prone to researcher bias, due to its subjective nature, this can only apply if the researcher’s selection judgements are not based on clear criteria (Rubin and Rubin, 2011). Given that the focus of the research was on transitioning into adulthood with prenatally acquired HIV and ethnic-related stigma, it was important that participants should fit these criteria. The participants needed to be able to talk about their experiences of growing into adulthood with HIV; thus, the sample needed to be comprised of young people within this phase. The age group was set to be between 16 and 25 years of age, so a cross-sectional understanding of their varying experiences could be gained if possible (Devitt et al., 2009).

Participants were included if they were under a specialist HIV clinic. This not only ensured that those with prenatally acquired HIV were recruited, as they would have the experience of growing up with HIV, but it also ensured that there would be emotional support if needed (Rubin and Rubin, 2011). Bearing in mind that HIV is such a sensitive topic and semi-structured interviews could potentially evoke emotional distress, only participants who had known about their diagnosis for at least twelve months were included as it was deemed that they would have had time to adjust to their status and could emotionally cope with the interview (Liamputtong, 2006).

Initially, the plan was to recruit most of the participants (about eight) through a non-NHS voluntary organisation which supports young people living with HIV in the UK. However, recruiting through this organisation proved difficult as they later learned that, because the young people were only under their care for a brief period whilst they attended yearly camp meetings, the organisation did not have the ethical right to broker access to the young people. All participants ended up being recruited from two NHS organisations. It was anticipated that recruiting through the non-NHS voluntary organisation would allow for the widest range of participants to be reached (Dworkin, 2012). Nonetheless, it turned out that recruiting from the two NHS organisations did not make any difference to the category of participants as it was the same category that would have been recruited through the non-NHS organisation. Their ethnic mix was similar to the distribution and pattern of HIV infection among Africans in the UK (Conway, 2006).

Recruiting young people who had emigrated from different African countries enhanced the credibility of the research findings since different individuals might reflect varied perspectives of growing up with HIV depending on their country of origin (Rubin and Rubin, 2011). Although all the participants were from Africa, they had various distinguishing cultural characteristics shaped by their country of origin and these were anticipated to influence their experiences of stigma (Rubin and Rubin 2011).

Gaining access to the participants was negotiated through the nurses and consultants from the NHS HIV clinics, since they had legal responsibility for the young people under their care (Masson, 2004; Dempsey et al., 2016). Whilst they had legal responsibility and acted as gate keepers, it should be emphasised that the staff could not force the young people to participate in the study and the importance of voluntary participation was highlighted in the participants' information sheets (Heath et al., 2007). However, there still could have been some selection bias as the staff might have approached only the young people they felt might be willing to participate (Dempsey et al., 2016). Nevertheless, support from the staff was extremely crucial in gaining access to the young people as it would have been difficult to gain access to such a vulnerable group otherwise (Alderson and Morrow, 2011; Heath et al., 2007). It was critically important for the staff to understand the purpose of the study. In order to ensure that they did, following ethical approval from the National Research Ethics Service Committee West Midlands – Coventry and Warwickshire (Appendix 3) and the NHS Governance Committees, meetings were arranged with the HIV clinic staff to present details of the proposed study (see Appendix 5 for the information letters). The consultants and nurses assisted in identifying eligible and potential participants and gave them the research invitation letters and consent forms (see Appendices 7 and 4) as they attended their regular appointments at the clinic.

The sample for this study was comprised of thirteen black African youth between the ages of 16 and 25 years with prenatally acquired HIV living in the UK (below are the participant demographics with pseudonyms).

Participants' Demographics

Name	Age at Interview	Age came to UK	Gender	Country of birth
Camz	17	12	M	Cameroon
Licky	19	14	M	Zimbabwe
Twingo	17	3	M	Congo
Pistachio	20	10	M	Zambia
Sassy	18	15	M	South Africa
Nicky	25	22	F	Zimbabwe
Daisy	25	20	F	Uganda
Eunice	21	10	F	Zimbabwe
Irene	20	9	F	Zimbabwe
Vicky	18	13	F	Zimbabwe
Trixy	17	3	F	Congo
Hazy	22	15	F	Kenya
Mimmy	19	5	F	Zimbabwe

The sample size may seem small; however, the use of small sample sizes is typical of qualitative research, since it focuses on acquiring in-depth understanding rather than making generalisations for a larger population (Crouch and McKenzie, 2006; Dworkin, 2012). Thus, the small sample offered the researcher valuable insight into the way the young people perceive the meaning of their experiences of growing into adulthood with layers of stigma (Boddy, 2016; Bryman, 2012).

Moreover, the sensitive nature of the topic and the hard to reach population group meant that it was not possible to recruit a larger sample; however, the sample included the widest possible range of young people from Africa, particularly sub-Saharan Africa which is the area most affected by HIV (WHO, 2014). Dorrell and Katz (2013b), who have also conducted qualitative research on young people growing up with HIV, used a small sample (28 participants).

Unlike quantitative research, there is no formula for calculating an appropriate sample size in a qualitative study (Baker et al., 2012). Instead, the sample size depends on what the researcher is trying to achieve (Baker et al., 2012; Guest et al., 2006). The general principle for qualitative exploratory studies is that small sample sizes facilitate in-depth data collection, something which was useful in this study (Baker et al., 2012; Crouch and McKenzie, 2006). While some qualitative researchers such as Mason (2010) and Morse (2000) advocate for a sufficient sample size to achieve data saturation, this was not the case in this study since the notion of data saturation is contentious. Some researchers argue that data saturation is impossible, as there are always unheard of and unknown experiences that exist beyond the reach of the study; new possibilities for understanding are limitless (Dibley, 2014).

3.6. Data Analysis

Meaning making in qualitative data analysis does not just happen; no categories or themes will emerge on their own without the researcher so identifying them (Howitt, 2016; Bryne, 2001). The researcher interacts dynamically with the research material as he/she tries to make sense of the data through coding, then creates order by comparing the codes and placing them together based on similarities; this results in the creation of a certain amount of structure so that the material is more accessible (Braun and Clarke, 2006; Howitt, 2016; Sgier et al., 2012; Mason, 2017). Finally, the researcher interrogates the data to be able to gain some insights and understanding from them (Silverman, 2015; Mason, 2017).

In line with the approach discussed above, the data analysis process used in this study was guided by the thematic analysis approach as described by Braun and Clarke (2006). Thematic analysis was chosen for its flexibility. Flexibility meant it was useful to this study which is positioned within the constructionist paradigm (Braun and Clarke, 2006; Liamputtong, 2009; Evans and Lewis, 2018). In the context of this study, thematic analysis was useful as it allowed an examination from a constructionist methodological position of the young people's experiences of transitioning into adulthood with stigma, the meanings they attached to the stigma and their social constructions of it (Terry et al., 2017; Evans and Lewis, 2018). At the same time, thematic analysis enabled the examination of how these social constructions reflected the reality of the participants' lived experiences; the social contexts in which they lived and how these constrained their opportunities for a successful transition into adulthood (Evans and Lewis, 2018).

The data set for this study consisted of three categories that were to be analysed. These were: audio recordings from individual face-to-face interviews, email interviews and a written piece of work which one of the participants wrote prior to knowing about the study just to describe her experiences of living with HIV; she felt this could supplement her interview.

The preliminary step in the data analysis process involved transcribing verbatim the audiotaped face-to-face interviews, a task that commenced after the first interview so attention could be paid to identifying issues that needed to be addressed in subsequent interviews (Sutton and Austin, 2015; Rubin and Rubin, 2011). Reading whilst typing also helped to get some sense of what the data were about and to get a feel of possible themes. The transcripts included recordings of pauses, silence, indications of emotions, such as laughter, and stalling words, such as um and ah. These were useful as they did not just prompt my memory of the interview, they also allowed the data to be interpreted more accurately (Sutton and Austin, 2015).

The email interviews already provided immediate transcripts but the actual conversation had to be copied and pasted into a word document with the sender's and receiver's email details deleted from the thread both for confidentiality purposes and to clean up the transcription so the conversation flowed coherently. Following this, the conversation was re-arranged since it was bottom up (the start of the conversation was at the bottom and vice versa). Each interview was given a number and, for confidentiality reasons, interviewees were later assigned pseudonyms. Similarly, other identifiable materials were removed from the transcripts to maintain confidentiality (Miller et al., 2012; Ryen, 2011).

After transcription, the next step was coding but, before coding, it was important to bear in mind that researchers do not code just for the sake of it; they should decide on what kind of codes they want to produce (Mason, 2002). Failure to make this decision will result in what Mason (2002) describes as a procedure deprived of strategy or philosophy. It was important to be aware of the issues of power and exploitation that could arise during the data analysis since, as a sole researcher, I was the only one making choices about the codes. In order to deal with the potential bias, coding the data was therefore open-ended in order to stay close to the data and be able to bring out the voice of the participants (Deterding and Water, 2018).

I immersed myself in the data by re-reading the transcripts, browsing through all the transcripts whilst noting down initial ideas about the data. The process of coding was done manually by working through each individual transcript line by line and highlighting salient features of the data that related to the research questions as well as any other chunks, sentences or words that were interesting (Saldana, 2015). For each highlighted feature of the data, a code was provided in the margin, representing the meaning of the segment of the text highlighted. To avoid bias, it was important to stay close to the data as I coded and I sometimes used the exact words from the highlighted sentence as codes to prevent imposing my preconceived beliefs on the data (Rubin and Rubin, 2011).

When all the transcripts had been coded (see Appendix 10 for the coding schema), the next stage was to create some order. This entailed comparing the codes and identifying those that were common and grouping them together to form overarching themes encapsulating the similar codes (Braun and Clarke, 2006; Fielding, 2001). Grouping the codes involved not only identifying common elements in the young people’s narratives but also differences; those narratives that highlighted something different from the rest were valuable to the research (Silverman, 2015). The process of grouping the codes into themes was iterative; I went back and forth reviewing and refining the themes by reading through all the extracts related to the codes in order to explore if they supported the themes (Deterding and Water, 2018; Clarke and Braun, 2012).

The next step was to determine how the themes were connected to each other in answering the research questions (Saldana, 2015). The assumption was that the two layers of stigma, HIV and ethnicity, were impacting on the young people's transition into adulthood. However, the study was not just of interest to me but also represented a personal predicament; therefore, I was aware of my own potential bias and the possibility that I may only see that which I expected to see (Silverman, 2015). I was therefore careful not to exclude evidence that suggested the opposite to my expectations; for instance, the notion of agency in the young people's narratives suggested that they were not passive recipients of stigmatising attitudes (Bradford and Clark, 2011; Clark, 2012).

Three overarching themes emerged: parents'/carers' role, peer and romantic relationships and employment and these formed the findings chapters. The issues of ethnicity, stigma and disclosure weaved through the themes. The themes connected to show how the young people were socialised into stigma and how the ethnic-related stigma reinforced the HIV-stigma in impacting on the young people's navigation through the markers of adulthood such as employment and the formation of romantic relationships.

3.7 Validity and Reliability

Whilst the issues of validity and reliability have been discussed in the preceding sections with reference to credibility and trustworthiness issues around the selection of interviewees and addressing researcher bias at various stages of the study, this section will revisit these aspects to capture additional areas where validity and reliability were demonstrated but have not been fully articulated in the previous sections. Validity of data was sought by giving the participants the opportunity to reflect on their interviews (Mero-Jaffe, 2011). After each interview, I made a telephone call to those who were happy for me to do so to check that they were not distressed and to allow them to reflect on the contents of the interview. Some writers have highlighted that the researcher's assumptions regarding the topic under research and the data may influence the transcripts and this could result in a biased analysis of the findings (Davidson, 2009; MacLean et al., 2004; Tilley, 2003). Thus, to curtail such bias and ensure validity and trustworthiness of the findings, the participants were offered the opportunity to review and edit their transcript when they were ready. In addition to ensuring validity, this was also to preserve the research ethics as well as empowering the participants so they could have control over what was transcribed (Polit and Beck, 2008; Davidson, 2009; Mero-Jaffe, 2011). However, none of the participants accepted the offer to validate their scripts. The literature suggests that participants may be reluctant to be critical of the researcher; moreover, they may have felt embarrassed about reading their transcripts because of their perception of how their narratives might have been presented in the transcripts (Forbat and Henderson, 2005; Turnball, 2000). In view of this, review of the transcripts by the participants might have added very little to their accuracy (Hagens et al., 2009; Mero-Jaffe, 2011). In addition, the participants might have decided to delete some information resulting in a loss of valuable data (Hagens et al., 2009). Nevertheless, the use of recapping phrases during the interviews served as clarification, confirmation and validation (Dibley, 2014). To further ensure robustness and trustworthiness of the study findings, concurrence with previous evidence and transparent theories was sought (Creswell, 2009; Polit and Beck, 2008).

3.8. Addressing the Ethical Issues

Consent, confidentiality and vulnerability were the three ethical issues that needed to be addressed throughout the study and these were highlighted in the ethics application to the National Research Ethics Service Committee West Midlands – Coventry and Warwickshire. Consent in qualitative research is a continuous process, which requires the researcher to renegotiate periodically, throughout the research process (Byrne, 2001). Continually seeking consent establishes the necessary trust to continue with the research ethically (Kidd and Finlayson, 2006; Walker, 2007). Informed consent was sought from participants at various stages of the research process. From the point of recruitment, the participants had the process explained to them verbally as well as in writing through the information sheets; they then gave their initial consent. Consent was formalised through signing the consent forms. Participants were made aware that no coercion would be used to keep them in the study; after they had volunteered to participate as such, they could withdraw at any time without any repercussions (Lancaster Faculty of Health and Medicine Research Ethics Committee (FHMREC), 2008). In addition, the participants were made aware that their healthcare would not be affected by withdrawing from the study. They were also informed that should they withdraw from the study, their data would be deleted and would not be included in the study. Participants were also made aware that they could express their wish to withdraw by contacting the researcher by email, phone or during the interview. Furthermore, consent was re-established before commencing each interview and consent was also sought from participants for the conversations to be audio-recorded. The researcher reaffirmed consent during the interviews, particularly if there were interruptions during the interview or when she sensed distress (such as the incident described in the vulnerability section).

3.9. Confidentiality

Maintaining confidentiality and anonymity were both of paramount importance throughout the study. As such, several steps were taken to ensure that participants' information was handled with respect and in a discrete manner (Alderson and Morrow, 2011). I was aware that when the participants agreed to take part in the study, they expected their disclosed information to be handled with respect and in a discrete manner (Kaiser, 2012). However, I explained to the participants that confidentiality may be broken if I thought they were in danger, for example, of abuse (Alderson and Morrow, 2011). Had such a situation arisen, I would have clearly discussed it with the participant first and sought specialist advice and expertise from both the respective HIV clinic and my supervisor (McCosker and Barnard, 2001).

The face-to-face interviews were audio taped using a voice recorder and this was kept in a locked cabinet where only the researcher had the pin and access to. During transcription, all identifiable information was removed, and participants' names anonymised through the use of pseudonyms. To further ensure confidentiality, the participants who took part in the email interviews were strongly advised not to participate whilst in a public place and to ensure no one was overlooking them as we exchanged emails. In addition to advising the participants to have their computers/laptops password protected to ensure security, I also stressed the importance of maintaining firewalls and virus scans to prevent any information being accessed by outsiders and to prevent both my laptop and participants' computers from picking up viruses (Kelly and McKenzie, 2002).

Participants' information, such as names, telephone numbers and emails obtained for the purposes of arranging an interview, was stored electronically on a private and password-protected laptop which was locked in a private cabinet when not in use. The information was deleted after the interviews and each study participant was allocated a pseudonym and was identified by this pseudonym in all study-related documentation throughout the course of the study. For security and confidentiality reasons, all paper files, including the anonymised email and transcribed face-to-face interviews, were kept in a securely locked cabinet to which I had sole access and knowledge of the code.

3.9.1 Vulnerability

Any qualitative interview has the potential to evoke distress. Participants may find it upsetting being asked about their life experiences, particularly those that relate to sensitive phenomena (Liamputtong, 2006). Given the sensitive nature of the study and the potential for semi-structured interviews to delve into unanticipated areas which may leave the participants vulnerable, there was a need to ensure the psychological safety of the participants (Dickson-Swift et al., 2008; Elmir et al., 2011). Prior to the interviews, the participants were reminded of the list of support networks included in their information sheets. Recruiting participants who were receiving HIV treatment ensured that the young people already had support from their respective HIV clinics. It was discussed and agreed with staff from the young people's respective clinics that they would offer emotional support should the young people experience distress. Only one participant became quite tearful as she narrated her experience of finding out she was born HIV positive. However, she confirmed that despite being emotional she was still happy to continue with the interview. Utilising my clinical training and experience as a mental health nurse to deal with distressed individuals, I allowed the participant time to cry and express her emotions. It was important for me to validate the importance of this to her well-being (Alderson and Morrow, 2011). I remained calm, whilst gently offering her the option to take a break and have a drink or defer the interview to another date (Ashton, 2014; Mitchell, 2015). She declined both options and insisted she wanted to continue with the interview. Withdrawing her from the study might have caused her more harm than good since withdrawing was not her preferred outcome (Alderson and Morrow, 2011). King and Horrocks (2010) suggest that emotional distress does not necessarily indicate that the participant is finding the interview experience negative. They further argue that, in many cases, participants appreciate the opportunity to describe their difficult experiences to a sympathetic listener. I reminded her of the support networks listed in her information sheet and reassured her that she could contact the clinic should she need to talk to someone after the interview. After the interview, it was important to phone and check on her welfare and she assured me that she was fine; moreover, I did not detect any indications of distress in her voice.

3.9.2 Impact of Researcher

There is active interaction between the researcher and the whole research process, resulting in unavoidable effects of the researcher’s self on the research process; this is not inherently negative (Sutton and Austin, 2015). However, it does mean that effective qualitative research requires a reflexive researcher who reflects on and articulates his/her subjectivity, position, perspectives and biases so readers are aware of the lenses through which data have been gathered and analysed (Sutton and Austin, 2015). During different stages of this study, I made efforts to reflect on my world view as I gathered and interpreted data in a manner that illuminated the research questions while uplifting the voice of the participants (Le Compte and Schensul 2000; Sutton and Austin, 2015; Rubin and Rubin, 2011).

Some researchers suggest that to eliminate any suspicions, participants often want to know what made the researcher interested in the study (Aston, 2001; Rubin and Rubin, 2011). I used this knowledge as an opportunity to show empathy and build trust with the participants as I explained my involvement with HIV positive young people.

Aston (2001) argues that self-revelation can help build trust with participants whilst at the same time showing the participants that you empathise with them and understand their difficulties; this may result in them being more open in what they tell you about their experiences. However, I was cautious not to be too empathetic or identify too closely with the participants to the detriment of collecting credible data. To address this pitfall, I was careful not to ask questions that were biased and would reveal my views whilst obscuring the participants' true experiences (Rubin and Rubin, 2011).

In creating a relationship and building trust with interviewees, some researchers often cross boundaries from being an outsider to an insider, as the role of an insider gives participants confidence that the researcher sympathises with them and understands their issues (Zinn, 2001). However, I was already an insider by virtue of sharing the same ethnic background with the participants; therefore, I may have seemed less threatening to them, allowing me to gather certain information that someone from a different ethnic background might not have had shared. Nonetheless, I was cautious not to utilise the role in a manner that would harm the participants (Rubin and Rubin 2005). Whilst I viewed myself as an insider on the grounds of ethnicity, I was aware that the participants might have treated me differently on the grounds of different characteristics (De Andrade, 2000). Though I am a black African, the age difference and my role as a researcher might have set me apart; therefore, I might have been considered an outsider by the participants. This, however, would not necessarily have been detrimental to the research (Cannon et al., 1988). Some researchers argue that in being an outsider, a researcher may gather better findings as they are not caught up in the dynamics of the group. Moreover, if the researcher is an insider, the participants may tell the researcher what he/she wants to hear (Naples 1997; Zinn, 2001).

3.9.3 Summary

Conducting research with HIV positive young people is particularly sensitive and as such, it carries risks of increased vulnerability in the young people. The methodology of this study has demonstrated how it was designed with this in mind as it sought to ethically identify appropriate and effective ways in which the young people would voluntarily engage with the research process. Allowing the young people to choose the mode and place of interview provided them with safe environments where they were able to articulate their experiences and feelings of growing up with HIV. The interviews were conducted in a manner that minimised power differentials; thus, the young people felt relaxed and not threatened. As a result, the data collected was rich and reflected the participants’ voices.

The data analysis has provided insights into how the codes were derived before being amalgamated into themes. The data analysis has also shown that the major themes to emerge from the data were mainly around the issues of: awareness of stigmatised identities, challenges in forming peer and romantic relationships as well as pursuing employment aspirations. The following three chapters will now present the key findings of the study in relation to these themes. To maintain anonymity, none of the young people's real names have been included; pseudonyms have been used instead.

The next chapter now presents the findings for the first of the three themes, exploring the young people's narratives revealing how they were socialised into stigma by their parents.

Chapter 4

Parents'/Carers' Role in the Stigma

4.1. Introduction

Whilst it has been acknowledged in previous studies that parents play a role in socialising their children into HIV stigma, it has not been explored how this role might impact on transition challenges for the young people (Dorrell et al., 2008). This chapter therefore presents data relating to how the young people's accounts reveal the parents' and professionals' contribution to the onset and progressive awareness of HIV stigma in their lives and how this, to a larger extent, is the source of their felt stigma which is a potential impediment to a successful transition into adulthood. The first section focuses on the young people's lives prior to finding out they are HIV positive. Attention is drawn to patterns relating to disclosure of HIV status to the children in particular, and how their parents/guardians were instrumental in socialising them into the stigma. The second section discusses how, despite not being formally informed of their diagnosis, the young people still suspected that whatever they had was not desirable and these suspicions were finally confirmed. Focus will then turn to some significant events that resulted in the young people knowing their diagnosis. Finally, the last section explores the impact on participants of knowing about their HIV status and how this, to some extent, reinforced the stigma which might be a barrier to attaining adulthood markers.

4.2. Conception of HIV Stigma; Life Prior to Knowing

Half of the participants in this study reported a long history of regular hospital appointments from as early as three years of age with two thirds of them commencing prophylactic or respiratory related medication at around the age of five. Whilst a few did not question the reason for the medication and hospital appointments, several of them spoke of being curious and seeking valid explanations from their parents and the health professionals about why they attended the hospital so often. A few of them had not had any illness at all as far as they could remember while others had experienced a one-off episode of illness. Consequently, they deemed hospital attendance unnecessary particularly when they could not get a satisfactory explanation. Trixy, a 17-year-old female participant talked about how frustrated she was at the lack of satisfactory explanation from the adults in her life.

> *Nobody was explaining anything to me clearly since being a child. I felt I couldn't keep on asking about this as the people around me would yet again explain everything and nothing. I felt like a puppet who had no control over what was going on with her body.* (Trixy)

Another young person recalled a time during one of her appointments at the hospital when she was still a child; she tried to prove to the doctors that she was well and therefore did not need to take the prophylactic medication and attend hospital.

> *I remember visiting the doctors a lot since the age of five. I remember having to take this medicine which tasted funny. I really did not like the medicine and didn't understand why I was always going to see the doctors. I would do handstands and cartwheels all over the clinic floor just to show the doctor I was healthy and didn't need medicine anymore... because I had been in hospital with a fever or something… but, I thought I was well now, so I didn't understand why I still had to take the medicine.* (Mimmy)

The above extracts are consistent with findings from other studies which suggest that, unlike adults, HIV infected children often have little control over when they are given information about their status (Lesch et al., 2007). However, findings from this study go beyond this by demonstrating that by refraining from explaining the frequent hospital attendance to their children, the parents were, in a way, inadvertently orientating their children into stigma (Scambler and Hopkins, 1986). The parents' role relates well to what Goffman describes as protective capsules; the parents were trying to protect the young people from a stigmatising society (Goffman, 1963). It is also possible that the parents' protectiveness could have been exacerbated by ethnicity. Findings from a UK study with HIV positive adults revealed that people from ethnic minority background have a lower HIV disclosure rate (Petrak et al., 2001). This suggest that ethnicity might have exacerbated the parents' struggle to disclose their own HIV status, so they were literally passing onto their children their fears and conclusions from their own experiences. Perhaps if they had raised their children in Africa, among their own ethnic groups, where communities have a high exposure to HIV, they may have found it easier to explain the frequent hospital attendance to their children. They would only have had to contend with the HIV stigma (Lekas et al., 2006).

Accounts like the ones below further demonstrate the role of carers as protective capsules when they chose non-stigmatising explanations. For instance, one participant recalled being told some story to explain the hospital visits.

> *The doctor at the time said it was a bug that everybody has. Sometimes it's sleeping and sometimes it wakes up and sometimes with some people it wakes up and starts affecting your white blood cells and you have low immune system.* (Mimmy)

In referring to HIV as the bug, the professionals carefully avoided revealing the actual name by providing the young person with only a description and symptoms of the disease. Such use of metaphors has been referred to as partial disclosure in the literature and these echoes explanations described in other studies on young people with HIV (Kallem et al., 2011; Dorrell, 2010; Lesch et al., 2007). Whilst data from this study support these earlier findings, as pointed out previously, partial disclosure in this study could possibly have been influenced by ethnicity, since the parents were also HIV positive in a foreign country. Studies with HIV positive immigrant adults show that those from ethnic minority groups were reluctant to disclose their status (Petrak et al., 2001). This study also differs from previous ones in that it explores these patterns of HIV disclosure to the young people further, particularly in terms of their effect on the young people's own disclosure patterns and the impact this has on their transition to adulthood.

Although partial disclosure of the young persons' HIV status by their parents/carers can be justified, such strategies which attempt to protect the young people from stigma may, on the other hand, succeed in coaching/socialising the children into stigma when the young people eventually find out their actual diagnosis (Scambler and Hopkins, 1986). The literature suggests that hiding information from children about their disease does not protect them from knowing (Clarke et al., 2005; Bluebond-Langner, 2000). As they listen to and hear conversations between professionals and parents, they soon realise they have been lied to and deduce that whatever they have is not desirable and that is why it has to be concealed (Dorrell et al., 2008). This inevitably makes it difficult to disclose their status to potential employers and partners, consequently making their trajectories into adulthood roles a challenge.

Whilst some participants had their quest for answers explained by a partial disclosure of their status, others described how frequent hospital attendance was explained away by hiding the illness behind non-stigmatising co-existing conditions such as asthma. In the quotation below, Sassy, who had been living in the UK for two years, recounts:

I grew up in hospital… every time from my childhood usually I was in hospital most of my time, almost all the time… I am asthmatic, that's all I was told. (Sassy)

Funck-Brentano et al. (1997) refer to such explanations as illness deception. Vaz et al. (2011) also identified similar patterns of illness deception in their study on patterns of disclosure of HIV-status to infected children. Illness deception, as revealed in the interview excerpt from Sassy, could possibly be another ethnic-related cover up story to protect the young people from stigma.

However, illness deception and partial disclosure identified in the above extracts reveal further examples of parents socialising the young people into stigma. By controlling information regarding how much the young person should know about their status, the parents and professionals were socialising the young people into what Goffman (1963) refers to as "moral careers". Goffman (1963) defines a moral career as a patterned way of bringing up, for example, those born with a stigma in contexts that make them aware of their difference. Through information control, the families unconsciously socialised the young people into stigma and made them aware of the stigma attached to their HIV when they finally found out. Therefore, it can be argued that by acting as protective capsules for the young people against stigma, ironically the family and professionals socialised the young people into the very shame they were trying to protect them from. This aligns well with Erikson's conceptualisation of youth transition regarding the influence of significant others on identity development (Erikson, 1968; Vogel-Scibilia et al., 2009). As highlighted earlier, this has significant implications for disclosure. Disclosure of their status determines successful navigation into markers of adulthood such as the formation of romantic relationships and fulfilment of employment aspirations (these issues will be dealt with in subsequent chapters) (Fussell and Furstenberg Jr, 2005).

4.3. Suspicions Confirmed

Whilst cover up stories, such as that cited above were legitimate and had some element of truth and, most importantly, managed to suppress the child's curiosity and suspicions for a while, the desired effects were not long lasting. As the young people got older and could read, they became more inquisitive and could no longer be deceived. Mimmy, a 19-year-old who had been attending the HIV clinic since she was five years of age, had started taking antiretroviral (ARV) medication when she was 10 years of age. However, her parents and professionals had still not fully disclosed her status; she was still living with the "bug story". Nevertheless, she suspected there was still something they were hiding from her. Mimmy talked about how her suspicions were confirmed:

> *… At a young age, I became a regular at the sexual health clinic. Well, the clinic had loads of signs and HIV posters and stuff like that and you just do one plus one and you find out.* (Mimmy)

Mimmy's account above demonstrates that young people pick up clues from their environment; consequently, they cannot be deceived forever (Dorrell et al., 2008). Regrettably, the HIV clinic environments, to the detriment of the parents' and professionals' efforts, did not conceal the secret and protect the young people from suspecting that whatever they had was socially undesirable. Mimmy, who attended the HIV clinic from when she was a child implicitly revealed the role of the hospital environment in communicating stigma and confirming the young people's suspicions.

Her comment implies that it was strange at her age to be a regular in such an environment. Although she had not been told about her status, the description of the clinic she attended gave away clues about what type of illness she might have and that it was not a good thing since parents/professionals were hiding it from her (Dorrell and Katz, 2013a). These findings support Goffman's assertion that those born with a stigma, although not implicitly made aware, can be socialised into stigma through the settings/environments they are brought up in (Goffman, 1963). The findings reveal further that the young people who started attending HIV clinics at a very young age were socialised quite early in their lives into stigma by the hospital contexts which became a significant part of their lives. Data from this study suggest that the longer the young people were repeatedly exposed to such stigma-inducing environments, the more ingrained the stigma identities became, consequently resulting in strongly impermeable privacy boundaries which are huge barriers to a successful transition into adulthood (Petronio, 2002).

In addition to the hospital environments, the anti-retroviral (ARV) medications themselves provided clues that raised suspicions among the young people. Vicky, a 17-year-old whose parents did not even partially disclose her status to her even after starting ARVs at ten years of age recalled:

> *I started getting sick and they took me to hospital; they gave me loads of medications and they said I have to take them every single day, so at that time at school we were learning about HIV and AIDs, so I just looked at the description and I found out what I just suspected… but they never told me.* (Vicky)

Vicky's narrative is a further demonstration that being kept ignorant of their status does not prevent the young people from guessing and consequently from knowing of their status. Although they might decide to keep silent and pretend to be ignorant, their silence cannot be taken for granted and assumptions cannot be made that the young person is not aware of their HIV status. Findings from this study suggest that not being told of their status raises suspicions among the young people, and these are eventually confirmed, inevitably, making the young people aware of the stigmatised identities they carry. As mentioned earlier, this may be an impediment to successful transitions into adulthood as the young person fears the potential vulnerabilities associated with disclosing their status to peers or romantic partners (Goffman, 1963; Attell, 2013).

4.4. Significant Events Triggered Disclosure

Whilst just over fifty percent of the participants had experienced a lifetime of hospital appointments marked with suspicions and guesses about their health until their status was finally disclosed to them, the rest of the participants had no regular hospital attendance or ill-health and therefore did not suspect anything prior to finding out about their status. A majority of these participants came to the UK when they were a bit older; with ages at entry ranging from 14 to 20 years of age.

However, due to significant events in their lives, the young people's HIV status could no longer be kept a secret. Some found out about their HIV status following the death of a parent. Hazy, who had never been ill and only found out when she was fifteen years of age explained:

> *But um, my mum passed away… Yes, so um, I think through that they found out. And then um, they did some tests and then called me in to let me know, yeah.* (Hazy)

Other young people learned about their status after falling ill; Licky, for example, contracted TB when he was 14 years of age:

> *Well… I was admitted to hospital for I think two weeks and then they found out I had TB and then they started the treatment for that but they thought it might be… it was something else instead, that's when they did the HIV… and they said, "Oh yes, you're HIV positive".* (Licky)

Though the asymptomatic state of the young people may have provided the parents/guardians with comfort and saved them the burden of disclosure, it was only a matter of time before the young people found out about their status.

4.5. The Impact of Knowing about Status

While there are various circumstances under which the young people found out about their status, of interest is the difference in impact the disclosure had on each of them. For some participants, like Irene, knowing their status was a relief:

Well, I was happy that I had a name to it because before it was not… I didn't know what it was at all and why I was taking medication and so when I got a name to it, it means I kind of know more… I can find out and know more about it better but I kind of understood why my parents and the doctors said not to tell other people whereas before I didn't understand. (Irene)

The above excerpt echoes findings from a Congolese study examining the impact of disclosure of HIV status on children. The findings highlighted that children reported feeling calmer after disclosure because knowing their HIV status removed some of the uncertainty surrounding their illness. The children felt that knowing HIV status was important and necessary (Vreeman and Gramelspacher, 2013). Though findings from this study mirror those from Vreeman and Gramelspacher, their study does not put its findings into the context of transition. In contrast, this study, take these findings further and explores their influence on stigma awareness and, in turn, how this might have an impact on transitioning into adulthood. The findings suggest that knowing their HIV status, in fact, sensitised the participants more to their stigmatised identities. As is exemplified by Irene's statement above: "but I kind of understood why my parents and the doctors said not to tell other people whereas before I didn't understand". Irene's statement underscores the parents' and professionals' role as stigma coaches Scambler and Hopkins, 1986). The findings suggest that, for the young people who received full disclosure of their status after it had been kept a secret, although it was a relief, they became aware of the imbued social information in their stigmatised identities making them feel vulnerable to judgements by society (Goffman, 1963). Such awareness influenced their need to keep their identities concealed which, as has been highlighted before, has potential repercussions for successful transition into adulthood.

However, for some, disclosure had a profound impact. Participants described feeling betrayed, particularly those like Sassy whose status had been hidden behind co-existing conditions such as asthma:

> *So, like when they told me that I was HIV positive, that's when I realised like, everything started to add up. I felt betrayed... thinking about everything that's been going on in the past few years... I mean like going to hospital and everything while my parents knew... but they never told me.* (Sassy)

The impact of keeping HIV a secret in order to protect young people from distress and stigma cannot be underestimated. It can be quite hurtful for the young people and may raise issues of trust when they realise that they have been lied to for years. However, in addition to feeling betrayed, disclosure reinforced the HIV stigma; after being informed of his status, Sassy embarked on a journey to learn more about the disease:

> *... that's when I started learning more about HIV. Like starting to accept it a bit... but I started hating myself... I would isolate myself because I felt different.* (Sassy)

Sassy's excerpt demonstrates further Goffman's observations of the parents' role in socialising their children into stigma and moral careers (Goffman, 1963). Sassy's narrative reveals how the realisation that he had been lied to made him want to find out and this led to a profound sense of difference which, in turn, resulted in him isolating himself. Goffman (1963) affirms that those whose stigma is not outwardly visible can choose to control the social information attached to their stigmatised identities and one such form of control is isolating oneself from others. However, isolating oneself from others can be detrimental to intimate relationships which are so crucial in cushioning the young people from all the challenges of transitioning into adulthood (Worth, 2009).

While for some, stigma was reinforced through feelings of betrayal and the desire to know more, for others, the instructions they received impacted most upon their sense of stigma. This was particularly true for those whose parents were still alive. Most of them remembered being instructed by parents not to disclose their status to anyone. Such instructions saved as re-enforcers of stigma and made their status more real in their lives, Camz and Mimmy recalled:

> *… plus, mum told me not to tell anyone… Like, it's not looked at as a good thing to have HIV basically.* (Camz)
>
> *My parents and doctors said not to tell other people… because, it's socially… it's a social taboo to have HIV and you are automatically ostracised.* (Mimmy)

The above excerpts further confirms Erikson's claim that during transition, parents are influential figures on their children's identity formation (Erikson, 1968).

In keeping with a life of secrets and strengthening stigma, the young persons were also socialised to tell lies, further implicating parents as playing a role in coaching their children into stigma and privacy orientations (Scambler and Hopkins, 1986; Petronio, 2002). Mimmy recalled:

> *I remember when it came to overnight school trips and I would have to take my medication. I remember my mum telling me to say the medication was for ear ache and she would stress this so fiercely.* (Mimmy)

The above findings are consistent with those from other studies, which highlighted that biological parents insisted on the young people keeping their status a secret (Waugh 2003; Michaud et al., 2009; Madiba, 2013; Mandalazi et al., 2014; McHugh et al., 2018). Parents may not only have been concerned about protecting the young person from stigma but also masking their own HIV positive status perhaps for fear of being subjected to stigma themselves and this might have been exacerbated by ethnicity (Michaud et al., 2009; Petrak et al., 2001; Lekas et al., 2006).

Whilst it can be appreciated that these attitudes and behaviours were passed on in good faith, they socialised the young people into stigma. They had a world view that their HIV was a stigma, hence it needed concealing (Scambler and Hopkins, 1986). By adopting the same position, the young people were consequently hiding themselves from the opportunities and support that might channel them into successfully attaining adulthood markers (Scambler and Hopkins, 1986). It is possible that if the young people had not been lied to or encapsulated in the protective custody of their parents and if their status had been disclosed to them earlier and, in turn, they were not shielded from disclosing it, they may have had the confidence to disclose and fight the shame associated with the disease (Herek, 2002).

4.6. Summary

This chapter has demonstrated how parents and health professionals, in their efforts to shield the young people from HIV stigma, contributed to the young people’s challenges relating to a successful transition into adulthood. The young people’s narratives revealed how the parents and professionals used various strategies ranging from complete non-disclosure to partial disclosure (use of metaphors such as the sleeping bug) or illness deception where non-stigmatising conditions such as asthma were used to explain medical appointments. However, controlling the information about the young people’s HIV status, nonetheless, failed to control the young people's curiosity and frustration, given the frequent check-up appointments at hospital that some of them had to endure from a very young age with no valid explanation.

In the absence of valid explanations for the hospital appointments and silence from the adults, some of the young people became suspicious. The hospital environments with all the HIV-related posters and information gave them certain clues and led them to conclude that whatever they had was undesirable, hence it should be kept a secret.

However, the silence, metaphors and illness deception could not be maintained forever and the young people finally had their HIV status disclosed to them. At this point, the parents and health professionals maintained their role in providing protective capsules and coached the children all the more into becoming hyper-sensitised to stigma and leading secretive lives by instructing the young people to keep their status concealed. Thus, the contexts in which the young people were brought up, involving silences about the disease, metaphors and illness deception, were the mechanisms by which the young people were socialised into stigma and a life of secrets. This in turn induced felt stigma which then impacted on their pathways to adulthood. Had they taking an alternative route and disclosed their status, this may have helped them to establish intimate and long-lasting relationships. These findings are important as they may challenge parents to support their children to overcome the fear of disclosing their status which might be impeding young people's ability to navigate into adulthood.

Having explored the role of parents in socialising young people into stigma, the next chapter will focus on the impact of this role as well as ethnicity on the young people's experiences of forming peer and romantic relationships.

Chapter 5

Peer and Romantic Relationships

5.1 Introduction

This chapter now provides the opportunity to explore the impact of stigma on how the young people form peer and romantic relationships as they transition into adulthood. The transition from adolescence to adulthood is an important developmental process in the life course of an individual. Some of the most common aspects of this transition for all youth are: developing peer relationships, romantic relationships and attaining employment (Erikson, 1968; Pittman et al., 2011). However, the focus of this chapter will be on the domains of peer and romantic relationship formation whilst employment will be dealt with in the next chapter.

The period of transition into adulthood can be difficult for many young people (Mortimer and Larson, 2002). Youth with prenatally acquired HIV go through the same developmental processes and challenges as their peers without HIV (Harris, 2015). However, the existence of ethnic and HIV stigma coupled with stigma coaching from parents may exacerbate the issues experienced by black African young people living in the UK as they transition into adulthood (Lekas et al., 2006; Huynh and Fuligni, 2010; Lotfy et al., 2012). Disclosure to others and managing their difference is a major challenge for a majority of the participants due to the stigma attached to their status and the constant underlying awareness of the stereotypes attached to them as African people with HIV.

5.2 Social Networks: Friends

The need for social connection and peer acceptance is one of the most fundamental and universal human needs (Baumester and Leary, 1995). As the young people grow older and transition into adulthood, stable social networks with peers become increasingly important sources of interaction and support necessary to protect against the challenges of growing into adulthood (Erikson, 1968; Masten et al., 2004; Schoen et al., 2007; Huynh and Fuligni, 2012; Hagell et al., 2018). School is a key setting for forming and developing such connections (Huynh and Fuligni, 2012; Telzer et al., 2018). However, for many young people in this study, school environments have not always promoted the development of positive social bonds. The excerpts below from two participants, Hazy and Twingo, illuminate the young people's experiences among their peers in school.

> *... just when I am in school and stuff, I hear things, people talk about it (HIV)... not a lot of people are educated about it. They are just like… really ignorant and horrible about it. If someone thinks it's only spread through sex, how much does that person care?* (Twingo)

> *... around that time for some reason, it (HIV) was just the topic in school. And um in class, they talk about the transmission of diseases. You know that will be the first one they will say. People were quite horrible to others. Like, they will say "Oh you look like you have AIDS" or something like that and you just automatically feel like "Is it written on me" (laughs)... and I was quite scared, and I didn't know how people would react. For some reason, I'd think maybe someone might be able to see… I would sort of brush it aside but, at the same time, it helped me to sort of realise the sort of friends I was with. I felt that sometimes, what people say can… portray the sort of people they are.*

> *So, the ones that were being, you know, abrupt about it (HIV) and negative… it made me think, "Oh, this is not the people I want to be with".* (Hazy)

The above findings resonate with Twingo's narrative later in Chapter 6 where he witnessed black African pupils being teased by fellow classmates as having HIV. Here, the narratives describe the same horrible attitudes and Hazy proceeds to explain how these attitudes made her feel scared and wonder if her HIV was visible. Such an experience led her to decide she was not going to forge relationships with peers with such stigmatising attitudes. These findings resonate with Erikson's claims and also findings from other studies which reveal that threats to one's identity during transition phase may affect their willingness to form intimate relationships with peers (Erikson, 1968; Kerpelman et al., 2004; Blank et al., 2004). The intolerant attitudes about HIV among classmates may affect the young people's ability to safely navigate into adulthood in the domain of friendship formation.

Another participant, Daisy also felt uncomfortable about her status among some of her peers due to their negative attitude towards HIV, despite sharing the same ethnicity:

> *I have got many African friends, born here. I was talking to one about HIV and she was "I wouldn't want someone HIV positive close to me". And in my head, I am thinking, I've been close to you many times. It shocked me. It's just like lack of education.* (Daisy)

Daisy's narrative showed that she was shocked that someone she shared the same ethnicity with would have a stigmatising attitude towards HIV. It also reveals that education about HIV plays a huge part in people's attitudes towards the disease. Due to such negative attitudes, even though they have the same ethnicity, the young people are still selective about whom they tell.

Daisy's narrative implies that although some peers were African, they still have stigmatising attitudes, particularly those born in the UK. This indicates the influence of culture; Daisy's peers were only Africans by descent so they had been brought up in a society whose beliefs and values regarding HIV are stigmatic (Herek, 2002).

These findings indicate how prejudice and negative attitudes towards HIV among peers reinforce stigma. The young people are left vulnerable and marginalised during a crucial period of identity formation in their lives through a lack of peer acceptance (Erickson, 1968). They may feel socially excluded and this poses a huge challenge in terms of how they are going to formulate close relationships with their peers who are supposed to be supporting pillars as they navigate into adulthood (Worth, 2009).

Whilst most of the participants' discussions indicated that horrible attitudes towards HIV among peers in educational institutes were barriers to establishing intimate relationships, one female participant, Eunice, recounted how she did not have an intimate relationship with her peers at university due to differing ethnic backgrounds:

> *The girls that I lived with, we didn't really connect on that level; I was black and they were all white, and the cultural aspect, so we never really got on, so I never really made friends,* close *enough to feel comfortable to tell them something like that.* (Eunice)

The above excerpt demonstrates that young people of ethnic minority background face challenges related to perceived racial tension and discrimination in educational institutes which may limit their opportunities to form intimate relationships with peers. Eunice's narrative further suggests that knowledge related to stereotypes of black people and HIV may even make it more difficult for young people to form relationships with peers which are close enough for them to share their status even in the absence of tangible prejudiced generic comments about HIV (Lekas et al., 2006; Lotfy et al., 2012). The inability to forge intimate relationships with peers may deprive the young people of peer support that might buffer them from the stresses of growing up, a protection that is considered necessary for young people as they transition into adulthood (Worth, 2009).

Literature suggest that friendships are an essential part of school life and are key to future opportunities and resilience; as such, they are important in shaping young people's transitions into adulthood (Worth, 2009). However, findings from this study show that young black people with prenatally acquired HIV tend to feel marginalised within the school environment; they do not feel safe at a time when peer support is critical as they transition into adulthood. Failure to form supportive relationships with peers may result in threats to their psychological well-being and development, an experience that might hinder successful transition into adulthood (Worth, 2009).

5.3. Ethnic-related Stigma-free Environments

To demonstrate how the absence of ethnic stigma might lessen the burden of transitioning into adulthood for young people, the excerpts below, from Sassy, Twingo and Daisy, exemplify how a number of the participants felt that there is a greater tolerance of HIV among people of the same ethnic background, making it more comfortable to disclose their status:

> *I mean like, as I said, like in the UK, you don't hear it (HIV) more than when you are in Africa. So, I feel like in er, like even sharing with someone here, it is more shocking than when you are with your friends back home in X (an African country).* (Sassy)

> *I feel like, where I come from, in east Africa, it's (HIV) very common, yeah like in Africa it's very common. Like, the people I hang around with, my friends they are smart so they know much about it so it's like um it's okay like, if I speak to them.* (Twingo)

> *That's why like, here (the UK) I haven't told the friends I have here. I only like, have one friend or two who know about it and these are friends I have known for a long time, and they're like proper Africans and it's okay, you can tell them things like that.* (Daisy)

The above narratives demonstrate that black African youth with prenatally acquired HIV in the UK are highly sensitive to being stigmatised on the basis of their ethnicity in addition to HIV (Huynh and Fuligni, 2010; Blank et al., 2004). Nicky, a female participant who grew up in Africa and came to the UK when she was 21 years of age, revealed how young people may feel comfortable with their HIV status among other young people of the same ethnicity. Nicky, whose HIV symptoms were quite visible whilst still in Africa, reported that despite her frequent illness, visible rash and spots, she did not feel discriminated against:

> *I didn't find it so much difficult with the other young people. They didn't say much, they just knew I didn't feel very well. I think it's different with Africa… Africa's children, they really do understand. When I came back to school, they would ask "How are you feeling" even my teacher, because my grandmother told my headmaster and my teacher as well.* (Nicky)

These findings are similar to those from a study with black and Puerto Rican women which indicated that, in ethnic communities where there is higher exposure to HIV, people are more accepting and less likely to stigmatise those with the disease (Lekas et al., 2006). Such findings are important as they demonstrate that, had it not been for the added burden of ethnic stigma, the young black African people born with HIV living in the UK might not have to struggle so much in their pathways to adulthood. Understanding the added burden of ethnic-related stigma on the disclosure of an HIV status is important as this may inform stigma-reduction interventions that aim to educate society against race-related stigmatising attitudes.

5.4. Challenges in Opening Privacy Boundaries to Peers

Peer relationships become more important as the young people transition into adulthood. Transition creates changes in the individual's life that seem to elevate the importance of forging intimacy by opening one's privacy boundaries in order to disclose and share private information with peers despite privacy orientations from parents (Petronio, 2002; Greene et al., 2003). One narrative from Eunice, a 21-year-old female participant, brings this out clearly, as she recalled a time when she decided to disclose her HIV status to her best friend:

> *... so, we had quite some years of friendship... I told her and she was like "okay" ... but she didn't come to school for the rest of the week and I was like "My God!". I was worried... she is going to tell everyone; she is going to tell our social group and it's just going to get full blown to the whole school.* (Eunice)

The above excerpt aligns well with Petronio's Communication Privacy Model (CPM) in that giving others co-ownership of your private information and remaining in control of the information can be a challenge as it might be difficult to control third party leakage (Petronio, 2002; Greene et al., 2003). The findings demonstrate how it may potentially be dangerous for the young people to forge intimacy in relationships with peers as they have to navigate cautiously through the process in case all the chances of successfully forming lasting relationships are fractured as information about their HIV status can potentially become free for public consumption. For young black African people living with HIV in the UK, forging intimate relationships with peers involves opening up privacy boundaries and breaking the rules of the privacy policy engrained in them by their parents and reinforced by ethnic-related stigma (Petronio, 2002; Scambler and Hopkins, 1986; Lekas et al., 2006). Such a move can make individuals vulnerable as they risk losing control of their private information by relinquishing co-ownership of their HIV status (Petronio, 2002). As evidenced by the excerpt above, it became apparent that the young person's disclosure could have potentially severed her completely from her social network. She could have lost a friend whom she had been close to for a significant amount of time. In addition, she may suddenly have automatically fail to fit in within their social group and this could have led to rejection and non-acceptance by the whole school. Such a scenario might have barred her from the support she needed in her journey into adulthood.

Fortunately for Eunice, the situation did not turn out as she had feared. Eunice spoke about the relief she had when the friend turned out to be sympathetic and still accepted her regardless:

> *... she did come back, obviously, we talked about it afterwards. She had a lot more sympathy to be honest, because, she was like "I can't believe you were going through all that and you didn't feel you could trust me; you shouldn't have to go through it alone." At the time we were really close and we still are; we spend Christmas at their*

> *house; it's literally a tradition, we go to their house for Christmas every year... She told no one; obviously, she told her mum and dad because she needed someone to ask questions... It was scary but, she never told anyone else because, believe me, the social group that I used to hang around with, if she had told them, they would have said something.* (Eunice)

Eunice was further reassured when she learned that, not only did she still have the support and acceptance of her friend but also the whole of her social network remained undisturbed, indicating that she still had ownership of her private information. Such findings parallel the PCM theory which assumes that despite sharing private information, an individual still wants to retain ownership of their information (Petronio, 2002). These findings are important as they demonstrate the positive impact of non-stigmatising attitudes on the young people's journey into adulthood; this may, subsequently, inform stigma-reduction interventions that promote sympathy as opposed to differential treatment from peers.

However, Eunice's experience is not universal. Not all the young people who disclosed their status managed to or at least feel they retained support and acceptance from their peers. Mimmy, a 19-year-old female participant, recalled a time when she and her newly met group of white volunteers were preparing to go to Malawi to raise HIV awareness and support among the young people of Malawi:

> *... I remember telling some other volunteers that I have HIV... they said "You shouldn't say that you are HIV positive so easily" ... I remember much later on, I regretted*

> *disclosing this information and slightly felt paranoid about what they might think about me. So, when I did go to Malawi for 10 weeks, I didn't tell a soul that I too have HIV.* (Mimmy)

Perhaps Mimmy was expecting to fit in with her fellow volunteers and assumed that they would consider her status as acceptable and not something she should hide and feel ashamed of since, although they were not of a black minority and ethnic background, they all had HIV on their agenda. The impact of this was so significant that she did not feel comfortable disclosing her status later in Malawi, even to a group with whom she shared the same ethnicity and where HIV was possibly common and more acceptable. This implies that whilst she might be a valuable source of support for other young people affected by or infected with HIV, she herself might never be able to draw on the same support from her peers, an issue that could negatively impact on her successful transition into adulthood.

5.5. Isolation from Peers

As they transition into adulthood, young people are likely to spend more time with their peers and these become vital sources of support (Erikson, 1968; Brown and Larson, 2009). However, this was not the case for some of the participants in this study. For young African people with prenatally acquired HIV in the UK, who are trying to keep their status a secret due to the fear of being ostracised, spending more time with peers involves more risk of their status being found out, a scenario they would rather avoid. In order to escape from the potential consequences of status being found out, some of the participants reported resorting to reclusiveness; they decided to avoid peers at a time when they should be drawing support from them (Brown and Larson, 2009; Vogel-Scibilia et al., 2009). Twingo, a male participant, talked about how his HIV status and his fear of being found out dictates how much he socialises with peers:

> *Like, as in like… going out and stuff. Like I'm quite controlled I know… if um, I'm out too much then people like, start to learn more about your life… the first thing they look up is how is their health?... yeah, people are nosey… people try to know my life so, I try and keep it balanced … keep it private and people knowing just enough. Like in the city where I live, whenever there is a party or something, everyone is at the party… I try not to go as much. I don't really like telling people everything about myself … because then it's like people try and like contact you more and they see everything you do… so yeah, they don't really know where I am. So, it's good because, yeah, people aren't really in your life.* (Twingo)

Studies with young people transitioning to adulthood have shown that young people often define themselves in relation to their friends or other peers (Pittman and Richmond, 2008; Worth, 2009). However, the above excerpt demonstrates that HIV intolerance and negative social environments can lead HIV positive young people to a conscious decision to withdraw from peer social interaction. As exemplified by Twingo's narrative, young people may also make an effort to regulate the information they want people to know. Twingo's narrative reflects the influence of the privacy orientations from parents regarding HIV (Petronio, 2002). The young people are constantly conscious of keeping their HIV status a secret; secrecy becomes a moral career (Goffman, 1963). The statement also aligns well with Goffman's claims that the stigmatised can control the social information they present to the world and one way of doing this is by disassociating themselves from the biographical others who may be the cause of the stigmatisation (Goffman, 1963). Twingo's narrative also confirms Erikson's claims that as young people go through the intimacy formation phase, they may be faced with the potential of isolation (Erikson, 1698).

The findings, therefore, indicate that the policy of concealment/non-disclosure instilled in the young people by their parents may cause them to remove themselves from the context of peers. Consequently, young African people in the UK with prenatally acquired HIV may be transitioning into adulthood with fewer resources to help them through the particular challenges they face during this period; they may be deprived of the full benefits of the social and emotional support that friendships offer. Evidence from the literature confirms the importance of stable friendships/social networks in setting the context for transitioning into adulthood (Hagell et al., 2018). Peer relationships are critically important to young people's sense of wellbeing and connectedness as they give them the confidence and connections to navigate into the adult world (Jose et al., 2012).

Unlike Twingo, who made a conscious decision to limit his social interaction, and seemed to be contend with it, Licky, another male participant in the study, revealed how negative attitude barriers generated by peers left him feeling isolated and, in a way, forced him to refrain from socialising with friends.

> *To be honest, I feel like, I've been isolated from others... even if you go to school, everyone is talking about it you know "HIV, HIV" and I'm just there you know what I mean… I feel isolated everywhere I go... I can't socialise with my friends, no, not as much. You know... if I want to go with my friends or somewhere, you've got to take your medication... Living with this is a big toll on my head.* (Licky)

The above excerpt indicates that Licky has the desire to socialise, but he feels marginalised by his peers' negative attitude towards HIV. He wants to go out with his friends; however, he is aware of their stigmatising attitudes; therefore, taking medication whilst out with them would leave him exposed. Licky's statement: "living with this is a big toll on my head" echoes findings from a study by Scambler about young people with epilepsy; in that study, the researcher found evidence that managing a secret and concealing a stigma can be quite distressing (Scambler, 2009). However, this study builds on that evidence by exploring how concealing a stigma can be detrimental to young people's trajectories into adulthood with regard to friendship support.

Evidence from the literature indicates that friendships support young people on their journeys into adulthood by buffering them against the impact of burdensome issues faced by those growing into adulthood (Masten et al., 2004). However, for young African people in the UK with prenatally acquired HIV, such support maybe absent as they isolate themselves from peers due to felt stigma. The absence of such support networks may affect their social competence and might have negative consequences for their well-being in the future. Positive peer relationships provide a unique context in which young people may boost a range of critical social emotional skills such as empathy, co-operation and problem-solving strategies; such skills are important in adulthood (Pepler and Bierman, 2018). Lack of social interaction among young people has been shown to predict self-reported health and long-standing illness in adulthood (Lansu and Cillessen, 2012). Although it was impossible to measure and substantiate this claim among the participants in this study, it might be an interesting area for a follow-up study in the future.

Having explored how ethnicity and privacy orientations from parents might exacerbate HIV-related stigma among the young people concerning intimate peer relationships, the next section will now focus on the young people's experiences on their pathways into romantic relationships.

5.6 Romantic Relationships: Brave to Disclose

Forming a romantic relationship, getting married and starting a family generally remain key components of the transition to adulthood (Arnett, 2000). However, for prenatally infected HIV positive young people, falling in love and settling down into a relationship is not an easy exercise; it is a process characterised by fear, anxieties and hesitation. Black African young people with prenatally acquired HIV living in the UK may face even more challenges in navigating through this milestone due to privacy orientations from parents and stereotypes of Africans and HIV. As has been discussed above, ethnic-related stigma intensifies HIV stigma consequently escalating young people's fear of disclosing their status. Although the young people could manage to "pass" as normal when it came to peers, that strategy was not always the best option in trying to form intimate romantic relationships. Due to the infectious nature of HIV, some felt obliged to disclose to their partners but it was a huge challenge. The three excerpts below from Hazy, a 23-year-old single mother, Licky, a 19-year-old single male participant, and Eunice, a 19-year-old single participant, are examples of how most of the young people talked about how challenging and daunting the process of engaging in a romantic relationship was for them due to fear of rejection which might have been engrained in them by stigma coaching from their parents:

> *And it was like that fear of oh, when you meet someone, how do you tell the person? You know… can you have a family? As I got older and you see some of your friends grow and you see them settling down and you start to think "Oh actually mine's not going to be that easy, is it?" You know, then you start to think… the whole stigma… that stigma behind sort of HIV and what it is. I think that was my main fear, just how would you tell somebody. Maybe you meet somebody who you really want to be with and then it's going well, and you just tell them this and it's like "Bye" [laughter].* (Hazy)
>
> *Obviously, telling him was a big thing, I'm not going to lie. We'd been dating for a long time then, all of a sudden to… to tell him something so personal. That was like my deepest, darkest secret that I thought, I would take to the grave to be honest. So, I had to think about it like, gosh, I have to tell him… we've got that connection now.* (Eunice)

> *I tell you one of the hardest things to do was to tell her and I mean… now being told you have HIV was fine but to tell someone, you know, that was the hardest decision I've ever had to make. You don't know how to approach it and the worst thing is… you don't know their reaction… she was like, "It's fine, it's fine" but, you know, you can just see deep down, like this person is not coming back, you know… I just ended it.* (Licky)

The above extracts reveal the tension and fears faced by the young people as they navigate their way into romantic relationships. As is exemplified in Licky's narrative, even after disclosure, the young people are continuously apprehensive about maintaining the relationship.
Although these findings are similar to those of previous studies on youth born with HIV (Hogwood et al., 2013; Fernet et al., 2011), this study explores this issue further and

demonstrates that the fear of rejection even after disclosure can consequently be a barrier to forming and maintaining long lasting romantic relationships, subsequently impacting on successful transition into adulthood. The young people may lag behind their HIV negative peers due to stigma-induced paranoia. Furthermore, the tension they face in deciding to reveal their status to partners mirrors what Petronio (2002) refers to as a dialectical tension between disclosing and concealing private information with the tension emanating from the fear of rejection which was embedded in them by their parents' privacy orientations. They are faced with a dilemma; by disclosing their HIV status, the young people may risk being rejected whilst, on the other hand, by concealing their status, they jeopardise their opportunity to forge intimacy which is key to any relationship and a successful transition into adulthood (Silva-Suarez, 2014). Nevertheless, for some, like Hazy, the need to foster intimacy was greater than the fear of rejection; thus, she decided to test her partner's reactions before a full disclosure:

> *… it just started gradually. I started putting scenarios. So, I started to say, you know "What if, you know, this was the situation?" Without … not saying mine but different scenarios to see how he is going to react. In general, I saw how he reacts to other people who are ill… he is quite passionate. So, I sort of used that to determine whether I will tell him. Yeah, so when I saw he's quite a positive person… Then I was like Okay, "I need to tell you something".* (Hazy)

Hazy's strategy aligns well with the privacy boundary assumptions of the CPM model that boundary permeability can fluctuate and private information can be revealed in an incremental way (Greene et al., 2003). By progressively opening her privacy boundary, to some extent, Hazy still had control of her private information and the boundary could have shifted back to being impermeable had the boyfriend showed signs he would not be committed after disclosure. Similar patterns of disclosure were reported in a USA study with African-American HIV positive adolescents (Greene and Faulkner, 2002). However, the study does not relate the findings to transitioning into adulthood; in particular, they do not identify the possibility of a prevented adulthood or protracted transition, if the young people keep their privacy boundaries impermeable if they sense rejection.

The findings from this study also demonstrate how the young people have to manage the friction between the desire to disclose or conceal their HIV status to partners. As discussed and evidenced by the young people's narratives in earlier sections, the added layer of ethnicity intensifies the stigma, making their disclosure and attaining adulthood status particularly difficult (Lekas et al., 2006).

As articulated in Hazy's excerpt above, the young people are not just faced with the tension between revealing or concealing their status but are also questioning their chances of ever making it into adulthood and having families of their own:

5.7. In a Relationship but Not Disclosed:

While Hazy and Licky were some of the few participants who, despite the challenges and fear of being rejected, dared to disclose their status, some of the participants in the study were in a relationship but had not yet disclosed. For the young people, being HIV positive is a very sensitive issue and, as such, disclosure is not to the fore but tends to be reserved for the right time when they are intimately close.

Twingo, a 17-year-old participant, was in a relationship at the time of the interviews and the relationship had been going on for a year but he had not yet disclosed his status to his girlfriend.

Twingo pointed out how disclosure is not the priority:

> *... like you don't walk into a relationship with someone and tell them straight away... it's not really something you would want to share with anyone.* (Twingo)

The above extract suggests that the young people take time to build trust before disclosure. However, by delaying disclosure, any trust that might have been built is in jeopardy if the partner finds out. Twingo expressed his fears of such a scenario:

> *That's the scary thing. I don't know. Maybe she would wonder why I didn't tell her... I'm not sure how she would react... Yeah, how would someone close to you feel about you trying to keep a secret from them? There are times when I am with her, I would be like, how would she see me if I told her, if I disclosed it... Like would she still see me the same? Every time she looks at me, would she see the virus? That's what is scary*. (Twingo)

Twingo's narrative reveals that keeping secrets can be immensely uncomfortable for the young people; they live a life of constant fear. On the other hand, the fear of being judged is equally disabling. Given such a scenario, the longevity and quality of intimate relationships can be threatened subsequently and the opportunity to successfully transition into adulthood roles may be jeopardised.

Sassy, another 17-year-old male participant, was not in a relationship at the time of the interview but had been, twice, both in Africa and in the UK. He had not disclosed to either partner. Sassy described both relationships as not intimately close.

> *I did have a girlfriend here as well as in Africa... but like... I wouldn't say I took it far as being close.* (Sassy)

Sassy cited strong embedded instructions not to disclose status that had been instilled in him from when he was young. This appears to have had a profound impact on intimacy. He is aware he will have to finally disclose but he finds it hard to do so; therefore, the only way out of it is not to be too emotionally involved. Sassy recalled:

> *... from a young age you are told like... don't tell anyone. In your mind, you keep hearing it every time "Don't tell anyone"; it keeps ringing in your mind every time when you try to tell anyone... that's why I didn't take the relationships far.* (Sassy)

Sassy's narrative is a demonstration of the impact of repetitive stigma coaching and privacy orientations from families, a phenomenon explored in some work on stigma and the CPM (Scambler and Hopkins, 1986; Petronio, 2002). The findings indicate that privacy rules become so ingrained in the young people that they hinder people from revealing their HIV status and fostering intimacy which is necessary for a lasting romantic relationship. Sassy's experience is an indication of the challenges that black African young people in the UK may be experiencing in trying to enter into adulthood. These experiences echo those from a study elsewhere with adolescents born with HIV by Fair and Albright (2012). However, like many researchers who have explored the experiences of young people with prenatally acquired HIV, Flair and Albright did not conduct their study through the lens of stigma coaching from parents and its impact on transition into adulthood roles. As evidenced in the narrative above, stigma coaching adversely affects the formation of romantic relationship. Consequently, some of the young people tend to end their relationships prematurely, thereby sabotaging any chances they may have of a successful transition into adulthood.

Although Sassy expressed that he was considering having another relationship, he was still crippled by the fear of disclosure. This is partly because he did not know how to broach the subject and he feared a negative reaction from his partner. Secondly, he was concerned that a partner might not be able to keep his status a secret. Expressing his fears, Sassy explained:

> *I will definitely consider having another girlfriend and I am praying to have kids as well, but the problem is how to tell my girlfriend... how she will react... that's what scares me like. Will she keep it close between us... will she share it... that is what I don't like.* (Sassy)

Sassy did not completely rule out being in another relationship. His response, "I will consider" points to the future but does not indicate how far. There is no clear imminence, suggesting that until he gathers the courage to disclose his status and feels reassured that a would-be partner would keep it a secret, there might be a delay in engaging in another relationship. Subsequently, there might be a delay in marriage and the attainment of an adulthood role. The findings suggest that, due to the privacy orientations encouraged and practised by parents, aimed at protecting the young people from stigma, black African youth with prenatally acquired HIV in the UK may have protracted transitions as they grapple with disclosing their status to romantic partners.

By hesitating over and delaying major markers of transitioning into adulthood due to stigma, it is not certain if some will ever be in romantic relationships and be able to have families of their own. Mimmy, a 19-year-old female participant, confirmed these uncertainties:

> *It is not about the disease; the issue is with the stigma which results in people struggling to disclose. Often, I question my future relationship status with guys and the potential of being single for the rest of my life.* (Mimmy)

Mimmy's comment clearly emphasises the severity of the stigma for the young people and its adverse impact on such significant developmental milestones in their lives. The findings indicate that, rather than face the stigma after disclosure, some of the young people may never marry. The phenomenon of never being able to transition into marriage is a scenario confirming Erikson's claims that those with a stigmatised identity may be less willing to share their identities and intimacy with romantic partners (Erikson, 1968; Lenz, 2001). This indicates that some young people with prenatally HIV may never assume some adult roles at all. HIV-related stigma exacerbated by privacy orientations from parents and ethnicity may discourage disclosure and consequently impact on the formation of relationships and marriage. Research suggests that marriage can be positive for the individual as it might boost mental and physical well-being (Montgomery, 2005; Gomez-Lopez et al., 2019).

Findings from other studies have similarly highlighted disclosure of HIV status to romantic partners as a daunting exercise for the young people due to fear of stigma (Michaud et al., 2009; Fielden et al., 2011; Philbin, 2014). However, these studies did not explore the challenges in the context of transitioning into adulthood. Moreover, they did not explore the impact of ethnicity as an added layer of stigma for the young people and how this might exacerbate the stigma, consequently impacting on their successful transition into adulthood. The following section will now focus on the participants who had never been in romantic relationships and explore how this could be related to the underlying issues of ethnicity.

5.8. Never Been in a Romantic Relationship

Whilst some of the participants were on the precarious journey into romantic relationships, some of the young people had abstained from engaging in romantic relationships completely. For instance, Camz and Pistachio, both 20-year-old male participants, reported not having been in a relationship before. They reported that their HIV status and fear of rejection were the major concerns and reasons behind their abstinence:

> *It's a factor that's affecting my romantic relationship; however, I would always make sure that my partner was well informed about what it is and how it can affect our relationship. I think with the right information and some optimism, the relationship would be able to stabilise. However, I know that even if it won't be especially difficult to disclose, it won't be easy either as it depends on the knowledge that my partner has of it beforehand. If they are more knowledgeable, they will be more willing to accept it.* (Pistachio)

The extract reveals on the importance of taking responsibility to educate a partner about the virus for the relationship to work and indicates efforts to address and reduce the stigma first. Concern is around a would-be partner's knowledge about HIV. It shows that the young people believe that the more informed a person is about HIV, the less likely they are to stigmatise and the more likely they are to be receptive. This supports findings with HIV positive adults from ethnic minority groups (Lekas et al., 2006).

Similar to Pistachio, Camz had never been in a romantic relationship at the time of the interviews and he also reported that his HIV status was the influencing factor:

> *… actually, it is yes, because like when you think about getting in a relationship, like you think about you being pressurised into sex as well, you know, stuff like that so,*

> *yes, it is part of the reason. Actually … I had that thought the other day… I think it will be quite difficult… I feel when it comes to that stage, I will distance myself from the person, yes, and that's what I think. I think the average person don't understand HIV… they don't understand like, it is treatable… I think the partner would probably be worried that you might pass it onto her and stuff like that… well people will look at you differently… like it's not looked at as a good thing having HIV you know… people look at it like it is some kind of disability.* (Camz)

Camz's narrative suggests that some black African young people born with HIV in the UK might abstain from romantic relationships due to fear of being pressurised into sex, implying that, in such circumstances, the individual would have to disclose his status. Camz believes people have a very limited understanding of HIV; they do not know it is treatable. Thus, a would-be partner might treat him differently if he discloses his status. However, Camz felt that, had he still been in Africa, he might have been in a romantic relationship:

> *Yes, probably yes, because like… from my experience, when I was there, you always see like others talking about HIV like, prevent it, stuff like that, so it's more like… it's a common thing. It's like really a part of the culture basically. But, here it's different, it's not like… it's not part of the culture. For example, here you hear like, people talk about cancer and stuff like that more than people talk about HIV; yes, so, it's not frequent, people don't understand it here.* (Camz)

Camz's narrative validates arguments from the literature that the added layer of ethnic-related stigma may intensify difficulties associated with disclosure of HIV (Flaskerud and Nyamathi, 2000). The finding suggests that the added impact of ethnic-related stigma on black African youth in the UK born with HIV might be a huge impediment to some milestones in youth transition that should be exciting, such as the formation of romantic relationships. The experiences of some participants who came to the UK when they were a bit older are examples that indicate that, without the added layer of ethnic stigma, black African young people with prenatally acquired HIV in the UK might not find their transition so perilous. The next section will further investigate this argument.

5.9. Romantic Relationship without Ethnic-related Stigma

There was a stark contrast in this study, in terms of the formation of romantic relationships, between participants who came to the UK at a younger age (2-15 years of age) and those who came when they were much older (16 years of age and above). The latter had been in romantic relationships before they moved to the UK and it appears, although they were aware of the stigma attached to their HIV status, disclosing to boyfriends was much easier for them compared to those who came to the UK much earlier. Below are some excerpts from two female participants who came to the UK much later.

Daisy, a 25-year old participant, knew of her status when she was sixteen and she came to the UK when she was 20 years of age. At the time of the interview, she had a son and was living with her partner. Below is how she talked about disclosing her HIV status to romantic partners:

> *At that time, I had a boyfriend. I did have a boyfriend and I told him. I told him and he was very supportive. Actually, we are still in touch. But, when I came here (UK), before I met my current partner, I was seeing someone else and he, fun enough, was a doctor. Yeah, I met him, and I told him. I actually didn't hesitate. I told him, not straight away but after a few dates. It didn't feel like oh God, how do I start? And he was like, um, I*

> *like you but, I don't want to spend my life… he was telling me some funny story… he couldn't bring himself to it.* (Daisy)

Similar to Daisy, Nicky, a 23-year old female participant, had her first boyfriend at 16 and came to the UK when she was 22 years of age. Nicky's narrative in a previous section reveals that, although she was symptomatic at a young age whilst in Africa, she did not experience any differential treatment. Below, is an excerpt from her narrative describing how, like Daisy, she also navigated the romantic relationship pathway with fewer challenges compared to the participants who came to the UK much earlier:

> *But to tell the guy, it wasn't, it wasn't hard for me because, I just told him, "I was born like that". It's not like I found it somewhere, or whatever… It wasn't hard but I know… if I am talking to other people, they say, "It's very hard to disclose that." But for me, to be honest… it was just, I just tell the person, "If you don't want me, you just have to tell me now because, I am telling you the truth."* (Nicky)

The above narratives indicate the ease with which the two participants navigated romantic trajectories, perhaps suggesting that because they grew up in Africa, where HIV is common and the communities have higher exposure to HIV compared to the UK, the young people felt less stigmatised (Lekas et al., 2006). In contrast to the other young people, who came to the UK and were socialised into stigma at a young age, Daisy's and Nicky's privacy boundaries were quite thin-walled in terms of disclosing status to romantic partners (Petronio, 2002). In addition to the possible absence of the added layer of ethnic-related stigma, their boundary permeability could also have been influenced by the contexts they were brought up in. They were not socialised into stigma and had not had the concealment policy engrained in them by their parents/guardians. The two excerpts below give us some insight into the context, free from stigma coaching, in which Daisy and Nicky were brought up. In the first excerpt, Daisy recalls when she was informed of her status after her mother's death:

> *So, my sister, when I had the eye problem, straight away said to the doctor, can you do an HIV test as well please. So, when they checked, the doctor said, I was HIV positive.* (Daisy)

> *I think my grandparents had talked to the counsellors and they were told, you have to tell her the situation so that she knows… so, they sat down with me and told me.* (Nicky)

Like Daisy, Nicky had full disclosure of her HIV status. Compared to most of the young people in this study who lived a life of secrecy and were socialised into privacy rules, Daisy's and Nicky's HIV statuses were not hidden from them. The guardians and professionals did not try to be "protective capsules" and coach them into a life of secrets, something that would have made it difficult for them to disclose their status and navigate successfully into adulthood (Goffman 1963; Scambler and Hopkins, 1986). Moreover, they were both brought up in similar contexts that allowed openness:

> *My mum was very open. She was very, very open. She wasn't the kind who tried to hide, like other people try to hide and things. My mum, her sisters knew about it. She told people about it; I remember my mum telling me she has HIV.* (Daisy)

Whilst Daisy's motivation to disclose to partners might have been influenced by her mother's openness, Nicky recalled the counselling she had from professionals and the advice she received from her guardians:

> *But um… when they were trying to counsel me and stuff, they told me, "If you have a boyfriend, you have to tell him about everything, the situation."* (Nicky)
>
> *My grandparents and even my uncle… they wanted to make sure I told my boyfriend.* (Nicky)

The literature suggests that it is important to consider cultural values and beliefs as these may shape an individual's decision to conceal or reveal their HIV status (Yoshioka and Schustack, 2001). The CPM also maintains that, in a culture where openness is valued, people tend to disclose their private information more easily; it is also the case, however, that the opposite is true in cultures that are stigmatising and do not encourage openness (Petronio and Reierson, 2009; Herek, 2002).

The above findings are significant in that they reveal how, without the added layer of ethnic-stigma and stigma coaching from parents, transition into adulthood would be less precarious for black African young people with prenatally acquired HIV living in the UK. The findings are also important in that they can inform stigma reduction strategies that will educate society in an effort to challenge ethnic-related stigma towards young black African people born with HIV living in the UK so they can transition successfully into adulthood.

5.9.1. Summary

The narratives have revealed that young black people with prenatally acquired HIV living in the UK are aware of their racial differences and the racist notions attached to their HIV status by peers; hence, a majority of them were not able to form intimate friendships with peers within educational environments. Educational environments are important settings that provide sources of peer connection and support and are vital for the transition journey. However, this chapter has demonstrated that, for a majority of the young people, this was not the case. They felt marginalised by their peers and this particularly made it difficult for the young people to disclose their HIV status. Some managed the horrible HIV-related comments from peers by resorting to what Goffman (1963) termed “passing”; they endured the comments and pretended they did not have HIV. However, some managed to control the information about their status by isolating themselves from peers. Both strategies left the young people at risk of transitioning into adulthood with fewer resources to buffer the challenges of this period of their lives.

This chapter has also demonstrated a remarkable difference in the formation of romantic relationships between the young participants who came to the UK at an early age and those who came when they were at least 20 years of age. The narratives have made it clear that the former were struggling with disclosing their HIV status to romantic partners and forging intimacy, while, on the other hand, the latter were sailing through despite the HIV stigma. These differences indicate the impact of ethnicity as an added layer of stigma which makes transitioning into adulthood more difficult.

Not only are the young people faced with the possibility of missing out on the benefits of romantic relationships, the added layer of ethnic-related stigma can equally reduce their chances of transitioning into satisfying careers. The following chapter will explore the career trajectories of the young people.

Chapter 6

Employment Trajectories

6.1. Introduction

The young people's narratives about employment mostly highlighted their fear of disclosing their HIV status to employers. However, in order to fully understand the forces behind the fear and the precarious position the young people occupy in their transition to employment, we need to think beyond HIV stigma and outside the spheres of jobs and firstly, re-examine the relationship between ethnicity and HIV. This focus is important because it is the experience of this relationship that preconditions the young people's perceptions and assumptions about society at large and employers' attitudes toward HIV (Conkel-Ziebell et al., 2019). Failure to pay attention to race/ethnicity and its link with HIV means that young people's transition to employment may be interpreted in simplistic ways (Crewe and Aggleton, 2003). The next section will illuminate the racial climate which subsequently shapes the young people's perceptions about the world of work.

6.2. The Racial Climate

The young people talked a lot about the stereotypes associated with black people and HIV, revealing that, behind their HIV, was ethnic-related stigma which, in turn, exacerbated disclosure issues. The excerpts below from some of the participants' narratives exemplify most of the participants' perception of how society views Africans in relation to HIV:

> *They mostly blame it on the country which the person originated from and I think some people also believe that only people of colour have it, which is not true.* (Pistachio)

A female participant, Trixy, echoed the same view that people hold this fixed idea about Africans and HIV when she mentioned, “I think it’s sometimes a stereotype like, because you are from Africa”. Taking the issue of stereotyping further, participants believed that, in UK society, the perception is that it is normal for an African to have HIV. The following excerpt from a female participant, Eunice, describes the young people’s understanding of the stereotypes and the psychological effect they have on them:

> *I think from a white person’s point of view, it’s a normal thing to hear that a black African person has HIV, because there was a bit of a campaign last year, when you had quite a few adverts about it on TV and you had Pipi a girl from X (an African country) and she is talking about HIV and all of a sudden, it was all of these black African people shown on the campaign …it really bugged me because it was like, it isn’t fair, they were probably the only people who volunteered to do the advert but then you just had one white person, but they weren’t even English, they were European. So, I feel like, for a white person, to hear something like that, it’s the norm… you are African and you’ve got HIV.* (Eunice)

> *I mean like, everyone thinks if you are African, usually you have the disease. Let’s say, I went back to X (an African country) and came back here (UK), people will think you have the disease (HIV), even if you start coughing but, if I was in X, people don’t even have to think about it “Oh, he is coughing and all those things”.* (Sassy)

Similarly, Vicky, a female participant, referred to the stereotyping of Africans as HIV carriers and how she does not agree with the prejudice:

> *… they think it's dominant in Africans, so anyone from Africa who admits they have it, it's kind of normal for people from Africa to have it but, I don't think that's true.* (Vicky)

This notion that it is considered normal for Africans to have the disease was also echoed in the following statement made by Twingo, a male participant:

> *It's just the way it's been pictured really. Like people believe that it (HIV) came from Africa and it's probably what they see on TV… so like a really skinny malnourished young African child they think probably has it (HIV). Yeah, like because of how people have seen it before, they've now got that picture in their head for the rest of their life, … so when they see someone that's not black, let's say for example X, a comedian was recently diagnosed with it (HIV), he is white… but people didn't really expect it but it's like anyone can get it, yeah.* (Twingo)

The above narratives resonate with the history of race and diseases. Throughout history, since the slavery era, Africans have always been stereotyped with regard to diseases (Wailoo, 2006). Since the beginning of HIV/AIDS, the disease has been blamed on Africans; society assigns blame and responsibility for disease appearance to a certain group in society, often one considered inferior (Herek, 1999; Wailoo, 2006; Koku, 2010). The findings reveal the racial climate in which the young people live, which shapes their sense of stigma. A similar climate was cited in an American study with HIV positive women of a black minority and ethnic background who maintained that society's views in relation to people of colour and HIV are laced with some racist notions. Whilst for a person of colour it is considered normal to have HIV, a white HIV positive person is seen as an unfortunate victim (Lekas et al., 2006).

Whilst findings from this study substantiate the history of negative racial attitudes towards Africans and diseases and also echo the findings from other studies, this study differs in that it takes these findings further and explores how such ethnic-related stigma might make it even more difficult for young people to disclose their HIV status in work places, an issue that might hinder successful transition into employment for some young black African youth in the UK born with HIV.

6.3. The Racial Climate and the World of Work.

Below is an excerpt describing one participant's experience whilst on a work experience placement at a certain school where he witnessed black children being teased by fellow white students based on the assumption that blacks were expected to have HIV:

… they were quite naughty… there were a couple of African kids in there and they (the white kids) were saying they have HIV, the Africans, the few African kids… that the African kids had HIV, yeah… I was sad because like they (the African kids) thought they were not normal and felt out of place… it's not ideal to have HIV but, it happens but you can't really do anything about it. (Twingo)

In further describing the impact of such a scenario, Twingo revealed how such stereotypes might make the young people feel uncomfortable about disclosing their HIV status in work places:

> *… because, like, my health is personal, so I don't think I would tell them… because if they already got that mind-set, then they need education.* (Twingo)

A narrative from another male participant, revealed how ethnic-related stigma might have intensified his fear of disclosing his HIV status to his employer; he found himself inadvertently pushed out of a career where he had achieved relative economic self-sufficiency. The excerpt below details how Licky found himself feeling uncomfortable in his work environment.

> *Once I used to work in mental health. Now I work at a warehouse earning less, which is terrible. Because when I used to do care work, some of the patients would tell me they have got this disease, which if you've got open cuts, you can get infected and I have HIV, you know. I'm just thinking "Why did I even put myself in this situation?" I'm thinking to myself, "They will fire me; they will get me prosecuted for that."* (Licky)

The above narrative is evidence of how the young people may find themselves in precarious situations where they fear that keeping their information privacy boundaries shut may lead them to being prosecuted. On the other hand, revealing their status may leave them vulnerable and they did not feel that this was an option so, they are left with one choice: abandoning their dream career.

The excerpt below demonstrates how ethnicity may have made it difficult for Licky to disclose his HIV status to his employer. Licky felt that because of the people's attitudes towards HIV here in the UK, once his status is known, he would go back to Africa:

> *If they find out, then I am going back to my country because, the way they are on about it (HIV), you can tell that if they find out it's going to be a whole different situation… in this country, definitely it will be a different situation. If I was black and didn't have HIV, you know, I'm black that's fine by me but, being black and having HIV, it's too much… If I am among black people and they know about my status, you know, I just feel like you know, we are all equal.* (Licky)

Licky's fears demonstrate how the young people are aware that being black alone attracts stigma; however, the differential treatment is greater with the added layer of HIV-related stigma. The finding reveals the equal social standing that the young people may feel among people of similar ethnic background, suggesting that if they are among other blacks, they only have the HIV stigma to be concerned about; hence, they might be inclined to open their privacy boundary and reveal their status to their employer (Petronio, 2002; Greene et al., 2003). Licky's statement; "… If I am among black people and they know about my status, you know, I just feel like you know, we are all equal" is a reflection that stigma (ethnic stigma in this situation) elevates some groups as superior and consigns others to an inferior position (Koku, 2010). If the young people feel inferior and looked down upon, this might also impact on their willingness to disclose their HIV status in work-places, resulting in them leaving for less satisfying jobs, as was the case for Licky.

6.4. Career Aspirations Stifled

Another male participant, Pistachio, explicitly revealed that being black and having HIV "makes it a bit more difficult to disclose". Thus, the added layer of ethnic-related stigma as well as influence from parents acting to create protective capsules might impact on career aspirations. Some young people might avoid certain jobs because of the exacerbated fear of having to disclose their status subsequently, preventing successful transition into employment (Catan, 2004). The excerpt below from Camz, one of the male participants, is an example of how some of the young people's career aspirations were thwarted:

> *From an early age, I wanted to be a doctor. That was like my first call; I wanted to be a doctor... my mum once told me like, you can't do anything that is going to make you famous or anything like that because of the HIV thing... that is the only thing that like changed my decision.* (Camz)

The above reflects the young people's high career aspirations which are quite common for most youth in the transition phase. However, for young people with prenatally acquired HIV, the likelihood of achieving such aspirations may be limited as they are influenced by the privacy orientations from parents who may also be acting to create protective capsules due to ethnic-related stigma (Goffman, 1963; Petrak et al., 2001).

While others like Camz had to change their career aspirations due to stigma, Daisy, one of the participants who came to the UK when she was 20 years of age, talked about how her career aspirations were being thwarted by her immigration status:

> *My issue is, if I could do what I want to do. I want to be in some kind of profession, I wanted to do support work or nursing but they (Home Office) won't let me. I can get everything apart from education, which is very strange… because I am black, I am non-EU.* (Daisy)

Daisy's excerpt demonstrates how, in addition to HIV, immigration status may also play a role in constraining the career opportunities of the young people. These findings are similar to those from a UK study of HIV positive adult immigrants by Dodds (2006). Participants from the study expressed their struggle to attain employment due to their immigration status. Although the impact of ethnicity has been investigated among immigrant adults with HIV, no study has ever explored the impact of ethnicity/immigration on the employment trajectories of young black African immigrants born with HIV living in the UK as they transition into adulthood. Exploring such issues will inform wholesome strategies that will support all aspects of the young people's lives that can potentially hinder successful transitions into employment.

Research argues that transition to adulthood should be a time when young people increasingly make choices but, for some black African young people with prenatally acquired HIV in the

UK, such an experience with regard to career choices may be limited by the layering of ethnic- and HIV-related stigma (Chinouya et al., 2017). Findings from this study reveal that due to fear of being ostracised, some young people may decide not to formally apply for jobs but become self-employed in order to avoid stigma-related restrictions and barriers to successful transition into employment. For instance, Camz spoke about how he wanted to be a doctor from an early age but then changed his decision due to his mother's advice against being famous when HIV positive. During the course of the conversation, Camz mentioned how he did not want to work for anyone and was planning to form his own business: "... I don't want to work for anybody... I am focussing on starting my business". Camz's statement echoes findings from a study on disabled African youth which also highlighted the impact of stigma on the young people's occupational trajectories (Grigoriuos, 2014). A significant number of the participants in the African study reported becoming self-employed in order to escape the barriers to formal employment caused by stigma. Unfortunately, this did not significantly contribute to successful economic independence due to the meagre profits they made (Grigoriuos, 2014). Although there may be a number of interplaying factors, it is important for us not to assume that being self-employed will automatically transition the young people with prenatally acquired HIV into successful career trajectories.

There was further evidence in the young people's narratives of how the privacy orientations from parents and ethnic-related stigma may significantly affect their career aspirations. Some participants in this study talked about how they would deliberately avoid high profile employment positions in order to escape the stigma.

> *I am finding the things I want to do in life like acting. I have searched a lot about celebrities and actors and like, celebrities you know where they are... whereas actors*

> *normally work, work, work ... so you don't really follow them. Like if I did become successful in acting, maybe I could just try and hide my private life; I wouldn't really show it off.* (Twingo)

Similar fears were echoed by Mimmy as she explained how high-profile positions would inevitably leave her vulnerable to society's stigmatising attitudes.

> *If I want to do anything in life, I have to not just consider taking medication but, how others perceive me if they knew what the medication is for. Any aspirations of becoming a reality TV star or even the President of a country are out of question if you don't want your family to be criticised. Being an MP, people will scrutinise everything about you, including your health and your fitness for the position. As HIV attracts a negative perception, people look beyond health and question your moral integrity and then they will attack your family e.g. your children get bullied, your parents are criticised.* (Mimmy)

Twingo's and Mimmy's narratives demonstrate how the young people carefully choose their career options and make an effort to remain hidden from the public eye so as to shield themselves and their families from the stigmatising attitudes of society. The fear of status being found out and the inevitable consequences of that take on far greater significance for the young people than the wish to realise high-profile careers. Thus, ethnic- and HIV-related stigma may rob the young people of opportunities to excel and fulfil career aspirations in ways other HIV negative youth might.

The young people may have been able to pursue their career aspirations if ethnicity was not an issue. The narratives below suggest that had the young people been in Africa, they would have found it easier to disclose their status to employers, thus allowing them to fulfil their career dreams and transition more easily into employment with fewer barriers. The young people felt their HIV status would be more tolerable had they been in Africa, where the disease is quite common; they would only be stigmatised on the basis of their HIV status not on the grounds of ethnicity as well, an issue which makes it more difficult to disclose their status. In the excerpt below, Sassy explains why he thinks he would find it easier to disclose his status in Africa in spite of the stigma:

> *I know it will still be shocking and like people will treat you differently but like at least they know the disease that is affecting everyone around the community but, like here (UK), to be honest, I've only heard about it probably after three to four months in the newspaper but like in X (an African country), it's one of the common things there. But like, in the UK, you hear more about cancer and all those like diabetes… you don't want to disclose.* (Sassy)

Similarly, Camz reiterated how he would probably find it easier to disclose his HIV status in Africa compared to the UK:

> *Yes… in a way, because if you look at society like, it is different here (UK) from there (Africa) because like, people tend to judge you more here and stuff like that so, yes. It's (HIV) seen as a more like normal thing in Africa.* (Camz)

It is clear from the above excerpts that the young people feel more stigmatised and judged in the UK than they think they would in their native countries. Thus, the data suggest that ethnicity is an added layer of stigma that exacerbates disclosure issues, meaning that some of the young people find themselves precariously transitioning into the world of work or sometimes contemplating low-paid jobs where they may not need to disclose their status.

6.5. Precarious Transitions into the World of Work

Hazy, a female participant, revealed this challenge when she talked about how, whilst on placement as a student nurse, although she had disclosed her status to the Occupational Health Department, she had not disclosed it to the ward manager:

> *They do their risk assessments and then they end up putting you in those sort of environments that you can't work in…. on one of my placements, there was a lady with TB. I had been told by Occupational Health that I shouldn't work there because, obviously, I am putting myself at risk. So, what I said in the end was um, I can't, I haven't had my jab… If it was a different profession, it would be easier. Working in retail, they don't want to know. I wouldn't have the fear of "Oh you have to go to the Occupational Health". You have to tell them everything; it's the fear of okay, who is going to know.* (Hazy)

The young people also talked at length about their ethnicity and HIV status and how a combination of the two may make it harder for them. The following narratives from two female participants, Eunice and Mimmy, reveal the impact of the layers of stigma on young black people with prenatally acquired HIV living in the UK.

> *I feel like it's a horrible thing… fair enough, I do have it (HIV) and I am African, so that pushes that stigma that's there already… it makes me a bit upset.* (Eunice)

Similarly, Mimmy's narrative reveals how being HIV positive and the added burden of ethnic stigma may make it "harder to push" against the stigma to successfully navigate into employment:

> *… the race is an issue because people automatically judge you or perceive you on what they have heard in the media so their perceptions of you are automatically screwed (laughter)* so, *because of that perception, it therefore means being black and also having HIV, people's views of me are negative and they may not be willing to allow me to participate in things… but if I were to follow that… I wouldn't be able to step outside… I think I am still able to get where I need to, though it may be a little harder to push.* (Mimmy)

Both the narratives above reveal that the young people are aware that they do not just have HIV stigma to contend with but ethnic-related stigma as well. Eunice's statement "that pushes that stigma that's there already" is evidence of the two layers of stigma that the young people might be experiencing as they try to find their way into employment. Mimmy's narrative is a further demonstration of how having the two layers of stigma, the young people might have to push a "*little harder*" to navigate their way into employment. This is in line with evidence from the literature suggesting that experiences of intersecting stigma can potentially make the transition into adulthood more difficult to navigate compared to a single layer of stigma (Shanahan, 2000a; Mahaffy, 2003; Lee and Waithaka, 2017).

The excerpt below, from one female participant, is further evidence suggesting that the young people are aware of the precarious nature of their journey to employment due to ethnic- and HIV-related stigma, even though some try and resist it:

> *I think part of it is to do with how people perceive their own self. If they allow social constructs to determine how they live then they will be forever stuck.*

> *Other people in my situation, who are black and have HIV, may feel like people are trying to attack them so, they won't be able to get where they want, because they feel they don't have the support… but, I don't allow a social construct to determine how I live, though some people may hate another race for whatever reason…* (Mimmy)

Mimmy's narrative suggests some sense of agency in some of the young people who, despite the barriers to employment, are determined and will push harder to try to achieve their career aspirations. For example, one female participant was well aware of the career restrictions imposed on her by stigma; however, she was determined not to let the stigma deter her. She went ahead and trained in a career of her choice. Hazy, a trained nurse, was not practising at the time of our discussions but spoke about how she followed her desire to work in the health sector despite the barriers:

> *Before I even knew about the diagnosis and everything, I always wanted to be in the health sort of sector. And I think there was a time when I wanted to change but, because you know, when you have a passion to do something, you can't just go to anything else. So, I think it was that thing of "I'm just going to do it, when I finish then I'll sort of look at what areas." So, now I have finished, I'm actually interested... it's quite funny, I'm actually interested in areas that I know I can't actually work in. So that's the sort of dilemma I'm in now.* (Hazy)

Hazy's narrative demonstrates how passionate the young people can be about developing vocational identities, suggesting that an inability to attain such identities feels unimaginable for some and this might lead to negative life outcomes for the young people. Hazy's statement "so that's the dilemma I am in now" refers to the inevitable challenges that she is now facing despite following her passion. Although she was hoping to start practicing as a nurse sometime, Hazy was aware that she will still face certain challenges.

The evidence detailed above from this study's data, strongly supports the argument for exploring HIV stigma faced by young people in relation to their ethnicity. Ignoring the powerful social inequalities and prejudices inherent in the young people's experiences of HIV stigma might not fully reveal the prominent but seemingly subtle impact of ethnic-related stigma that might be lurking in the background and consequently influencing disclosure of HIV status to employers. Non-disclosure of status, due to fear of stigma, might hinder successful transitions into adulthood domains such as employment. These findings further substantiate the importance of challenging racist stereotypes in relation to HIV. Understanding how racism may exacerbate HIV-related stigma can inform ethnic-related interventions that challenge the stigma felt by the young people which, in turn, may promote successful transitions.

This is new evidence in the context of young black African people with prenatally acquired HIV in the UK as no previous study has explored the added impact of ethnic-related stigma on HIV stigma and how this may be simultaneously hindering young people in their attempts to transition into employment successfully. In the face of HIV alone, it is already difficult to disclose one's status to potential employers, and the stereotypes attached to black people and the disease may make it even harder for young black HIV positive people to disclose, resulting in potentially protracted and fractured transitions or even prevented adulthood in some cases (Catan, 2004; Hendry and Kloep, 2010).

6.6. Summary

What is clear from this chapter, which has not been established in other studies on young black people with prenatally acquired HIV in the UK, is that stigma related to the young people's HIV status is exacerbated by their ethnicity making their transition into employment even more challenging. The racial climate they are experiencing determines their perception of varying work environments. The negative stereotypes in society about Africans and HIV shape the young people's sense of stigma and pre-condition them to fear disclosing their status to employers. In addition, the climate of rejection and intolerance around Africans and HIV left some of the young people feeling insecure in their jobs resulting in precarious navigations into employment for them.

The narratives further revealed that the young people felt that their HIV status might be more tolerable in their native countries because of the higher exposure rates to HIV in Africa. This signifies the need for stigma-reduction interventions that are ethnically sensitive and focus on challenging the ethnic-related stigma directed at young people in order to allow them to transition successfully into employment.

Chapter 7

Discussion

7.1 Introduction

This chapter synthesises the key findings of the study and highlights its major empirical contributions. The first section briefly highlights different perspectives defining a successful transition into adulthood. This will be a build up to demonstrating how the study reveals the potential risks to transition caused by stigma at the intersection of HIV, immigration, age and race/ethnicity. Guided by the intersectionality framework, the second section will theorise how the stigmatised social identities the young people simultaneously occupy, intersect with power dynamics to shape and pose transition challenges in the domains of work, peers and romantic relationships. The third section will be guided by the bounded agency framework to explore how the young people try to overcome these challenges as they negotiate their way into adulthood.

7.2. What would be an ideal transition?

The extant literature defines successful transition into adulthood as achievement of certain developmental tasks (Arnett, 2001, Ghavami et al., 2016). Role transitions such as moving out of parental homes to establish independent living, gaining full time employment and getting married and starting a family are the most common criteria used to evaluate successful transition into adulthood (Arnett, 2001, Settersten and Ray, 2011, Pao, 2018, Henninger and Taylor 2014). Although there are still universal concepts of what is considered to be a successful transition, there is not one specific pathway to transitioning into adulthood (Pao 2018). Transitioning into adulthood vary by context and opportunity. Some writers have therefore stressed the importance of redefining what it means to successfully transition into adulthood (Arnett, 2001, Henninger and Taylor, 2014). They adopt a viewpoint that transition into adulthood is focused on the individual's perspective rather than on normative assumptions (Arnett, 2001, Henninger and Taylor, 2014, Wood et al., 2017). They argue that an individual's interactions during transition to adulthood are varied and complex and this leads to multiple different ways of negotiating entry into adulthood (Henninger and Taylor, 2017). Data from this study supports this latter notion and offer insight into the complexities of negotiating entry into adulthood with intersecting stigmatised identities as experienced by the black African youth in the UK born with HIV.

7.3 Growing up with HIV

A considerable number of researchers have conducted some work with young people growing into adulthood with HIV (Swendeman et al., 2006, Dorrell et al., 2008, Michaud et al., 2009, Darrow et al., 2009, Fielden et al., 2011, Szelag, 2011, Fair and Albright, 2012, Hogwood et al., 2013, Philbin, 2014). The researchers have adopted different frameworks on which to build an understanding of the challenges of growing into adulthood with a stigmatised identity faced by the young people. Dorrell and her colleagues for example, have conceptualised these challenges through a biographical disruption lens while others such as Szelag (2011) have built an understanding of the young people's position based on the medical ecological framework. While such perspectives help to explain the challenges of growing into adulthood with HIV, they do not capture the complexities of sitting at the intersection of multiple and mutually constitutive marginalised identities as experienced and conveyed by the young people in this study.

7.4 Intersectionality

Intersectionality as a paradigm has its origins from various studies by feminists of colour such as Crenshaw (1991 and Collins, 2002). The paradigm challenges essentialising a single identity or group status. Instead, intersectionality advocates for examining how multiple social identities such as race, gender, disability operate simultaneously to compound the experiences of oppression (Benbow et al., 2011, Collins, 2002). In this study, intersectional stigma was a distinctive feature of the young people's narratives and these brought to the surface race/ethnicity, immigration and age- related issues interconnected to their HIV stigma. This underscores the need to conceptualise the complexities of growing up into adulthood with HIV through an intersectional lens to avoid essentialising a single stigmatised identity (HIV positive) by attending to other interlocking stigmatised categories as well.

Failure to acknowledge the intersectionality of the other stigmatised categories that the young people simultaneously occupy, means that their needs will not be fully understood hence, they will be underserved. Intersectionality brings to light how the young people in this study were affected by a number of discriminations and disadvantages related to their HIV identity such as age, race/ethnicity and immigration. For the young people, these identities do not exist independent of each other but, they interconnect and work simultaneously to shape their lived experiences through interlocking systems of power such as racism, immigration policy and the legal system that exist in their social structures. Thus, the simultaneous operation of micro, meso and macro social processes and structures experienced by the young people determined how they negotiated their identities into adulthood in the domains of work, love and peer relationships. These issues are discussed in detail in the subsequent sections below.

7.5 Manifestations of Intersectional identities

Issues of identity are particularly salient during the transition phase (Fulign and Tsai, 2015). Research suggests that most identity exploration take place during the transition to adulthood period (Schawrt et al., 2005, Arnett, 2008). During this phase, identity exploration takes on a new meaning and importance (Arnett, 2006). As the young people try to determine who they are and how they fit in as members in various social groups, the transition phase is also marked with an increase in racial/ethnic identity exploration (Syed and Azmitia, 2009, Ghavami et al., 2016). This is so because, transition is often a time when the young people find themselves in shifting contexts that promote examination and negotiation of their ethnic and racial identities in different social groups (Syed and Azmitia, 2009, Phinney, 2008).

During the transition into adulthood phase, further identity explorations are also taking place in the domains of love and work in addition to for example, their sexuality and personal values as the young people try and take on new roles (Arnett, 2008). A distinctive feature of the transitioning phase, however, is that identities are no longer explored in isolation but rather simultaneously (Syed and Azmitia, 2009). For the young people in this study, it is a time when the intersections of an HIV identity with age, ethnic/race and immigration identities are coming to the forefront as they try and take on new roles in the domains of work, peer and romantic relationships. Data from this study showed that their understanding and a perception of a stigmatised HIV identity was filtered through the lenses of these other identities at the intersection of power issues. The young people’s narratives highlighted the inextricability of HIV, race, age and immigration and power dynamics operating on the micro, meso and macro levels and how these constitutively created challenges in their navigation into adulthood.

7.6 Interlocking identities and power dynamics at the micro level: Familial

One of the assumptions underlying intersectionality is that, embedded within the interlocking marginalised identities is a dynamic related to power and the mechanisms through which power is gained, held and deployed (Atewologun, 2018). In their study with professionals who care for HIV positive young people, Fielden et al., (2011) highlighted some issues of power and inequity between the young people and their parents/guardians. Evidence from the study suggested that some of the HIV positive youth may have diminished capacity to access resources independent of their parents. Parents were cited as controlling the young people's decision to disclose their HIV status hence, the parents were identified as potential barriers in terms of the young person accessing programmes such as support groups or recreational camps that promote social inclusion (Fielden et al., 2011).

Evidence from this study support these findings in that the young people's narratives revealed inequalities embedded within the interpersonal power domain with parents/guardians and healthcare professionals in relation to disclosing their HIV status. Whilst this study supports Fielden's work, it builds on this evidence by exploring the impact of and challenges posed by these power dynamics on the transition to adulthood in a foreign context. In this study, the young people's navigation into adulthood was not only complicated by the intersection of HIV-related stigma and their position as minors but this also intersected with their transnational position (being African-born) as well as their black and ethnic minority background.

Within the family context, the young people's understanding of their stigmatised HIV identity was filtered through their status as being minors. The HIV positive identity converged with their age (being minors) as this interlocked with the interpersonal power domain whose means and mechanisms were perpetuated by their parents/guardians. The issue of power dynamics between the young people and their parents/guardians arose from the role of parents as what Goffman (1963) refers to as “protective capsules”. In trying to protect their children from stigma, the parents trained the young people into learning and accepting their perceived deviance. Findings from this study show that this was achieved through information control by the parents in various ways. Firstly, data from this study reveal that the parents kept the young people from knowing their HIV status despite frequent hospital appointments. Many of the young people’s narratives demonstrate how, from an early age, they were suspicious of the unexplained regular hospital appointments and of how, when they learned to read, the HIV-related posters in the HIV clinics eventually confirmed their suspicions and, in so doing, communicated stigma to them. The young people also picked up clues from the doctors’ and parents’ conversations. Coupled with the hospital environments they had experienced, the young people understood that having HIV was not socially desirable; hence, they learned to hide it, a strategy that became a challenge to negotiating an entry into strong peer and romantic relationship bonds.

Partial disclosure and illness deception were two further forms of information control that emerged from the young people’s narratives. The young people were not told the actual name of their disease, instead, the professionals and parents used metaphors such as “a sleeping bug” to justify the hospital appointments and explain the diagnosis to the child. Another method of information control utilised by the “protective capsules” was what Funck-Britano (1995) refers to as illness deception. Parents sometimes chose to hide the child’s HIV status behind non-stigmatising co-existing illnesses such as asthma. Though such strategies temporarily protected the young people from stigma, longer term, this reinforced the stigma when the young people eventually learned about their illness.

Lastly, the power differentials between the young people were perpetuated when eventually the young people learned about their true diagnosis. Parents and professionals fully initiated them into a culture of secrecy and silence when they instructed the young people not to disclose their status to anyone. Although this was a well-meaning attempt to shield them from the many challenges linked to HIV stigma, it was a misguided message as it simply solidified the stigma in the young people's lives; keeping their status secret became a "moral career" around which their lives revolved. This situation, in some ways, contributed to the challenges they were facing in their transition into adulthood (Wiener et al., 2007; Persson and Newman, 2012). Parents' role had a disempowering effect on the young people. The power differentials inherently afforded parents/guardians the power/authority to manage their children's HIV-related stigma by preventing them from disclosing their status making it more difficult for the young people to negotiate their HIV identity into adulthood. Due to being minors, the young people had diminished capacity to exercise agency and parents were potential barriers.

These power dynamics and experiences mirrored evidence from studies with a similar population in African countries (Hodgson et al., 2012, Mburu et al., 2014). However, the young people in this study were unique in that their experiences were influenced and exacerbated by being immigrants. They were growing with HIV in a foreign country where they are already stigmatised on the bases of their race. The intersection of these identities intensified their experiences given that HIV stigma draws heavily on existing lines of race inequalities (Deacon, 2005, Castro and Farmer, 2005). It is therefore reasonable to argue that the power dynamics between the young people and their parents were more intense compared to those in Africa since the parents were also HIV positive in a foreign country. The young people's disclosure would consequentially risk the parents' disclosure as well. Evidence from a number of studies revealed that people of an ethnic minority background have lower levels of HIV status disclosure (Korner 2007, Petrak et al., 2001, Worth et al., 2001).

7.6.1 Micro level interpersonal relationships: Peers

A number of studies with young people living with perinatal HIV in Africa have examined the young people's experiences as they grow into adulthood (Hodgson et al., 2012, Mburu et al., 2014a, 2014b). Evidence from these studies revealed how the young people experienced perceived and internalised HIV-related stigma and this initially affected their ability to socialise with peers. However, eventually, they were able to regain self-esteem and interact with peers (Mburu et al., 2014). This in turn strengthened their self-efficacy and resilience. Findings from these studies showed how the young people valued personal relationships with peers and tried to sustain them. Despite the HIV-related stigma, they had the desire to enjoy normal life like any other young person. Strong peer relationships have been cited as central to the young people's sense of wellbeing and connectedness necessary in boosting their confidence as they navigate into adulthood (Jose et al., 2012).

However, this is a sharp contrast to the experiences of the young people in this study as highlighted in their narratives. Data from this study demonstrated that the young people had perpetuating perceived and internalised HIV-related stigma and they consciously minimised social interaction with peers which, is contrary to the behaviours of their fellow young people growing up with HIV in Africa. Isolating self from friends allowed the young people in this study to keep their lives and HIV status private; a strategy which allowed them to control the information they disclosed to their peers. However, this left them disenfranchised of the benefits of friendships that can serve as supporting pillars as the young people transition into adulthood.

Unlike their counterparts in Africa, data from this study showed that the young people's HIV-related experiences and negotiation into peer relationships were filtered through the lens of race and the existing power dynamics. For instance, some expressed how disclosing their status to other black youth would not be so much a challenge due to the equal sense of power. A perceived racial difference implied power inequality which, was a major barrier for some of the young people to break into peer circles and be intimate enough to feel comfortable to disclose their HIV status. In addition, evidence from this study revealed the influence of cultural context with regards to disclosing to peers. Some narratives in this study indicated that although some peers were African, they still held stigmatising attitudes toward HIV particularly those born in the UK hence, the young people would not feel comfortable disclosing their HIV status to such peers.

The participants in this study further articulated in their narratives the common place behaviours and language exhibited by their peers which reified dominant norms and beliefs regarding black people and HIV. The young people identified the intolerable race-related attitudes of peers towards HIV as major barriers to the development of intimate social bonds with friends. They described enduring race-related negative comments about HIV from peers in silence, particularly within the school environment, and how this left them feeling vulnerable and marginalised among the very people they desired to form intimate bonds with.

Data from this study demonstrated how the intersection of HIV-and race-related stigma was embedded within the interpersonal power domain to magnify feelings of powerlessness and inferiority among the young people.

7.6.2 Micro level interpersonal relationships: the love domain

Studies on romantic relationship development posit that romantic relationships become increasingly significant and central to young people's social lives during mid to late adolescent life (Furman and Shaver, 2003; Bouchey, 2007). It is an exciting stage of growing up for many and young people spend a long time talking and thinking about it (Furman and Shaver, 2003). Evidence from studies with young people growing with HIV in Africa correspond to these findings (Mburu et al., 2014, Woollett et al., 2016). Findings from such studies demonstrate that despite the HIV-related stigma and the fear of disclosure, the young people referred to and looked forward to social role transitions from adolescence to adulthood within the love domain (Mburu et al., 2014). They had positive perceptions about marriage and childbearing.

While evidence from this study regarding fear of disclosure to romantic partners parallels that from the African studies, the young people in this study's experiences posed unique challenges. Their HIV-related stigma converged with being African in addition to their position as ethnic minorities in the UK. Instead of being optimistic and positively looking forward to romantic relations like some of their counterparts in Africa, the young people's narratives were a clear reflection of their dreary perceptions and experiences. The impact of being African on the severity of their perceived HIV-related stigma was so significant that some of the young people could not envisage a future in a romantic relationship and were contemplating to stay single. On the other hand, some idealised being in Africa as an alternative; they believed if they had remained in Africa, they would have been less anxious to engage in a romantic relationship. Such an alternative was constructed on the basis that HIV is highly prevalent and talked about more in Africa than it is in the UK hence, they would feel less challenged to negotiate their HIV identity into the love domain. Such idealised alternatives validate arguments from the literature that the intersection of HIV-related stigma and race intensifies difficulties associated with disclosing an HIV positive status (Flaskerud and Nyamathi, 2000). Findings from this study demonstrate that the intersection of HIV-related stigma and being an African immigrant in the UK is mutually constitutive and it is a huge impediment to navigating into romantic relationships for the black African youth born with HIV living in the UK.

Furthermore, the experiences of some of the young people in this study who grew up in Africa and came to the UK when they were a bit older (20 years or above) are clear examples of an idealised alternative of growing into adulthood in Africa. Despite the challenges of HIV-related stigma, these young people had disclosed their status to partners and seemed to have faced less challenges in negotiating their HIV positive identity into romantic relationships.

7.6.3 Intersecting identities at the meso and macro levels

Evidence from studies of young people growing with perinatal HIV in Africa showed that the young people often experienced HIV-related stigma and discrimination at the community level (Woollett et al., 2016, Mackworth-Young et al., 2020). The stigma encountered in many of these community settings for example, schools, was an explicit demonstration of the power dynamics between the young people and their teachers (Woollett et al., 2016). However, this was only related to the young people's HIV-related stigma of which, through the course of time, the young people's resilience eclipsed any sense of living with a stigmatised disease (Skovdal and Daniel, 2012, Woollett et al., 2016). This ability to flexibly respond to the HIV-related stigma was linked to their own personal aspirations. The young people aspired to have high profile and influential positions in life for example, some aspired to be managers (Mburu et al., 2014, Woollett et al., 2016).

Likewise, the young people in this study had similar high career aspirations nevertheless, the likelihood of achieving them was very limited due to the intersection of their HIV status, race and immigrant positions. Whilst the experiences at the community level for the young people in Africa was mainly influenced by HIV-related stigma and discrimination, the young people in this study's experiences at the meso level were largely shaped by the stereotypes related to HIV and being African; race-related stigma was simultaneously a force to contend with. Evidence from this study revealed how the young people's stigmatised identities were embedded within hegemonic power. Data from this study revealed that at the community level, HIV-related stigma manifested predominantly as prevailing stereotypes of who is likely to get HIV and this stemmed from common public misconceptions of its association with Africans. The media for example, reinforced the dominant beliefs of the society through stereotypes. Thus, the dominant groups and media prescribed how and what to talk and think about HIV; the disease was constructed as an African ailment. The young people's narratives revealed how the media stories and stereotypes perpetuated these dominant beliefs and ideologies thereby reinforcing the hegemonic power that the society/community hold over Africans and HIV. Through the power to stereotype, society caused the young people to internalise and endorse the negative attitudes associated with their HIV status and race consequently rendering them powerless and lacking confidence to disclose their HIV status to employers.

Contrary to some of their counterparts in Africa who were optimistic and aspiring for high profile jobs, some of the young people in this study would deliberately hide their private lives by avoiding high profile positions so they are not exposed to the society's stereotypes and stigmatising attitudes. Data from this study further demonstrates that due to fear of being ostracised, some of the young people would avoid applying for jobs but become self-employed. However, being self-employed does not always contribute to successful economic independence (Grigorious, 2014). Evidence from this study showed how the intersection of HIV and race hugely impacts on the young people's career trajectories. The young people sensed they were judged more in the UK than they would in Africa, hence; if status is found out some would not hesitate to leave for their native countries. Thus, the young people constructed alternatives of being in Africa; idealising being able to pursue their career aspirations in Africa where the disease is rather common and talked about more hence, they would feel less anxious to disclose their status to employers.

In addition to the hegemonic power dynamics at the meso level, data from this study revealed the structural forces at the macro level which simultaneously constituted to the young people's navigation challenges into employment. Evidence from this study show that some young people found themselves in precarious positions at work; they feared potential prosecution if they failed to disclose status and infect others. Leaving such positions for less paying contracts shrunk their career prospects. Data from this study further showed that being an immigrant also played a role in limiting educational and career opportunities. These findings mirror that of a UK study with HIV positive adults of an African origin (Dodds, 2006). Evidence from the study indicated that an immigration status can pose constrains on the chances of attaining employment or pursuing a career of choice. Data from this study demonstrate that the intersection of HIV, race and the power inequalities pushed the young people away from fulfilling the career aspirations of choice. Consequently, this caused the young people to recede further into marginality as they settled for lower paying jobs in fear of publicity or prosecution.

7.7. Agency

It is clear from the above discussion that the intersection of stigmatised identities embedded within power dynamics had a significant impact on how the young people negotiated their way into adulthood. Evidence from this study suggest that being a black African immigrant intensified the young people's level of vulnerability to the impact of HIV-related stigma. This is in line with other discourses of young people living with HIV which reveals the young people's vulnerability (Swendeman et al., 2006). However, Pincock (2017) argues that such discourses may overlook the daily strategies that the young people employ to overcome the challenges related to their HIV status. Clarke (2012) also cautions us not to overly portray the stigmatised as vulnerable and passive recipients of stigma with no coping mechanism whatsoever. Further researchers have argued against the preconceived ideas that the stigmatised lack agency and do not cope with stigma (Persson and Newman, 2012, Bradford and Clark, 2011). Instead, some research show that multi-stigmatised people can devise coping strategies to help them manage the stress of living with intersectional stigma (Logie et al., 2011, Remedios and Snyder, 2015). For example, findings from a Canadian study with HIV positive women experiencing intersectional stigma revealed coping strategies such as tenacity and optimism which the women utilised. The women's narratives were characterised by statements inferring to fighting against the stigma and being strong (Logie et al., 2011).

Similarly, evidence from research with young people with perinatal HIV in Africa showed that the young people possessed the ability to interpret and respond to stigma (Woollett et al., 2016, Skovdal and Daniel, 2012, Mburu et al., 2014). Despite experiencing and anticipating challenges around disclosure of their HIV status, the young people demonstrated positive adaptation to the challenges associated with living with HIV (Skovdal and Daniel, 2012, Woollett et al., 2016). Features of resilience such as self-esteem and acceptance of their HIV status were cited as the key elements enabling them to manage adversity (Woollett et al., 2016, Vale and Thabeny, 2015).

Likewise, the young people in this study demonstrated individual strategies of tapping into their inherent capacities to become agents. They tried to act and mediate the challenges posed by parental stigma couching, peer discrimination and anxieties around career aspirations and romantic relationships. However, the interplay between their intersecting stigmatised identities and power dynamics in their lives generated tension in the way they exercised their agency, particularly in the process of disclosing their HIV status. The young people's choices and ability to act were confined within the social and structural processes around them; a phenomenon conceptualised as bounded agency by Evans (2008). She described bounded agency as socially situated agency which is influenced but not determined by environments (Evan, 2008). The concept of bounded agency situates individuals as actors within structures, with room for action but within the constraints of social and structural factors (Evans 2007). Whilst some of these constraints can be circumnavigated, altered or be resisted, some are difficult to move (Mackworth-Young, et al., 2020).

This section now draws on the concept of bounded agency to demonstrate the way in which young people in this study articulated agency through silence, secrecy and isolation as strategies through which they negotiated their way into adulthood within the constraints of race, HIV as well as the adult dominance in their lives. Data from this study illustrate how the structural factors in the young people's lives shaped their daily experiences of disclosure across life domains of work, peer and romantic relationships. One of the starting points was the inequitable access to information regarding their status at the familial level. Parents/carers often decided how much information to disclose to the young people regarding their HIV status. However, data in this study show that despite the adult dominance, the young people still found ways to respond to such constraints.

While some narratives pointed to the frustration emanating from adult control, the young people soon became aware of listening and picking clues from adult conversations as a potential resource which could be mobilised to deduce their stigmatised HIV identity. They quickly became aware of the value of silence as a strategy not only to collect needed information but also to keep this information about their HIV status under cover. Nonetheless, even after gaining information about their HIV status, discussion about their diagnosis remained largely controlled by their parents/carers. Data in this study revealed how the young people were constrained by their parents' instructions regarding disclosure of their HIV status. They were strongly discouraged against disclosure but to keep their status a secret. Social norms and the expected consequences of what would happen should people know about their status was a factor that contributed to the silence and secrecy around their disclosure. Furthermore, persistent HIV and race- related stigma among peers and the community reinforced the employment of agency through the practice of silence and secrecy.

The thought of disclosing their status to peers provoked anxiety, since disclosure had a potential for a negative impact on the young people's identities and relationships. Youth is a period of social change, relationship formation and identity development as such, a negative impact of HIV disclosure to peers can have especially strong effects on the young people's identity (Skovdal and Ogutu, 2012). Goffman (1963) posits that people who are unable to conform to society's standards are often labelled as having spoiled identities. HIV and a black immigrant status can be seen as spoiling the young people's identities which then require repair and maintenance (Bury 1982, Cobin and Strauss, 1987). Data from this study revealed how the young people employed silence and secrecy as strategies to maintain and protect their identities from negative HIV and race-related comments from peers in order to pass as normal so they could negotiate their way into peer relationships. However, the value of secrecy and silence as strategies to enact agency was questionable in contexts where trustworthiness is called for in any intimate relationship. Moreover, the guilt this caused is a clear demonstration that the young people's agency was tightly bounded by their contexts and the persistent stigma. Social isolation was another strategy that the young people used to mediate the potential challenges relating to fear of peer discrimination. As highlighted earlier, this allowed the young people to have control of the information they disclosed to peers but, not without losing the benefits of friendship support.

Silence and secrecy were not only practised to overcome the fear of peer discrimination but, they were also strategically exercised in negotiating entry into romantic relationships. Evidence from a number of studies with young people born with HIV indicate that disclosure of an HIV status to romantic partners is the greatest concern for the young people (Mburu et al, 2014, Woollett et al., 2016, Mackworth-Young et al.,2020). Similarly, young people in this study were overly concerned about disclosure to romantic partners hence, silence and secrecy were the default strategies of agency. While most of the participants had kept their HIV status a secret from romantic partners, some had disclosed with caution, exercising incremental disclosure as a strategy to mediate potential rejection and third-party leakage. Whilst despite the structural barriers, some of the young people found ways to express their agency and precariously negotiated their way into romantic relationships, for some, their agency had remained overly constrained; the social barriers were difficult for them to move, circumnavigate or resist.

As has been outlined in previous sections, data in this study demonstrated how the intersection between being a black African in a foreign country and HIV-related stigma constrained the young people's employment trajectories. However, although the young people were surrounded by many structural barriers, they still negotiated their way into employment as they found ways to express their agency and overcome the challenges. Whilst most of the young people in this study, were aware of the limitations placed on their career aspirations by their intersecting stigmatised identities and power structures, data shows that they made decisions to circumnavigate these limitations. They decided to consider other avenues, such as self-employment, low profile jobs or jobs where it was not necessary to disclose their HV status. They used these alternative avenues to reframe their career aspirations. Thus, the young people were not simply passive objects but, they made decisions to resist or circumnavigate the constrains. Although some of the decisions meant they had to change career pathways, maintain low profile or settle for less paying jobs, they were still negotiating their way into employment albeit, through secrecy and silence. Mupambireyi (2017) argues that there is need to give attention to subtle manifestations of the young people's agency before concluding they lack agency.

Although the young people could be seen as social actors who could express their agency to reframe their goals and negotiate their way into adulthood, their agency was still bounded in social constructs. They had to constantly negotiate and find ways to resist or circumnavigate the social constraints which were difficult to move. Silence and secrecy were practiced as a form of resistance in an attempt to navigate into adulthood rather than as a way to alter the constraining environments.

These findings are important as much of the work done in the UK with young people in relation to challenging HIV-related stigma has not exclusively attended to issues pertaining to young black African youth. In particular, issues around their intersecting identities and the embedded power and oppression in their lives and how these impact on their passage to adulthood have not been attended to. Attempts need to be made to reframe HIV-related stigma interventions and policies, recognising that it is not enough to address HIV-related stigma and discrimination only but, it is important to also take action to dismantle systems of power and oppression that constrain the young people's agency consequently limiting their chances in life.

7.8 Reflections and conclusion

This section considers the methodology used for this study, reflecting on its strengths and limitations. Further reflections on the contributions of the study and suggestions for areas of future research will form subsequent sections.

7.9 Reflections on Methodology

This study set out to explore how young black African youth with prenatally acquired HIV experienced intersectional stigma in their everyday lives. The second objective was to capture and document the impact of these experiences on young people as they negotiated their way into adulthood. The study was, therefore, designed to provide the young people with an opportunity to freely articulate their experiences and feelings so these could be recorded, reflected upon and analysed. The study positioned the young people as the narrators of their own stories through semi-structured interviews which provided rich and in-depth data. Individual interviews afforded the young people with the privacy needed for such sensitive discussion. The flexible and informal approach to the interviews allowed the young people to feel relaxed creating an atmosphere conducive to in-depth data collection (Doody and Noonan, 2013; Rubin and Rubin, 2011).

The methodology was further strengthened by its flexibility in allowing the young people to choose how they wanted to be interviewed (face-to-face or synchronous email interviews) and also in allowing the participants to contribute any stories about their experiences they might have written prior to the study, although only one young person had something written prior. The methodology was further strengthened by my position as an insider: a black African who has been affected by HIV. They spoke quite overtly on issues of race, something they might not have done had they been interviewed by someone of a different ethnic background (Rubin and Rubin, 2011).

The participants were recruited through purposive sampling, a method that might have resulted in selection bias. Staff at the NHS sites assisted in recruiting participants. Whilst this was advantageous in that they could offer emotional support if needed and also to ensure the right participants, who fitted the study criteria, were selected, the staff might have been tempted to approach only those they believed would be willing to take part. Even so, those approached might have felt obliged to participate as they might have been concerned that their care would be affected if they refused. However, this was clearly addressed through the information leaflet and also by continuously seeking consent from the participants throughout the research process. Nevertheless, seeking the assistance of the clinic staff in recruitment was a pragmatic decision given the sensitive nature of the HIV phenomenon; those unwilling to participate might not have contributed in-depth data or might have withdrawn prematurely from the study. Generalisability of the study to the entire population of HIV positive young people, due to the small sample size, was a further limitation of the study. However, given the small population of prenatally infected black African youth in the UK, the sample size for this study was large enough in relation to the population. It was also large enough to identify the issues of concern in this study; a rich source of data was provided.

7.9.1 Contribution of the study

The study has made significant contribution to the existing body of literature. Most of the research on young people with prenatally acquired HIV living in foreign countries have focused mainly on the disease and the challenges this poses on the young people. This study has responded to some writers' concerns that studies about HIV have been decontextualized from the inequalities that are inextricably connected to HIV-related stigma (Aggleton and Parker, 2003, Castro and Farmer, 2005). As such, this study is the first to shift from essentialising HIV as the single stigmatised identity posing challenges for the young black African people in the UK and has examined specifically the other intersecting stigmatised identities the young black people simultaneously occupy. In doing so, the study has managed to demonstrate that the young people's marginalised identities (HIV, race/ethnicity, migrant and being a minor) do not exist independent of each other but they constitutively interact and intersect, creating a complex convergence that bind the young people's agency consequently exacerbating the challenges of living with HIV and navigating into adulthood. Understanding this convergence would be useful in developing inclusive anti-stigma policies and interventions that address the interwoven prejudices the young people face as they negotiate their way into adulthood.

7.9.2 Practical implications

The study findings suggest a number of recommendations that could be considered to support the young people in addressing the constraints in their lives. Firstly, the young people raised concerns about the negative views about Africans and HIV portrayed in the media which, they believe were the drivers of the society’s negative stereotypes and behaviours. Given these concerns, it would help if interventions targeted at altering the media narratives could be employed. The media could be encouraged to have more positive views of people living with HIV. It has been argued that negative HIV media representations increase stereotypes and loss of self-esteem (NAT, 2016). It was on this backdrop that the “Always Hear” anti-stigma campaign was launched in 2012 by Waverley care, a Scottish Aids charity, to promote more positive news articles around HIV in an effort to evoke public empathy (NAT, 2016, Waverley Care, 2020). The National Aids Trust in the UK has also partnered with Press Gang (a group of people with or affected by HIV who take action against misleading HIV information in the media) to challenge HIV information inaccuracies or discriminatory content (NAT, 2016). Although there has been a considerable reduction in inaccurate HIV news articles, a review of the programme later established that negative media portrayals regarding HIV were still issues of concern particularly around HIV transmission and criminal prosecution coverage (NAT, 2016). In view of this, such programmes are still valid and also campaigns such as the Scottish “Always Hear” could be scaled up and be launched throughout the UK but tailor-made to the needs of the black African youth living with HIV.

In the past, mass media HIV campaigns of the 1980s such as the “Don’t die of ignorance” have been used successfully as means of conveying information about HIV to a wide population (NAT, 2016, Hall and Lee, 2017). It is timely that such a programme has now been followed up by the Waverley Care charity in Scotland through the Undetected =Untransmittable (U=U) message; that is, a person living with HIV and is on treatment, cannot pass the condition through sex. Such a campaign, can be scaled up throughout the UK updating society with the current evidence-based advances in HIV. This vital information may reduce stigma among communities as well as boosting the young people’s confidence in disclosing their HIV status to peers, romantic partners and employers as they navigate their way into adulthood. However, to be effective, such campaigns should not be a one- off short term effort. An on-going programme delivered through various platforms can be key to the campaign’s success.

Although media campaigns can be effective in changing society’s attitudes toward the young people, the campaign may not be as effective in changing the intended behaviour (Time to Change, 2007, Beka et al., 2014, NAT, 2016). There may be need to involve the young people themselves in running campaign programmes through workshops. Evidence from different countries have demonstrated that when people attend face-to face workshops run by the people living with HIV themselves, they may be more empathetic hence, more likely to change their behaviour towards people living with HIV (Morolake et al., 2009). For the young people, this will increase their autonomy and help shift the power dynamics between the young people and the society as facilitating workshops will put the young people in a position of knowledge (NAT, 2016, Mahendra et al., 2006).

Some of the young people in the study also mentioned how meeting other HIV positive young people through camps organised by CHIVA boosted their self-esteem. During these camps, they did not have to hide their HIV status however, this was short-lived as they had to go back into a life of silence and secrecy to cope with stigma once back in the community. Following examples from Time to Change programmes and similar initiatives in Tanzania, Africa, in addition to the summer camps, CHIVA could organise similar events but aimed at encouraging social contact and also an opportunity to discuss stigma among the young people and non-HIV positive youth. Evidence from a similar Time to Change programme indicates that social contact between people with and without mental health issues was more effective in evoking positive behaviour changes towards mental health compared to media campaigns only (Time to Change, 2007).

In the UK, the Body and Soul (a charity supporting people of all ages living with or affected by HIV) also ran effective stigma reduction workshops in schools aimed at talking about stigma (Paul Hamlyn Foundation, 2011). They reported that such interventions were linked to reduced stigmatising attitudes. A similar programme could be tailor-made to the needs of the black African youth living with HIV in the UK. The young people could be helped in rolling out programmes to discuss intersectional stigma in different arenas such as schools or career development workshops in an effort to help them exercise more of their agency and ameliorate challenges they face in negotiating their stigmatised identities in different domains.

Many of the young people also spoke about the need to educate their peers about HIV in the hope that this might reduce the stigma. There is evidence indicating that essential facts about

HIV are not being disseminated in schools (NAT, 2016). CHIVA, a charity that works with young people with HIV has drawn up some good practice guide to assist educational institutions in supporting young people living with HIV (CHIVA, 2015). One of the recommendations included in the guide is for educational institutions to include HIV awareness in their policies. Findings from this study could be used by such charitable organisations to encourage the policy makers to incorporate into the awareness the social and structural contexts of the black African youth living with HIV. Whilst it is important that HIV awareness forms part of the sex education, it could be more important if this was included as part of a broader curriculum so as to understand HIV and the intersecting stigma related to it in a wider cultural context rather than just perceiving it as a sexually transmitted disease.

Finally, it is clear from the findings that although the young people exercised their agency, their choices remained constrained by the social and structural constraints. The secrecy and silence strategies were a product of anxiety. It is therefore important to support them in decision making as they try to negotiate their stigmatised identities into relationships and the world of work. There is need for HIV services to be tailor-made and understand the black African youth's complexities of growing into adulthood with HIV and the challenges brought by the intersection of their identities.

7.9.3 Areas of further research

While this study has provided new significant insights into the complex convergence of the young people's stigmatised identities and their impact on transition into adulthood, it leaves some areas not fully explored. There are two crucial areas of research that could be explored further. Firstly, future research could be conducted with the young people's parents/guardians. They are a missing group in this study whose views of bringing up the young people encapsulated in a life of secrecy and silence are only expressed through the young people's voices. The parents/guardians have only been present through the ways they have been constructed by the young people's narratives. It would be enlightening to hear from them directly and understand their own views and also elicit opinions on how best their children can be helped to fight the stigma in ways that do not constrain their agency. The second area of research would be a follow up study to assess the full trajectories of the young people and ascertain how they negotiated and eventually made it into relationships and employment.

7.9.4 Concluding Remarks

To conclude this thesis, I reflect on how well the objectives of the study have been achieved. The first objective was to explore and gain a better understanding of the experiences of intersectional stigma among black African youth with prenatally acquired HIV living in the UK. Special focus was on the intersection of race/ethnic- and HIV-related stigma as well as stigma coaching from parents in relation to the young people's position as minors. Prior to engaging with the young people through semi-structured interviews, the initial work involved engaging with stigma-related literature so as to locate theories that would enhance an understanding of the concept of stigma. Goffman's conceptual framework has become the benchmark for any stigma-related work (Goffman, 1963). So, Goffman's and Scambler and Hopkins' (1986) stigma frameworks were identified as illuminating, particularly on the role of parents in socialising and coaching the young people into stigma (Goffman, 1963; Scambler and Hopkins, 1986). Although Goffman's framework lays the foundation for ethnic-related stigma through his identification of tribal stigma, it does not explicitly expound on its convergence with other stigmatised identities. Hence, Aggleton and Parker’s conceptual framework was deemed appropriate in building on the work of Goffman as it sheds some light on the inequalities and power relationships between young people and the society they are living in (Aggleton and Parker, 2003). Aggleton and Parker’s stigma framework illuminates how HIV stigma is a perpetuation of already existing ethnic stigma and how this causes already powerless young people to feel more inferior, exacerbating the fear of disclosing their HIV status. Further literature on intersectionality highlighted the connectedness of ethnicity and HIV and the power of communities to stereotype and stigmatise (Bharat, 2002). There is some substantial evidence collected in the data for this study supporting these theoretical frameworks in terms of both the role of parents in modelling the young people into “moral careers” and also the presence of ethnic-related stigma in the racial climates described by the young people in educational institutions, within the media and in society. This thesis has provided evidence of how the young people’s position as minors and the power dynamics between them and their parents influenced their view that the HIV status they carry is stigmatised, hence it has to be hidden. The thesis has also provided evidence of how the stereotypes and prejudices the young people simultaneously experienced at the meso and macro levels substantiated their view making them more fearful of disclosing their HIV status to peers, romantic partners and employers. An exacerbated fear of disclosure leads us to the second objective which was to explore and understand the impact of stigma coaching, race/ethnicity and HIV stigma on the transition to adulthood of the young people. The intersectional framework further illuminates the exacerbated impact of the intersecting identities and power inequalities on the young people in particular the HIV disclosure dilemmas the young people face when trying to navigate into employment and relationships. Due to the social and structural constraints around them, the young people tend to exercise their agency through silence and secrecy as a way to mediate the challenges they face. However, denying peers and romantic partners access to their secret (HIV status) creates challenges as their navigation into adulthood is dependent upon fostering intimacy which calls for access to privately secured information regarding their HIV status.

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Appendices

Appendix 1

Literature search terms

Database	Search Terms	Articles Retrieved	No. of relevant articles
CDAS	transition AND adolescents AND frameworks	91	15
	transition AND youth AND framework	81	17
	career AND development AND transition	84	8
	employment AND development AND transition	92	10
	intimacy AND development AND transition	11	12
	transition AND romantic AND relationships	70	17
	transition AND intimacy AND relationships	18	2
	peer AND intimacy AND relationships	78	19
	friends AND relationships AND transition	80	11
PsyInfor	racism AND HIV	267	30
	race AND peer AND transition	109	21
	Racism AND disease AND HIV	64	15
SocIndex	immigrants AND stigma AND HIV	40	9
	employment AND stigma AND youth	9	1
	youth AND discrimination AND employment	79	8
	Employment AND HIV stigma	126	17
	Racism AND employment AND youth	21	6
	Ethnicity AND stigma AND HIV	107	16
	Racism AND discrimination AND HIV	102	12
Medline	Ethnicity AND HIV AND stigma	66	10

Appendix 2

Letter to HIV Specialist Consultant/Nurse

Date: 03.08.14

Re: Research Study: An exploration of the experiences and challenges faced by young people (16-25 years old) in the UK living with HIV since birth as they grow into adulthood.

Dear HIV specialist Consultant/ Nurse,

I am currently undertaking a PhD in Public Health with the Lancaster University. As part of my degree programme, I intend to carry out a study on exploring the experiences and challenges of growing up with HIV.

There is evidence to show that young people who are not members of the majority for different reasons for example, being born with HIV face a number of challenges as they try to manage their HIV and growing into adulthood. I believe that valuable information gained from talking to such young people may help in developing services and support that may help the young people to address the challenges of growing into adulthood with HIV.

I hope to interview between 4 to 6 young people (16-25 years old) from your clinic who have lived with HIV since birth. To be included in the study, the young people must have been aware of their HIV status for at a year and are on HIV treatment. They also must be able to understand, read and write English and feel comfortable talking about HIV. Young people may not be included if they have any cognitive impairment that impedes capacity to participate.

The participants will choose between a face to face or an online interview, which will be 40 to 60 minutes long. I would be very grateful for your permission and assistance in recruiting participants by giving the enclosed study invitation to potential young people as they attend clinic or by phoning and emailing the invitation to potential participants. I would also be grateful for your assistance in facilitating a private room should any of the young people prefer a face-to-face interview.

Thank you for your time and consideration. I look forward to hearing from you.

Yours Faithfully

Salome Muchena

PhD Student Lancaster University.

Appendix 3

Date and version No. 10.06/14 (v1.0)

NHS
Health Research Authority
NRES Committee West Midlands - Coventry & Warwickshire
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 883 9440

01 August 2014

Mrs Salome Muchena
Dudley and Walsall Mental Health Trust
Falcon House
Ground Floor
Dudley
DY2 8PG

Dear Mrs Muchena,

Study title:	**Understanding the experiences and challenges faced by young people (16-25 years old) in the UK with prenatally acquired human immunodeficiency virus (HIV) as they grow into adulthood.**
REC reference:	**14/WM/1011**
IRAS project ID:	**146379**

Thank you for your letter of 01 August 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further

information, or wish to make a request to postpone publication, please contact the REC Manager, Rebecca Morledge,
NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

<u>Registration of Clinical Trials</u>

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only)		
GP/consultant information sheets or letters	V (1.0)	10 June 2014
Interview schedules or topic guides for participants	V(3.0)	30 July 2014
IRAS Checklist XML [Checklist_01082014]		01 August 2014
Letter from sponsor		
Letters of invitation to participant	V (1.0)	10 June 2014
Other [Response to recommendations 3 and 8]	V(1.0)	18 July 2014
Participant consent form	V(2.0)	18 July 2014

Participant information sheet (PIS)	V 3.0	30 July 2014
REC Application Form [REC_Form_13062014]		13 June 2014
Research protocol or project proposal	V 1.0	10 June 2014
Summary CV for Chief Investigator (CI)	V (1.0)	10 June 2014
Summary CV for student	V (1.0)	10 June 2014
Summary CV for supervisor (student research)		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

14/WM/1011 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely,

pp

Dr Helen Brittain Chair

Email:NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Debbie Knight, Lancaster University*
Ms Sarah Glover, Royal Wolverhampton Hospitals

Appendix 4

Consent Form

Study Title: Young people's experiences and challenges of growing into adulthood with HIV.

I am asking if you would like to take part in a research project aimed at exploring the challenges and experiences faced by young people infected with HIV since birth. Before you consent to participating in the study, I ask that you read the participant information sheet and tick each box below if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Salome Muchena on 07917184022(work number) or email on s.muchena@lancaster.ac.uk

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study ☐
2. I confirm that I have had the opportunity to ask any questions and to have them answered. ☐
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. ☐
4. I understand that audio recordings will be kept until the research project has been examined. ☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published ☐
8. I consent to information and quotations from my interview being used in reports, conferences and training events. ☐
9. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will/may need to share this information with her research supervisor. ☐
10. I consent to Lancaster University keeping electronic transcriptions of the interview for 3 months after the study has finished. ☐
11. I consent to take part in the above ☐

Name.......................................Signature..Date..................

Date and version No.: 18.07.14 (v2.0)

Appendix 5

Participant Information Sheet

My name is Salome Muchena and I am a PhD student at the University of Lancaster in the United Kingdom. As part of my course, I will be conducting a study to explore the experiences and challenges faced by young people (16-25 years old) in the UK living with HIV since birth. In order to help you decide whether to take part in the study or not, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

What is the study about?

The purpose of this study is to explore the experiences and challenges of growing up with HIV faced by young people who have lived with HIV since birth.

Why have I been approached?

You have been approached because the study requires information from people who are between 16-25 years of age, have had HIV since birth, and are under the care of an HIV specialist clinic.

Do I have to take part?

No. Taking part is voluntary. It is completely up to you to decide whether you take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You will need to email the consent form to the researcher within one week from the date you receive this form. If the researcher does not receive your form, it will be assumed that you are not willing to participate and no further contact will be made. You can withdraw from the study without giving a reason at any time before and during the interviews and up to two weeks following interviews. Your withdrawal will not affect the care you receive from your HIV clinic, which will continue as normal.

What will I be asked to do if I take part?

If you decide that you would like to take part, you would choose to meet with the researcher for a discussion either online via email or by attending your regular HIV specialist clinic and meet the researcher face to face. You will have your travel expenses reimbursed at reasonable local bus or train fares if you choose to attend the clinic. You will be kindly asked to show a receipt/ticket. Travel expenses will still be reimbursed even if you decide not to continue with the interview. You will choose a day convenient to you between the ...2014 and .... 2014. During the discussion, you will be asked some questions about your experience of living with HIV and telling others about your HIV status, the challenges you face/have faced in different areas of your life because of your status and how you have or are coping with these challenges. The face-to-face discussion will take place in a confidential room at your regular HIV specialist clinic with just you and the researcher. It will take approximately one to one and a half hours to talk about the experiences. For accuracy, I would also like your permission to audio record our discussion. If you decide to take part in the email interviews, I will ask for your telephone number prior to the interview in case we have internet or other problems and I need to contact you. I suggest you ensure your phone is fully charged. Internet interviews will take place within reasonable day-evening times.

Will my data be confidential?

The information you provide is confidential. If you take part in the online discussion, I will remove any identifiable information from our email conversation before storing them securely on a password-protected computer and the researcher will be the only one with access to this information. The original email conversation will then be deleted. You are also advised to choose a quiet and private room during the conversation and never to have anyone overlooking or to leave your computer unlogged off even for a short break during the discussion. Likewise, I will strictly follow the same security measures.

The audio recordings and any other data collected for this study will be stored securely and only the researcher conducting this study will have access to this data.

- Audio recordings will be stored securely until the end of data analysis after which the recordings will be destroyed and/or deleted.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- The files on the computer will be encrypted (that is no one other than the researcher will be able to access them) and the computer itself password protected. These will be kept by Lancaster University for 5 years after the study has finished. They will be destroyed at the end of this period.

However, there are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, are at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this. In the event that you terminate the email interview abruptly, I will immediately try to contact you on your phone to make sure you are not distressed. If you do not answer your phone or call me back in a reasonable time and I am very concerned about your safety, I will have to break confidentiality and ask the police to come to your house to check if you are safe. Other than your name and address, I will not disclose any other information to them.

What will happen to my information if I decide to withdraw from the study?

Should you decide to withdraw from the study, I will destroy any information you will have given me if you do not want it to be used in the study.

What will happen to the results?

The results will then be summarised and reported in a thesis for examination by Lancaster University in fulfilment of the PhD in public health programme. The results may also be submitted for publication in an academic or professional journal such as Aids Care. A report of the findings will also be placed on the voluntary organisation website for your access no more than a year after the thesis has been examined by Lancaster University. You can obtain the website address from your HIV clinic.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. However, the information you give may help to provide better support for young people with HIV in future.

Who has reviewed the project?

This study has been reviewed and approved by the NHS Ethics Committee.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher or her supervisors:

Salome Muchena

s.muchena@lancaster.ac.uk

07917184022(work number)

Liz McDermott

e.mcdermott@lancaster.ac.uk

Mark Limmer

limmer@exchange.lancs.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Liz McDermott
Division of Health Research
Furness Building
Room C53, Lancaster University
Lancaster

LA1 4YG
01524510847

If you wish to speak to someone outside of the Public Health Doctorate Programme, you may also contact:

Professor Paul Bates Tel: (01524) 593718
Associate Dean for Research Email: p.bates@lancaster.ac.uk
Faculty of Health and Medicine

Patient Advice and Liaison Service (PALS).
You can get details of your nearest PALS by phoning NHS 111.

Resources in the event of distress

Should you feel distressed because of taking part, you may contact your GP or the specialist HIV nurse from your clinic. The following resources may also be of assistance.

Samaritans: A 24-hour telephone and email support for anyone who is worried, upset, or suicidal; 08457 90 90 90; email: **jo@samaritans.org**.

NHS Direct: a 24 hour helpline for health advice – you can call either 0845 4647 (depending on your area) or 111.

The Big White Wall (www.big.whitewall.com): a 24/7 online emotional support network

Children's HIV Association (CHIVA)

Telephone: 01173155100

www.chiva.org.uk

Child line

https://www.childline.org.uk

Telephone: 0800 1111

Body and Soul peer mentors

Telephone: 02079236880

www.bodyandsoulcharity.org.uk

Positively UK peer supporters

Telephone: 02077130222

Email: info@positivelyuk.org

www.positivelyuk.org.uk

Appendix 6

Interview Guide

Date and version No. 30.07.14 (v3.0)

Introduction and key components:

I want to thank you for taking time to meet with me today.

Purpose of the interview:

My name is Salome and I would like to talk to you about growing up with HIV. We will also talk about things that help or make it difficult to live with HIV.

I will ask you general questions about your own experiences. Remember you do not have to talk about anything you do not want to and you may end the interview at any time. If you decide not to continue with the interview, I will delete all the information you will have given if, you tell me to do so.

The interview should take 40-60 minutes and everything we talk about in the interview will be kept private.

Should you feel distressed either as a result of taking part, you may contact your GP or the specialist HIV nurse from your clinic. You may also find useful the resources listed in your information sheet which are, the Samaritans, NHS Direct, The Big White Wall, CHIVA, positively UK peer supporters and Body and soul peer mentors. I can email you the full details again if you no longer have them.

After the interviews, I will remove all your identifiable information before storing the interview in an electronic file on my password-protected computer and no one else except me has access to the information. The original email exchange will be deleted. Your name and any information that could identify you such as second name, area you live will not appear on the written interview or any information I include in the writing about the interviews.

> However, if what you tell me during the interview suggests that you may be in danger of harming yourself or someone else, I might have to tell appropriate people in order to help you. In the event that you terminate the email interview abruptly, I will immediately try to contact you on your mobile phone to make sure you are not distressed. If you do not answer your phone or call me back in a reasonable time and I am very concerned about your safety, I will have to break confidentiality and ask the police to come to your house to check if you are safe. Other than your name and address, I will not disclose any other information to them.

Do you have any questions about what I have just explained?

Do you still want to continue with the interview?

(Email interviews) In case we have internet or any other problems and I need to contact you, can I have your telephone number please? Is your phone fully charged? (If it is a mobile phone)

Topic arears

The interview will address the following four topic areas:

- How are the young people's identities being shaped by the significant others(parents/carers) in their lives?
- What is the impact of the impact of the significant others on the young the young people's transition into adulthood?
- How are the young people experiencing stigma as a form of power in the context of ethnicity?
- How does ethnic-related stigma compound the young people's HIV-related stigma as they transition into adulthood?

Interview questions based on the Four topic areas:

1. Can you please tell me about how you first knew you had HIV?

Prompts: How old were you?, who told you?, what were you told? How did it make you feel? What happened after you found out?

2. What was your understanding about having HIV?

Prompts: Illness, death, stigma, shame, sex, treatment

3. Have you ever told anyone about your HIV status?

Prompts: if no, why not?, if yes, tell me about it, who did you tell?, what made you tell?, How did it feel?, what happened after?

4. So, tell me, have you got a boy/girlfriend?

Prompts: If so, does he/she know your status?, if yes, how did you find telling him/her?. If no, why have you not told him/her? If no boy/girlfriend, any reason why you are not in a relationship.

5. I was just wondering, have you ever felt you have been treated differently because of your HIV status or race?

Prompts: If so, where, when and how did that make you feel?

6. Are you working?

Prompts: If yes, what made you choose this job? how do you manage your HIV status at work? Have you ever told anyone at work?, If no, why?, If yes, how did you find it? If not working, why?

7. What do you think would be different if you lived in Africa?

Prompts: Would that have an effect on how you talk about your HIV status? If so, why? If no, why

Demographics:

Age: ....

Name of clinic/hospital you attend for HIV treatment: ....

Home Address: ....

Debriefing

We have come to the end of our interview, thank you very much for your time and your contribution. Is there anything else you want to add?

I just want to remind you that everything you told me today remains confidential; no one will ever know or have access to the information apart from myself. I understand that talking about sensitive issues can bring back sad memories, are you okay?

In the event that you feel sad because of what we talked about, do you have anyone you can talk to about it?

Remember, you can talk to the nurses at your clinic who are available between 9.am and 5p.m Monday to Friday. Alternatively, you can contact the support groups I mentioned in the beginning.

Once again, thank you very much for your time.

Appendix 7

Date and version No. 30/07/14 (v3.0)

Invitation for a study

Research study: An understanding of the experiences and challenges faced by young people (16-25 years old) in the UK living with HIV since birth as they grow into adulthood.

Hello, my name is Salome Muchena and I am currently studying for a PhD in Public Health with the Lancaster University. As part of my degree programme, I intend to carry out a study on exploring the experiences and challenges of growing up with HIV.

There is evidence to show that young people who are not members of the majority for different reasons for example, being born with HIV face a number of challenges as they try to manage their HIV and growing into adulthood. I believe that valuable information gained from talking to such young people may help in developing services and support that may help the young people to address the challenges of growing into adulthood with HIV. As you have been living with HIV since birth, I will be interested in your experiences and views.

I intend to interview young men and women (16-25 years old) living in the UK and have had HIV since birth. You must have been aware of your HIV status for a year or more and are on HIV treatment. You also must be able to understand, read and write English and feel comfortable talking about HIV.

The interviews will last 40-60 minutes long and all information obtained will be strictly confidential.

If you are interested in taking part in the study please contact me for more information by email on s.muchena@lancaster.ac.uk. alternatively, phone 07917184022. Please respond by ....14.

I look forward to hearing from you.

Salome Muchena.

Appendix 8

Date and version No. 10/06/14 (v1.0)

NHS
National Research Ethics Service

RESEARCH IN HUMAN SUBJECTS OTHER THAN CLINICAL TRIALS OF INVESTIGATIONAL MEDICINAL PRODUCTS

After ethical review – guidance for sponsors and investigators

This document sets out important guidance for sponsors and investigators on the conduct and management of research with a favourable opinion from an NHS Research Ethics Committee. Please read the guidance carefully. A failure to follow the guidance could lead to the committee reviewing its opinion on the research.

1. Further communications with the Research Ethics Committee

1.1 Further communications during the research with the Research Ethics Committee that gave the favourable ethical opinion (hereafter referred to in this document as “the Committee”) are the personal responsibility of the Chief Investigator.

2. Commencement of the research

2.1 It is assumed that the research will commence within 12 months of the date of the favourable ethical opinion.

2.2 The research must not commence at any site until the local Principal Investigator (PI) or research collaborator has obtained management permission or approval from the organisation with responsibility for the research participants at the site.

2.3 If the research does not commence within 12 months, the Chief Investigator should give a written explanation for the delay

2.4 If the research does not commence within 24 months, the Committee may review its opinion.

3. Trial Registration

3.1 The registration of the clinical trial in a publicly accessible database is a condition of the favourable opinion for the following types of study:

- Clinical trial of an investigational medicinal product (CTIMP) (Please note, there is a separate copy of this document for CTIMPs).
- Clinical investigation or other study of a medical device,
- Combined trial of an investigational medicinal product and an investigational medical device,
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

For all other types of study, registration is strongly recommended for reasons of transparency but it is not currently mandatory.

4. Duration of ethical approval

4.1 The favourable opinion for the research generally applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Committee should be notified.

.2 Where the research involves the use of “relevant material” for the purposes of the Human Tissue Act 2004, authority to hold the material under the terms of the ethical approval applies until the end of the period declared in the application and approved by the Committee. In England, Wales and Northern Ireland, samples may be held after the declaration of the end of the trial, for analysis or verification of research data for up to one year. After this period legal authority to hold any human tissue under the ethical approval for this project will expire. To ensure that any continued storage is lawful, either the tissue must be held on premises with a storage licence from the Human Tissue Authority, or an application made for ethical approval of another project before the favourable ethical opinion of the existing project expires. Otherwise the tissue would need to be destroyed in accordance with the HTA Codes of Practice.

5. Progress reports

4.1 Research Ethics Committees are expected to keep a favourable opinion under review in the light of progress reports and any developments in the study. The Chief Investigator should submit a progress report to the Committee 12 months after the date on which the favourable opinion was given. Annual progress reports should be submitted thereafter.

4.2 Progress reports should be in the format prescribed by NRES and published on the website http://www.hra.nhs.uk/resources/during-and-after-yourstudy/nhs-rec-annual-progress-report-forms/

4.3 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss the progress of the research.

5. Amendments

5.1 If it is proposed to make a substantial amendment to the research, the Chief Investigator should submit a notice of amendment to the Committee.

5.2 A substantial amendment is any amendment to the terms of the application for ethical review, or to the protocol or other supporting documentation approved by the Committee that is likely to affect to a significant degree:

the safety or physical or mental integrity of the trial participants

the scientific value of the trial

the conduct or management of the trial.

A Notice of Substantial Amendment should be generated by accessing the original application form on the Integrated Research Application System (IRAS). The Notice of Substantial Amendment should be electronically authorised by the Chief Investigator and the sponsor of the study before the amendment is submitted to the Committee.

A substantial amendment should not be implemented until a favourable ethical opinion has been given by the Committee, unless the changes to the research are urgent safety measures (see section 7). The Committee is required to give an opinion within 35 days of the date of receiving a valid notice of amendment.

Amendments that are not substantial amendments ("minor amendments") may be made at any time and do not need to be notified to the Committee. However, changes to contact details of the CI, sponsor or R&D contact are helpful and can be notified by letter or email.

Further guidance on amendments is available at.

http://www.hra.nhs.uk/research-community/during-your-researchproject/amendments/

6. Changes to sites

Management permission (all studies)

6.1 For all studies, management permission should be obtained from the host organisation where it is proposed to:

include a new site in the research, not included in the list of proposed research sites in the original REC application

appoint a new PI or Local Collaborator at a research site make any other significant change to the conduct or management of a research site.

In the case of any new NHS site, the Site-Specific Information (SSI) Form should be submitted to the R&D office for review as part of the R&D application.

Site-specific assessment (where required)

The following guidance applies only to studies requiring site-specific assessment (SSA) as part of ethical review.

In the case of *NHS/HSC sites*, SSA responsibilities are undertaken on behalf of the REC by the relevant R&D office as part of the research governance review. The Committee's favourable opinion for the study will apply to any new sites and other changes at sites provided that management permission is obtained. There is no need to notify the Committee (or any other REC) about new sites or other changes, or to provide a copy of the SSI Form.

Changes at *non-NHS sites* require review by the REC which reviewed the application for the research. Please submit the SSI Form (or revised SSI Form as appropriate) to the REC together with relevant supporting documentation. The REC will notify the Chief Investigator and sponsor of its opinion within a maximum of 25 days from the date on which a valid SSA application has been received.

Studies not requiring SSA

For studies designated by the Committee as not requiring SSA, there is no requirement to notify the Committee of the inclusion of new sites or other changes at sites, either for NHS or non-NHS sites. However, management permission should still be obtained from the responsible host organisation (see 6.1 above).

7. Urgent safety measures

7.1 The sponsor or the Chief Investigator, or the local Principal Investigator at a trial site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.

7.2 The Committee must be notified within three days that such measures have been taken, the reasons why and the plan for further action.

8. Serious Adverse Events

8.1 A Serious Adverse Event (SAE) is an untoward occurrence that:

results in death

is life-threatening

requires hospitalisation or prolongation of existing hospitalisation

results in persistent or significant disability or incapacity

consists of a congenital anomaly or birth defect

is otherwise considered medically significant by the investigator.

A SAE occurring to a research participant should be reported to the Committee where in the opinion of the Chief Investigator the event was related to administration of any of the research procedures, and was an unexpected occurrence.

Reports of SAEs should be provided to the Committee within 15 days of the Chief Investigator becoming aware of the event, in the format prescribed by NRES and published on the website: http://www.hra.nhs.uk/resources/during-and-after-your-study/progress-and- safety-reporting/

The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss any concerns about the health or safety of research subjects.

Reports should only be sent to the REC which reviewed the application.

9. Conclusion or early termination of the research

9.1 The Chief Investigator should notify the Committee in writing that the research has ended within 90 days of its conclusion. The conclusion of the research is defined as the final date or event specified in the protocol, not the completion of data analysis or publication of the results.

9.2 If the research is terminated early, the Chief Investigator should notify the Committee within 15 days of the date of termination. An explanation of the reasons for the early termination should be given.

9.3 Reports of conclusion or early termination should be submitted in the form prescribed by NRES and published on the website: http://www.hra.nhs.uk/research-community/end-of-study-andbeyond/notifying-the-end-of-study/

10. Final report

10.1 A summary of the final report on the research should be provided to the Committee within 12 months of the conclusion of the study. This should include information on whether the study achieved its objectives, the main findings, and arrangements for publication or dissemination of the research including any feedback to participants.

11. Review of ethical opinion

11.1 The Committee may review its opinion at any time in the light of any relevant information it receives.

11.2 The Chief Investigator may at any time request that the Committee reviews its opinion or seek advice from the Committee on any ethical issue relating to the research.

Appendix 9

Coding Schema

	Code name	Code Definition
A	Finding out	Data where the young people (YP) describes how they first knew about their status: Regular hospital attendance, guessing, parent dies, sibling's death, illness, age, place, family member, professionals, explicit disclosure, virus unnamed. : Need for more explanation, lack of satisfactory explanation, adults evasive, discontent, growing in isolation, being controlled
B	Response to finding out	Data where the YP describes their first reaction to finding out they are HIV positive: frustration, shocked, scared of death, distressed, why me?, sad, confused, upset, researching more, not concerned, it didn't sink, too young to understand, pondering, no hope, relieved, get on with it, betrayed
C	Peer perception	Data where the YP talk about how HIV/AIDs is perceived by their peers: lack of understanding, not sensitive, negative statements, horrible, the psychological impact, paranoia, trying to be brave, normalising conversations, fear of rejection, treated differently, teased
D	Keeping a secret	Data relating to how the YP keep their status a secret: lies, isolation, hard to disclose, paranoid, dilemma, fear of rejection, , hiding medication, missing doses, told not to disclose, passing, controlling information
E	Disclosure to romantic relations	Data where the YP talk about their disclosure experiences to romantic partners: Paranoid, expecting rejection, hard to disclose, making up scenarios, cautious, ambivalent, disclosed with ease, partner not on board, partner avoiding discussion, supportive partner, direct rejection, implicit rejection, partner scared, building trust, easy, hard, progressive disclosure
F	Age and disclosure	Data where the YP discusses whether disclosure becomes harder as they grow up or not: easier when younger, didn't think about it, worry increases with age, increased stigma awareness, sympathy when younger
G	Career choice and HIV	Data referring to career choices in relation to the YP's status: restricted choices, employer exaggerating risk, treated differently, made to feel strange, immigration restrictions, self - imposed restriction, you cannot be famous, self-employment, fear of disclosure
H	Isolation	Data relating to where the YP implicitly talk about isolation, HIV not a good thing, distancing from relations, HIV a disability, emotionally detached, limited friends, avoiding social groups

I	Ethnicity and disclosure	Data where the YP discuss ethnic-related stigma; anticipating rejection, common ground, will not disclose, uncomfortable disclosing, we are all equal, HIV common in Africa, comfortable in Africa, stereotypes, judged more in the UK, Africans associated with HIV, prejudiced
J	Coping	Data referring to the YP's coping strategies: acceptance, struggling to cope, hope, counselling others, not a big deal, religion, positive, support network, Prognosis
K	Romantic relation abstinence	Data relating to when the YP give inferring or explicit statements about romantic relations abstinence; shyness, uncertainty about the future, easier to stay single, fear of disclosure an obstacle
L	Reasons for non-disclosure	Data where the YP talk about the reasons behind non-disclosure in general; negative HIV talk in school, society's ignorance, society's arrogance, public intolerance, resentment, status catastrophised, need for normalcy, bad experiences, need for confidentiality, avoiding attention, loathes pity, protecting others, adults instigate secrecy, blame on stigma not illness, ethnicity
M	Managing accidental disclosure	Data referring to the YPs' differing reactions to accidental disclosure of their status; not concerned, respecting others' opinions, relocate, aggressive, defensive
N	Life with HIV	Data where the YP describe a life with HIV; accepting, increased knowledge, withstanding rejection, public HIV ignorance a concern, another chronic illness, false friendships exposed, inspirational figures influential, keeping secrets burdensome, life on medication annoying, constant fear of being judged, worry, disheartening, society's distorted view, ill-informed restrictions, frustration, defiance, fighting for identity,
O	Being young and HIV positive	Data relating to how the YP perceive society's view of them with regards to their status; stereotyped, labelled, promiscuous, a complete right off, no future, low opinion, marginalised, not expected to excel.
P	Ethnicity and HIV	Data where the YP talk about society's perceptions on ethnicity and HIV; virus associated with Africans, YP of BME stereotyped, ostracism, differential perceptions,
Q	Addressing stigma	Data where the YP suggest ways of addressing HIV stigma; prognosis, education effort, school and home's responsibility,