

**The experiences of older Black African women living with HIV in  
the UK: An IPA study**

**Kuljit Heer**

Student Number: 13088962

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## **Abstract**

Due to the improved availability of highly active antiretroviral therapy (HAART) life expectancy amongst people living with HIV has drastically increased. Older people, aged 50 and over now make up the fastest growing group of individuals living with HIV in the UK. Despite this little is known about their experiences of ageing with HIV. In addition, further still is known about older Black African women living with HIV in the UK, despite the complexity of their social and political context. This was, therefore, the first study to explore the lived experiences of this underrepresented group of women. The thesis adopted a phenomenological approach to examining how the intersections of older black African women's identities shaped their experiences of living with HIV in the UK. In addition, it explored the ways in which they coped with the devastating impact HIV appeared to have on their lives. Using interviews with seven women and interpretative phenomenological analysis, the results revealed three master themes. These were 'Spoilt Identities', 'A present without light and a future without hope' and 'Escaping the labyrinth of distress and uncertainty'. A detailed account of these master themes is provided. The findings are discussed in relation to existing literature, implications for clinical practice, methodological limitations and suggestions for future research.

## **Introduction**

### **1.1 Key Terminology**

The following section defines key terminology used throughout the thesis.

#### **1.1.1 Human Immunodeficiency Virus (HIV).**

HIV is a viral infection which can lead to Acquired Immunodeficiency Syndrome (AIDS). The virus attacks the immune system including white blood cells (CD4 / T-helper cells) weakening the body's ability to fight infections and diseases (Barre-Sinoussi et al., 1983). HIV enters the body through breaks in the mucous membrane through the exchange of body fluids. Common means of transmission are unprotected sexual intercourse, contaminated needles, breast milk and transmission from an infected mother to her baby during birth (Terence Higgins Trust, 2014).

#### **1.1.2 Black African.**

In the UK the term Black African refers to people and their offspring who originate from sub-Saharan regions of Africa. In the US the terms Black and African are often used interchangeably to refer to individuals with African origins (Agyemang, Bhopal, & Bruijnzeels, 2005). For the purpose of this study, the term Black African has been used, unless references are made to literature from the US.

### **1.2 Prevalence**

Globally, an estimated 35.3 million people were living with HIV in 2012, which has been an increase in previous years due to people living longer as a result of antiretroviral therapy (UNAIDS, 2013). The rate of new HIV infections has been shown to fall by 33% globally since 2001. Women are thought to represent approximately half of people with HIV, with this proportion being higher in certain parts of the world such as sub-Saharan Africa, where figures are believed to rise to 60% (World Health Organisation, 2011).

According to a report by Public Health England (PHE, 2014) approximately, 107,800 people were living with HIV in the UK in 2013. Gay, bisexual and other men who have sex with men make up the largest group living with HIV in the UK constituting 40% of the total population. Black African

heterosexual men and women make up the second biggest group contributing to an estimated 36% of the population. However, Black Africans only constitute 1.8% of the overall population of the UK, highlighting significant health inequalities amongst this group of people.

### **1.3 The psychological impact of living with HIV**

The prevalence of mental health difficulties amongst individuals living with HIV has been shown to be higher than the general population (Bing et al., 2001; World Health Organisation, 2008). For example, individuals living with HIV are approximately twice as likely to receive a diagnosis of depression when compared with matched control groups. Receiving a diagnosis of HIV and the challenges associated with living with HIV are likely to be causal factors in the onset of psychological difficulties (Power, Tate, McGill & Taylor, 2003; Fumaz, 2005).

Research has shown that people living with HIV report experiencing issues related to poor quality of life, social and medical issues, discrimination and isolation (Weatherburn et al., 2009). As a result, there has recently been an increased emphasis on improving the psychological well-being of individuals living with HIV. Recent guidelines by the British Psychological Society (2011) recommend the need for specialist psychological support for people with HIV which focuses on the impact of stigma associated with HIV, understands the experience of groups most affected by HIV and provides culturally sensitive and appropriate support for ethnic minorities. Recent advances in the treatment of HIV have also led to a greater life expectancy, which has resulted in new challenges for mental health services, an issue which will be explored next.

### **1.4 Medical advances and HIV as a chronic illness**

The improved availability of modern treatment advances such as highly active antiretroviral therapy (HAART) have led to HIV being re-conceptualised as a new “invisible chronic condition” (Clarke, 1994; Deeks, Lewin & Havlir, 2013; Schmitt & Stuckey, 2004). Consequently, it is no longer seen as a medical epidemic as it was in the 1980's and 1990's. Additionally, treatments have

meant that severe physical symptoms are much less likely to occur. Improvements in treatment have meant that people are living longer with HIV leading to an ageing cohort effect which introduces unique challenges for health and social care services. Although many individuals do not consider age 50 to be "old", statistics on "older people" with HIV and AIDS, use the cut-off age of 50 (Public Health England, 2013; UNAIDS, 2013).

## **1.5 HIV and Ageing**

Older people (50+) are the fastest growing group in the UK living with HIV. In 2013 approximately 27% of the individuals living with HIV in the UK were aged over 50, nearly double the proportion in 2004 (13%) (Public Health England, 2013). Estimates suggest that these figures are expected to increase over the next five years. Diagnoses in older age groups are also rising, with 1 in 5 heterosexual people newly diagnosed with HIV being aged over 50 (PHE, 2014). A lack of awareness of risk factors for getting HIV and misdiagnosis in older groups may have led to a surge in new diagnoses amongst this group. HIV may also result in accelerated ageing, although causes for this remain uncertain (Deeks & Phillips, 2009). Despite this increasingly ageing cohort, little research has explored the impact of ageing on those individuals living with HIV.

Much of the literature in the HIV field has focused on samples based on sexuality, gender or ethnicity as opposed to age. The few studies that have explored ageing and HIV have focused on older gay men (Lyons, Pitts, Grierson, Thorpe, & Power, 2010; Lyons, Pitts & Grierson, 2012; Pitts, Grierson & Misson, 2005). Very little research has examined the experiences of older ethnic groups. As a result, service providers working with older adults with HIV may be less aware of the specific needs and issues facing this group. Additionally, the management of older adults with HIV and multiple co-morbidities is likely to present unique challenges to HIV specialist services and geriatric services, which require further research and exploration to help service design and provision (Kearney, Moore, Donegan & Lambert, 2010; Nakagawa, May, & Phillips, 2013).



A recent national study by the Terrence Higgins Trust (Power, Bell & Freemantle, 2010) explored the views of a sample of 500 individuals aged 50 and over living with HIV in the UK about what concerns they had about growing old with HIV. The findings revealed a higher prevalence of comorbid health conditions, financial difficulties, people living in significant isolation and experiences of discrimination and mental health difficulties.

### **1.6 Older Black African Women living with HIV in the UK**

The findings of the above study also revealed that Black African women aged over 50 faced significantly more challenges than any other groups and that their experiences were often compounded by their immigration status. For example, this group of women were more likely to be extremely anxious or depressed and had less expectation that services could help with their mental health issues. They were also less likely to be economically active and consequently were more likely to be living below the UK poverty line for pensioners in the UK. They also reported facing stigma and discrimination which they attributed to the HIV diagnosis as opposed to their age. This led to them either not disclosing or facing difficulties post-disclosure.

Aside from the study above, little is known about the specific experiences of older Black African women living with HIV in the UK. However, research has explored the experiences of Black African women in general, looking at younger age groups. Studies have shown that Black African women are likely to have experienced trauma (e.g. rape, murder or death of a relative following illness), be seeking asylum in the UK, as well as living in poverty and poor housing situations associated with their migrant status (Doyal & Anderson, 2004). These experiences are thought to increase vulnerability to anxiety and depression. Sigma Research (2013) also found that Black African women living with HIV in the UK appeared to face issues around the fears of disclosure, in particular concerns about rejection.

## **1.7 A psychological model of coping**

As the research above has demonstrated, older adults living with HIV are likely to experience a complex array of difficulties including, comorbid health conditions, financial strain, isolation, stigma and discrimination. These experiences are thought to be compounded in individuals from ethnic minority groups, especially women from Black African communities. A striking feature of the research mentioned above is that they reported difficulties with mental health (Doyal & Anderson, 2004; The Sigma Research, 2013).

Models have been proposed to understand the onset of mental health difficulties, one being the stress vulnerability coping model (Zubin & Spring, 1977). This suggests that individuals develop a vulnerability to experiencing mental health difficulties as a result of biological, individual and environmental risk factors. Biological risk factors may include a family history of mental health difficulties, brain impairments, neurodevelopmental difficulties and physical health challenges. Individual risk factors may include poor coping skills. Environmental factors may include poor diet, substance abuse, inadequate housing, isolation, unemployment and bereavements. The model suggests that the more risk factors a person is exposed to the greater the chances of them experiencing some form of mental health difficulties. However, it also proposes that this risk can be reduced through adaptive coping strategies which often depend on coping styles, social support and service engagement. As a model, it can be usefully applied to understand the experiences of older adults living with HIV, as they are likely to experience a number of risk factors. Furthermore, it is especially useful for considering the context in which Black African women are situated considering the additional challenges, a migrant status poses. To determine more about the risk and protective factors that may be important in the lives of older individuals living with HIV a literature review was conducted which aimed to explore their lived experiences, meaning making, coping and psychological wellbeing of this group.

## 1.8 Literature search strategy

### 1.8.1 Aims.

The literature search aimed to identify peer reviewed research exploring HIV in older adults with a focus on the lived experiences, meaning making, coping and psychological wellbeing. The terms used to conduct the literature search are provided in table 1.1. These terms were then combined to conduct the literature search across four different databases. The combined terms are provided in table 1.2.

**Table 1.1: Search terms used to conduct the literature search**

Older OR Old* OR Aged OR Ageing OR Elder* OR Over 50 years OR fifty <sup>1</sup>	Women OR Female* OR Ladies	HIV OR Human Immunodeficiency Virus	Black African* OR Sub-Saharan African*	United Kingdom OR UK OR London OR United States of America OR USA <sup>2</sup>
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Databases searched: CINAHL, SCOPUS, Social Care, Pubmed

Search restrictions: Article title, abstract & keyword (to reduce irrelevant papers)

Inclusion criteria: (1) Publication in peer review journal; (2) Report of meaning, stigma, experiences, lived experiences, psychological wellbeing; coping (3) United Kingdom and United States of America samples; (4) Have a focus on the influence of ageing; (5) Include at least one subgroup aged 50 +; (7) Date published restricted to 1996-present.<sup>3</sup>

<sup>1</sup> 50+ years was used as a definition of 'older' which appears to be the standard used in HIV and ageing research (Public Health England, 2013).

<sup>2</sup> An initial search was conducted using the UK only as a search parameter, however this yielded very limited results. Having searched the reference lists of relevant articles from this initial search it became apparent that much of the research on ageing and HIV had been conducted in the USA. As a result, the final search included both UK and USA samples.

<sup>3</sup> This date range was chosen, as 1996 saw the introduction of antiretroviral therapy which played a significant role in the re-construction of HIV as a chronic as opposed to life threatening condition (Deeks, Lewin, & Havlir, 2013).

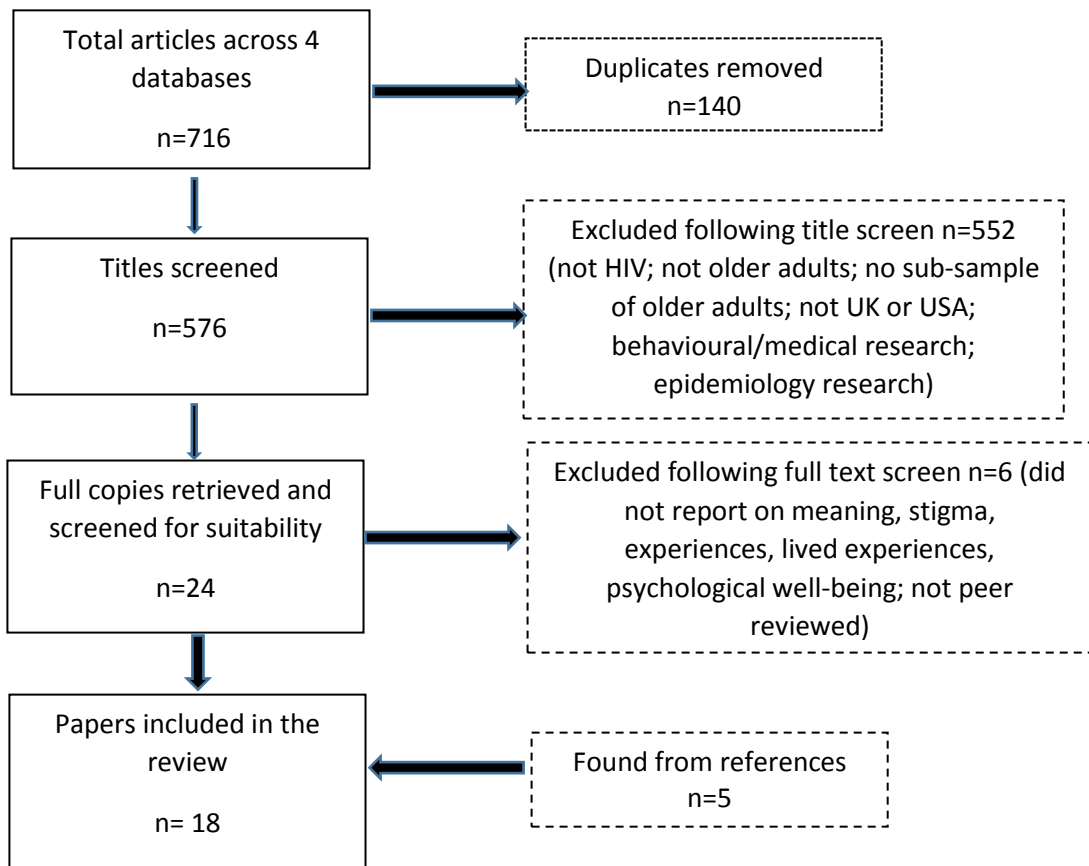
Exclusion criteria: (1) Behavioural/medical research (e.g. risk, testing, prevention, adherence, medication side effects); (2) Epidemiology research (e.g. prevalence, causes & effects of HIV); (3) Studies with no explicit sub-sample aged 50+

**Table 1.2: Combined search terms**

HIV OR Human Immunodeficiency Virus	AND	Older OR Old* OR Aged OR Ageing OR Elder*	AND	United Kingdom OR UK OR London OR United States of America OR USA		
HIV OR Human Immunodeficiency Virus	AND	Older OR Old* OR Aged OR Ageing OR Elder*	AND	Black African* OR Sub-Saharan African*	AND	United Kingdom OR UK OR London OR United States of America OR USA
HIV OR Human Immunodeficiency Virus	AND	Older OR Old* OR Aged OR Ageing OR Elder*	AND	Women OR Female* OR Ladies	AND	United Kingdom OR UK OR London OR United States of America OR USA

Figure 1.3 provides details of the number of papers identified following the search and the processes involved in selecting those that were relevant for inclusion. In total eighteen papers were identified for the review. Table A1 (Appendix 1) provides an overview of the each of the fourteen papers.

**Figure 1.3: Flowchart showing the process of inclusion/exclusion of articles**



## **Literature Review**

The following review will explore in detail each of the eighteen papers identified in the literature search described previously. Drawing on the stress-vulnerability model (Zubin & Spring, 1977), mentioned earlier, the research has been categorised into five main themes. The first part of the review explores risk factors associated with ageing and HIV, specifically, the uncertainty of living with HIV in later life; disclosure, stigma and discrimination, and isolation. Next, the review explores protective factors which have been shown to accommodate adaptation, resilience and coping in older adults living with HIV. Finally, the psychological impact of risk factors will be examined. A detailed formulation of the application of the stress-vulnerability model to the research is shown in Figure A1 (Appendix 2).

A critical appraisal of the research is discussed under each heading using quantitative (Spencer et al. 2003) and qualitative (Yardley, 2000) evaluation frameworks. Further details of each study are provided in Table A1, (Appendix 1).

Of the eighteen papers, fifteen were conducted within the United States and three within the United Kingdom. Thirteen of the papers adopted a qualitative methodology and five used a quantitative approach. Thirteen papers used a mixed sample of women and men and included individuals from a range of ethnicities including Black and African communities. Three articles focused specifically on women from different ethnicities including Black and African groups. Only two papers looked specifically at Black African women in the United States.

### **1.9.1 The uncertainty of living with HIV in later life.**

An ageing population of individuals living with HIV has led to a recent surge in studies exploring the interaction between ageing and HIV and whether the course of ageing will take a regular path. For example, Rosenfield, Ridge & Von Lob (2014) conducted qualitative interviews with ninety older people living with HIV in the UK as well as seventeen professional stakeholders (e.g. health

professionals, academics, policy makers, advocates). The participants included Black African and White heterosexual men and women aged between 50-86 years old, who had been diagnosed for between 1-28 years. The study explored how stakeholders and older people made sense of HIV and the ageing process. All narratives revealed uncertainties about growing older with HIV regarding the physical, social and mental health impact. Stakeholders, in particular, health professionals, focused their discussions on finding treatments to help make certain some of the physical uncertainties of growing older with HIV. However, people living with HIV had less optimistic narratives and instead focused on concerns about mortality, premature ageing, and difficulties attributing physical symptoms to HIV or the ageing process. As a result, many individuals felt uncertain about what the future would hold for them.

Other studies corroborate these results. For example, Emler, Tangenberg and Siverson (2002) found that a group of older women living with HIV in the United States reported experiencing fatigue and aches and pains which they struggled to attribute to HIV or as a natural part of ageing. They also reported uncertainty about the impact of ageing with HIV on treatment options. In particular, they raised concerns about the treatment of menopause as they worried about the possible interactions of hormonal therapy with antiretroviral medications.

Literature suggests that older adults living with HIV have fears that HIV and medication further accelerate the ageing process (Psaros et al. 2012). For example, in another study older women living with HIV in the United States talked about the uncertainty of living with HIV as they grew older in particular regarding how their ageing bodies would respond to treatment and tolerate the symptoms of HIV (Psaros et al. 2015). As a result, older adults appeared to want more information about the impact of ageing on biological processes such as viral loads and CD4 levels (Emler et al. 2002).

The above studies shed light onto an under-researched area exploring the uncertainty of ageing with HIV and the numerous challenges this poses. Rosenfield et al.'s (2014) study had the advantage of exploring the perspectives of a range of stakeholders, including health professionals and services users

which were helpful in identifying divergent views. In addition, Emler et al.'s (2002) study is one of the few to specifically explore women's experiences of ageing with HIV, a group who are often underrepresented in HIV literature.

Two studies used large sample sizes ranging from 19-25 participants and adopted a grounded theory approach to data collection. This fits guidelines which suggest that saturation based approaches should aim for approximately 25 participants (Charmaz, 2006). Conversely Emler et al.'s (2002) study used a small sample size of just seven participants to conduct one focus group. Guidelines for focus group methodology suggest the use of two or more groups per population studied and to conduct groups until saturation (Charmaz, 2006). Unfortunately, Emler's (2002) study provides no justification for their choice of one focus group and it is likely that such a small sample size would lead to the over-reporting of idiosyncratic experiences.

Combined, the above studies also failed to pay attention to the time since diagnosis, which ranged from 1-28 years. This is likely to impact uncertainty, as it would determine whether individuals were diagnosed pre or post the reconstruction of HIV as a long term illness. This may affect perceptions about the manageability of HIV. Also, the average age of the samples ranged broadly from 45-86 years old. It is possible that older age groups would experience more uncertainty due to the complex interactions between HIV and the natural age-related deterioration of health. However, using such broad age samples is unlikely to determine whether age does, in fact, have a moderating effect on uncertainty in individuals living with HIV. Overall, there appeared to be a lack of research in this area. An area which has received more attention is that of disclosure, stigma and discrimination in older adults living with HIV which will be explored next.

### **1.9.2 Disclosure, stigma and discrimination.**

Concerns about stigma and discrimination following disclosure seem to prevent individuals from revealing their HIV-positive status. For example, Shrimshaw and Siegel (2003) conducted semi-structured interviews with sixty-three older (50-68 years) men and women who identified as either African



American, Puerto Rican or White in the United States. The results revealed fears about the disclosure of HIV to family and friends due to concerns about how this would be received, not knowing how to disclose and worries about privacy. Although this appeared to prevent them from receiving adequate support, living with unmet needs outweighed the potential emotional distress and isolation they would face if people responded negatively. Participants also stated that friends and family were often unwilling to provide support due to stigmatising attitudes, such as fears about catching HIV, following disclosure. This caused a great deal of emotional distress and was worse for individuals who faced double discrimination for example based on their identities as homosexual and having HIV.

In contrast to the above, Foster and Gaskins (2009) found that disclosure was associated with increased support. They conducted four focus groups with twenty-four older African American men and women living with HIV within the United States. The findings revealed that those individuals who had disclosed had done so to a female family member. However, they described a reluctance to disclose to male or non-family members, due to fears about privacy. Disclosure of the HIV status also appeared to determine social support received, with those choosing to disclose reporting increased levels of support. Although most participants stated that they had not experienced direct stigma, they were aware of stigmatising attitudes towards people with HIV in society.

Emlet (2008) conducted interviews with twenty-five older adults living with HIV in the USA and suggests that non-disclosure, is impacted by three different factors. Firstly, protective silence which leads to a reluctance to disclose based on fears around stigmatisation, rejection and confidentiality. Secondly, anticipatory disclosure, which involves the weighing up of risks and benefits associated with disclosure. Thirdly violating privacy which includes others disclosing a person's status without their permission. Emlet suggests the process of disclosure is therefore either unintentional (e.g. not always disclosed voluntarily) or intentional (e.g. either choosing to tell a select few number of people or 'coming out' and making the diagnosis public news).

The interaction between HIV and age specifically about stigma has received very little attention with only two studies shedding light on this area. Shrimshaw and Siegel (2003) reported that adults held beliefs that society was less empathetic to older individuals living with HIV in comparison to younger people because younger people were felt to experience a greater loss regarding leading a normal life. There were also reports that HIV was related to risky behaviours such as drug-taking and prostitution which were considered highly stigmatising considering their age. They linked these beliefs to limited opportunities for support.

Furthermore, Emlert (2007) conducted twenty-five interviews with White and African American men and women aged 50 and over. The results revealed that some participants reported facing rejection from family, friends and their community based on their HIV-positive status but also based on their age, in particular by younger members of the community. Being HIV-positive and older was also linked to an increased sense of loneliness and isolation, as many participants stated having limited opportunities to be in intimate relationships, due to the diagnosis and their age. They also reported experiencing stigma in relation to employment, feeling that they had been discriminated against based on both their diagnosis and age.

Stigma amongst older Black African communities has also been found to be a barrier to service uptake. McDoom, Bokhour, Sullican and Drainoni (2015) interviewed twenty older Black women living with HIV to explore their experiences of stigma and its impact on social support and engagement with services. They found that stigma and fear of disclosure acted as a barrier to service usage and support. Often women were more likely to disclose if the benefits of accessing support and HIV care were perceived to outweigh the impact of the stigma. Support from service providers also appeared to foster better engagement with services and adherence to treatments, except when it was felt that they held stigmatised views about HIV.

The studies mentioned above highlight the complex relationship between disclosure, stigma and discrimination. However, many of the experiences described (e.g. HIV-related stigma, rejection, fears of disclosure,

reduced support following disclosure) are unlikely to be specific to older adults living with HIV. Only two studies (Shrimshaw & Seigel, 2003; Emler 2007), focused specifically on the interplay between ageing and HIV-related stigma, whereas others have failed to privilege age. This highlights the importance of intersectionality when considering the experiences of the participants. Intersectionality researchers (Bowleg, 2008) argue that it is important to make the intersections between ethnicity and gender (as well as other social identities) and the social inequality related to these identities explicit in order to make meaningful interpretations from data collected.

It is important to note that all of the above studies were conducted within the United States and explored the experiences of Black African and African American individuals, which may be different to the experiences of Black African's living in the UK. In addition, the age group of the samples studied across all four studies ranged from 50-88. Thus, it is possible that there will have been variation in experiences across different ages in relation to cohort effects, time since diagnosis and whether diagnosis occurred pre or post the re-conceptualisation of HIV as a chronic condition, however, this was not something that the studies explored.

Narratives alluding to oppression (e.g. racism, sexism, classism, discrimination) were largely absent from the all the studies, which was surprising given the ethnic diversity of the samples studied. Charmaz (2002) argues that silences during research interviews may reflect active signals, of meanings, boundaries and rules. In addition, Donnan and Simpson (2007), highlight how the experiences of the storyteller are positioned within a historical, political and cultural context in which silences can be self-imposed or imposed by others. This stresses the importance of power and context in the research process. However, these processes were not reported in any of the above studies.

### **1.9.3 Isolation.**

As a result of HIV-related stigma and a deterioration in physical health, older adults living with HIV have been shown to be at an increased risk of

experiencing social isolation. Isolation is thought to increase with age, with studies suggesting that although individuals reported being well connected to support groups and forums, as they aged they became more isolated (Owen & Catalan, 2012).

For example, Schrimshaw and Siegel (2003) found that 42% of a sample of 63 older adults interviewed within the United States felt that they did not receive enough emotional support, and 72% stated that they did not receive enough practical support. This support appeared to correlate with the severity of the illness, with individuals in a more severe stage of disease progression reporting feeling less supported. They also found the availability of support was limited due to their age, which meant their family and friends had died, lived far away, or were elderly themselves which made seeking support harder. Increasing age also meant that many of the people within the participant's social networks, who also lived with HIV, had passed away, this was commonly reported amongst those over 60. This appeared to be a huge source of emotional distress and seemed to lead to withdrawal from social activities, which heightened feelings of isolation and loneliness.

In addition, gender differences are thought to compound the situation further. Psaros et al. (2012) conducted semi-structured interviews with nineteen women diagnosed with HIV living in the USA. Participants described living in isolation often because they were not in intimate relationships. This appeared to be powered by HIV-related stigma, worries about body image and concerns about whether to disclose. Narratives revealed a fear of being judged negatively by potential partners as a result of the diagnosis as well as age-related concerns about the number of appropriate partners in their age group. The women talked about the importance of disclosure in order to prevent transmission to sexual partners. However, they described negative responses from men when they had done so, which resulted in a reluctance to disclose in the future. Participants associated these negative views with cohort values and beliefs amongst men of their age group, who they felt often judged women living with HIV more harshly than men.

Despite the above studies pointing to a link between increased ageing and a higher risk of isolation, another study has found conflicting results. Weibel et al. (2014) found that younger people living with HIV in the United States were significantly more isolated than older individuals. The authors provide several possible explanations for this including the fact that older individuals are more likely to have developed social networks and adapted to/accepted the chronic nature of HIV having lived with it for longer.

Other research suggests that older adults from ethnic minority groups are at an increased risk of isolation and report greater social withdrawal than older White groups living with HIV (Emlet, 2006). In another study Emlet (2008) found that older Black African HIV-positive men were shown to face adverse social circumstances, including being less likely to be in a relationship and therefore more susceptible to loneliness and financial difficulties. However, the possible link between ethnicity and increased isolation in older adults living with HIV remains unclear. Heckman et al. (2000) explored the relationship between ethnicity and social support amongst seventy-two older men living with HIV in the United States. African American men reported receiving significantly more social support from family than their White counterparts. This may be related to the fact that African American men were less likely to disclose than White men which may lead to less stigmatisation. They also identified ethnic variations in terms of socio-demographic factors and social support, revealing that Black African American men were more likely to face socio-economic disadvantage than their White counterparts. However, despite these challenges, they reported more adaptive coping strategies including holding hope for a better future.

Many of the studies described above have included either male or mixed gender samples. Only one study (Psaros et al., 2012) had a sole focus on the experiences of older women from a range of ethnicities living with HIV. The limited number of studies on older women may be a reflection of HIV prevalence figures. In the UK gay and bisexual men make up the largest group of people living with HIV, with Black African women and men, collectively making up the second largest group (PHE, 2014). Similarly, in the USA gay, bisexual and men who have sex with men are the largest group of people living

with HIV (Centre for Disease Control and Protection). These figures may explain why much of the research on older individuals with HIV has concentrated on male samples.

The above studies highlight the impact of HIV-associated stigma on both women and men from a range of different ethnicities. However, it appears to be inconclusive, suggesting somewhat conflicting findings. For example, in opposition to existing literature Heckman et al. (2000), revealed that Black African men adopted more adaptive coping strategies than their White counterparts. However, the majority of the African American men recruited for the study were involved in '12 step' programmes aimed at increasing optimism and reframing challenges into positive learning experiences, which may explain the differences observed in the study. In addition, Webel et al.'s (2014) study also found that younger adults living with HIV were more at risk of isolation than older adults, findings which went against the majority of the literature in the area. However, Webel et al.'s study used a sample of participants where the eldest 'older' adult was aged just 64. It is possible that had they recruited adults older in age, the results would have shown they faced more isolation, due to deteriorating health and loss of family and friends. It is likely that experiences of uncertainty, stigma, discrimination and isolation, highlighted in the review will have a significant impact on their quality of life. This reinforces the need to adopt adequate coping strategies, which will be explored next.

#### **1.9.4 Adjustment, resilience and coping.**

Research has demonstrated that older adults are more likely to draw on cultural values and beliefs when conceptualising and making sense of their diagnosis. In return, these understandings often shape the way they respond to the diagnosis. For example, Siegel and Schrimshaw (2002) conducted qualitative interviews with sixty-three older adults living with HIV in the United States, revealing that religion and spirituality influenced cognitive appraisals of HIV diagnosis and in doing so helped with the regulation of emotions. Drawing on religion and spirituality enabled participants to make sense of their diagnosis, by viewing it as God's 'plan' for them. This increased their feelings of control over the illness, by providing emotional strength and reducing

feelings of helplessness and uncertainty. In addition, religion increased participants sense of social support, through their association with religious communities and institutions, which protected against isolation.

As well as spirituality and religion, other research has pointed to other factors associated with resilience and coping in older adults living with HIV. Using qualitative interviews Emler, Tozay and Raveis (2010) identified seven factors influencing resilience. Self-acceptance of the diagnosis was important in terms of allowing participants to overcome the physical and social challenges associated with HIV. Optimism played a major role in setting goals for the future and self-management of one's health. Linked to optimism was a will to live and survive. Altruism and generativity appeared correlated with a will to live and gave meaning to the lives of older adults. As a result, their narratives alluded to the importance of sharing their experiences with younger generations and connecting with other survivors. Relationships formed an important part of their understanding of resilience, and many participants described the importance of family, friends, sexual partners and social groups in providing them with strength. Despite the need for others, self-reliance appeared to be a key theme in their descriptions of resilience.

Similarly, Schrimshaw and Siegel (2003) highlighted participant's focus on keeping well both physically and emotionally to attend to their needs. Self-reliance and the ability to problem solve appeared to be core values for the participants, as they seemed to protect against the significant isolation they lived in. Sometimes these values led to them refusing support, this was particularly important for men who appeared to want to hold onto their 'masculinity'. Other participants worried about being seen as a burden, which led to resistance to ask for help. They talked of their family members as having their own lives and caregiving tasks (e.g. to elderly parents and children) which made it harder for them to be able to ask for help. Some participants described the need to support themselves while they were able to, in order to avoid being seen as abusing the kindness and generosity of others in providing help. There appeared to be a need to wait until the support was crucial, for example when the illness became unmanageable on one's own, before asking for help.

In another study Psaros et al. (2015) explored the experiences of women over 50 living with HIV over time. They conducted semi-structured interviews with nineteen women diagnosed with HIV/AIDS living in Boston. The study included women from a range of ethnicities including Black or African American. Initially, women described a sense of hopelessness and resignation to death, due to prevailing discourses about HIV and increased mortality. They also talked about the shame associated with a diagnosis of HIV which left them feeling 'dirty'. However, growing older with HIV led to a reevaluation of these beliefs and resulted in greater acceptance of the diagnosis. Women also described the importance of relationships and finding meaning in their lives, most usually through engagement with support groups and volunteering opportunities.

Other studies have also demonstrated the importance of community projects in reducing stigma and giving meaning to the lives of individuals living with HIV. DeMarco and Lanier (2014) conducted a 10-year community-based participatory project with ageing African American and Black women living with HIV in the USA. 120 women took part in a structured writing intervention and outcomes were measured using quantitative scales. The results showed that the intervention increased perceived social support and provided a non-judgemental environment in which they were able to share their experiences. In doing so, they appeared to be able to co-create shared understandings of HIV as well as finding joint solutions to their difficulties and a sense of belonging. This study highlighted the need for more collaborative and culturally focused research and interventions to identify the specific needs of BME groups.

Other studies have also highlighted the importance of support groups, for example, Emler et al. 2002 found that a group of women living with HIV in Boston found emotional and practical support in the form of support groups. They revealed that as the trust between members increased conversations progressed from topics about medical adherence to discussions about more emotive issues such as the loss of sexuality and difficulties with disclosure and isolation which provided emotional support.



The time of diagnosis is likely to impact the adaptations of older adults living with HIV. For example, Emlet (2008) revealed that older people living with HIV appear to fall into two categories, the first being those diagnosed with HIV under the age of 50 whose life expectancy increased as a result of medical advances. The second group included individuals diagnosed over the age of 50 who were diagnosed following the reconstruction of HIV as a chronic as opposed to life threatening condition (Emlet, 2008).

Owen and Catalan (2012) explored the impact of the reconstruction of HIV as a chronic condition using a biographical narrative approach. They interviewed ten gay men, aged between 52-78 who identified as White British, White Other and Black Caribbean. The results suggested that individuals diagnosed before the introduction of life changing antiretrovirals faced greater struggles with adjustment. For some participants, the reconstruction of HIV as a chronic illness, as opposed to life-threatening appeared to minimise/forget the struggles they had encountered in the past. In addition, participants diagnosed pre-antiretrovirals were more ambivalent about living with HIV, which appeared to be compounded by the losses they experienced in relation to careers and financial strain. In comparison, those individuals diagnosed post-antiretrovirals viewed ageing as an opportunity to progress towards their life goals and acceptance of the diagnosis as a chronic health condition was fundamental to this progressive stance. It is possible that those individuals diagnosed post-antiretrovirals are likely to have faced significant social and economic health inequalities and discrimination which may have led to less optimistic narratives about the future. This study had the advantage of using smaller samples sizes and interviews which resulted in richer results, which were illustrated with ample quotes.

Only one of the studies mentioned above was conducted within the UK (Owen & Catalan, 2012) and the remainder were carried out within the USA. Although some of the studies explored coping in relation to gender, they failed to determine whether gender led to differences in coping styles. In addition, although the studies appear to have employed ethnically diverse samples, there is little consideration of whether coping varies by ethnicity. The studies also gave little attention to the context in which the participants were situated

which for any qualitative research is a fundamental part of the interpretative process in order to allow meaningful participant focused analysis. In addition, coping styles are likely to be influenced by the participant's personal situations such as socio-economic status and education levels, which again received little attention.

### **1.9.5 Psychological Distress.**

Literature has shown that older adults living with HIV are more susceptible to experiencing mental health difficulties in comparison to younger individuals, especially those with less adaptive coping styles. Depression, in particular, is thought to be linked to declining physical health, poorer social support, loneliness and increased socio-economic difficulties (Groves, Golub, Parsons, Brennan & Karpaik, 2010; Meadows, Le Marechal & Catalan, 1998). Groves et al. (2010) explored whether perceived health, stigma and isolation could predict depression amongst a sample of 914 older adults living with HIV in the United States. Using quantitative measures, they found that after controlling for demographic and perceived health factors, loneliness and HIV-related stigma were shown to be strong predictors of depression in older adults living with HIV.

Meadows, Le Marechal & Catalan (1998) also explored the psychological well-being of fifty-two older (aged over 54) and younger (aged under 54) individuals living with HIV in the UK who were referred to a psychological wellbeing service. The results showed that both younger and older adults most commonly presented with mood disorders, however fewer older adults (17%) had received previous psychiatric support when compared to younger adults (37%). Older adults were also more likely to be diagnosed with a brain disorder as opposed to younger adults who were more likely to be diagnosed with panic disorders. This may be as a result of the fact that HIV-related encephalopathy (loss of brain function) is more common in individuals aged 55 and over (Faerrio & Salit, 1992). The severity of the illness was also found to increase amongst older adults, which is thought to be linked to cohort effects (e.g. beliefs about managing on one's own) and a reluctance to disclose.

In contrast to Meadows et al. (1998), another study revealed no statistical differences between older and younger men and their experiences of mental health difficulties (Emlet, 2008). This suggests that the relationship between ageing and psychological wellbeing remains unclear.

Other studies have found an increased risk of mental health difficulties, specifically amongst older women living with HIV. Emlet 2002, revealed that older women reported a loss of self-esteem and sexuality. Participants talked about the diagnosis as taking them further away from what they considered being the idealised representation of women within their respective cultures. Often this led to depression and social withdrawal. They also stated that the age-related weakening of their bodies made them feel less valued members of society due to their limited ability to contribute in a meaningful way. Emlet's (2002) study has the advantage of being the only research identified which explored how multiple aspects of identity (e.g. age, gender, sexuality) interacted to shape the experiences of women living with HIV. By doing so, it highlighted the complexity of the experiences of these women and the importance of drawing out individual stories.

Other research has focused on the mental health outcomes of ethnic minority communities. For example, Whitehead, Hearn and Burrell (2014) conducted a quantitative study to explore the relationship between depression and anger on perceived social support in ninety-five Black men and women aged 50+ living with HIV in the USA. As a secondary aim, they also investigated whether life stressors had a moderating effect on this relationship. They revealed that depression and anger were inversely correlated with perceived social support. This may be because depression and anger are likely to impact an individual's ability to engage and interact with social networks. Life stressors did not have a moderating effect on this relationship but were associated with a reduction in perceived social support.

The above research provides insight into the psychological impact of ageing on adults with HIV. A limitation of Whitehead et al.'s (2014) study is that they did not appear to account for confounding variables during the analysis (e.g. age, gender, socio-economic status) although this data was collected and presented descriptively. Further, being a correlational design, it is not possible

to infer any causal relationships from the results. Despite this, it is the first study to explore the relationship between mental health outcomes and perceived support amongst this group. In addition, Meadows, LeMarchael & Catalan (1998) drew comparisons between older and younger individuals. However, they failed to provide details about whether the two samples were matched on non-age related variables such as gender, educational level, socio-economic status. Not controlling for these variables may have introduced a bias to the data. It is also unclear why the cut off age of 54 years and over was used to define the older group, especially when much of the literature uses 50+. However, this may be a reflection of the fact that the study was conducted in 1998 when there was very little literature around older adults with HIV.

Being primarily quantitative studies, they also failed to account for the role of culture in shaping the constructions and understandings of mental health. In addition, westernised psychological assessments were utilised, and it was unreported whether these measures were tested for reliability and validity across different ethnic and linguistic groups for their appropriateness.

### **1.9.6 Summary**

The research review highlighted that older groups living with HIV are likely to experience a multitude of socio-cultural difficulties which appear to be linked to quality of life and psychological distress. Some of the issues were HIV-specific whereas others seemed to be an interaction between HIV and age-associated difficulties. The review utilised the stress vulnerability coping model (Zubin & Spring, 1977) to demonstrate how the interaction between risk and protective factors may increase vulnerability to psychological distress.

A number of risk factors were highlighted, which were primarily environmental including the uncertainty that ageing with HIV poses in terms of illness prognosis and management; the experiences of HIV-associated stigma and discrimination which subsequently appeared to compound the ability to disclose and isolation which seemed to accompany these factors. The results regarding ethnic variations in risk factors were inconclusive. However, they point to the fact that gender may have led to increased risks in terms of

isolation. Despite this, only three studies explored gender and ethnicity specifically.

In keeping with the model the review also examined protective factors, which appeared to reduce the impact of risk factors. These included spirituality and religion; resilience, self-reliance and engagement in community HIV-specific based activities. Despite these protective factors research pointed towards the increased risk and vulnerability of older adults to experience mental health difficulties in particular depression, which would make sense given the isolating and stigmatising nature of the risk factors identified.

### **1.10 Gaps in the literature and rationale for the current study.**

The literature review demonstrated the challenges of living with HIV amongst older adults which included managing uncertainty about disease progression, stigmatisation and discrimination, isolation and social disadvantage. Combined these factors are thought to lead to significant psychological distress. Ethnicity and gender are believed to compound these difficulties further. Despite this, the review highlighted only three papers focusing solely on the experiences of women. In addition, only two studies looked at the experiences of older Black women in the US. Currently, no studies have explored the experiences of older Black women living with HIV in the UK. These women are likely to face a multitude of challenges associated with their HIV status, age, gender, ethnicity and migrant status. These factors are likely to interact to shape their experiences of living with HIV. Thus, the current study aimed to do this by using an intersectional approach.

Only one study appeared to have adopted an intersectional approach to exploring the needs of women living with HIV in the United States (Emlet, 2007). This study conducted focus groups with an ethnically diverse sample of older (Emlet, 2007) women living with HIV. Although the study spoke of the importance of intersectionality, the use of ethnically diverse samples of women and focus group formats appeared to have limited the results. For example, Emlet (2007) identified that narratives alluding to sexism, racism and HIV discrimination were absent from the focus group discussions. One participant reflected on the ethnically diverse nature of the group which made it difficult to

discuss issues about prejudice and discrimination openly. The present study however, hoped to overcome such barriers by using a homogenous sample of women who shared demographic variables such as gender, sub-Saharan African heritage and migrant status (all either currently or previously refugees or asylum seekers). In addition, the current study aimed to use individual interviews, to allow the women to speak freely and openly about their experiences, including those relating to discrimination.

In addition, Emllet (2007) adopted thematic analysis, focused on the creation of themes and patterns of similarity in the data, which limits the richness of the results. Conversely, the current study aimed to use IPA, with an interpretative stance to reveal the subtle nuances and idiographic nature of experience, which allows an exploration of context. As a result, the present study hoped to provide a unique and novel insight into how cultural and contextual factors informed the lives of this largely underrepresented group of women.

A number of guidelines have reinforced the need for inclusion of ethnic minority groups in social research in order to address the inequalities they face (Salway et al., 2011; Vickers, Gary, & Atkin, 2012). However, it is suggested that current research in the UK, either fails to include minority ethnic groups who are considered 'hard to reach' or does not engage with issues of ethnic diversity and inequality in a meaningful way (Salway et al., 2011). Guidelines suggest that in order for research to be conducted in a culturally competent manner it needs to engage with individuals: 'We suggest culturally competent research needs to engage more with the contingency of individual experience, particularly since the priorities of any individual might not be the same as those assumed by policy and practice' (National Institute for Health Research, Vickers, Gary & Atkin, 2002, pg. 3.) The current study hoped to achieve this through the use of in-depth, explorative interviews, adopting a flexible and open stance to allow participants to expertly guide the researcher through the most salient aspects of their experience. In doing so it was anticipated that they would be able to reflect on numerous aspects of their identity including ethnicity, gender and age, thereby engaging with the experiences of the women at a meaningful and culturally sensitive manner.

### **1.11 Aims of the current study.**

The present study aimed to examine the experiences of older (50+) Black African women living with HIV in the UK using a qualitative approach. Currently, in the UK it appears there are no peer reviewed studies which have explored this research goal. The study sought to do this by examining the following aims:

- How do older Black African women's multiple intersecting identities (e.g. age, ethnicity, gender, migrant status) shape their experiences of living with HIV in the UK?
- How do they manage the challenges of living with HIV on a day to day basis?

## **Methods**

The study explored the experiences of older Black African women living with HIV in the UK. It adopted a qualitative approach using Interpretative Phenomenological Analysis (IPA) as the method of analysis. This chapter will provide an overview of IPA and a justification for why it was chosen as the approach. Following this, the design of the study, ethical considerations and an account of how the analysis was carried out will be reported. Finally, the research will be evaluated following quality criteria and end with a reflexive account.

### **2.1 Why a qualitative approach?**

The current study aimed to address a gap in the literature, by exploring the experiences of older Black African women living with HIV in the United Kingdom. As the literature review highlighted, there are no qualitative studies investigating the experiences of this group of people directly. Research examining the experiences of Black African men and women living with HIV in general has highlighted the important interplay of different intersections of their lives in shaping their experiences. These intersections often include age, gender, culture, religion, sexuality, immigration status, social status. Given the possible complex experiences and intersections of Black African women living with HIV in the UK as well as the novelty of the topic area, a qualitative approach was deemed the most suitable research design as it allows for an open-ended approach to data collection and exploration of detailed participant accounts.

Qualitative approaches are suited to questions which aim to gain first-hand accounts of lived experience. Qualitative methods, such as IPA have been commonly applied to health research (Biggerstaff & Thompson, 2008). Additionally, Silverstein, Auerbach and Levant (2006) highlighted the effectiveness of qualitative research in improving clinical practices due to its focus on detailed individual experiences.



The current study drew on a phenomenological approach to data analysis using Interpretative Phenomenological Analysis (Smith, Flowers & Larkin, 2009) to explore the following research question: How do older Black African women in the UK experience and make sense of living with HIV?

## **2.2 Interpretative Phenomenological Analysis**

Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) is a qualitative approach to research which draws on three philosophical principles which are phenomenology, hermeneutics and idiography. The following section will give a brief overview of these three principles.

### **2.2.1 Phenomenology.**

Phenomenology focuses on how people make sense of their experiences (phenomena) as they occur. Phenomenology also considers the importance of how these experiences are influenced by personal interpretations as well as societal influences of 'what should be'. Phenomenology goes against a traditional positivist view to research which focuses on obtaining the truth of an experience. Instead, Phenomenology draws on the principle of transcendentalism (Husserl, as cited in Smith et al., 2009) which proposes that researchers should 'go back to the things themselves' and as a result focus on descriptions as opposed to searching for truth.

### **2.2.2 Hermeneutics.**

Hermeneutics draws on the work of Heidegger who proposed the idea of 'dasein' (being in the world) in which he highlights that it is impossible to interpret a person's experience in its entirety without consideration of the interpreter's biases, preconceptions and conceptions. IPA uses the principles of double hermeneutics (Smith et al. 2009) which suggests that researchers attempt to make sense of the participants who are themselves trying to make sense of their experiences. In doing so, IPA highlights the importance of the hermeneutic circle which explores the relationship between the part and whole,

which both must be fully understood to enable interpretation. As a result, IPA is an iterative process during which the researchers moves back and forth through the data.

### **2.2.3 Idiography.**

Idiography utilises small sample sizes in an attempt to explore detailed experiences and the meaning of those experiences (Smith et al. 2009). Idiography attends to personal experiences as well as consideration of the importance of contextual factors in shaping these experiences. In doing so, it focuses on the reality of lived experiences by considering the importance of various psychological factors such as desires, wishes, beliefs, behaviours and actions. This can be especially useful in terms of informing service delivery, especially mental health provision, for groups of individuals experiencing health difficulties such as HIV (Biggerstaff & Thompson, 2008).

## **2.3 Why IPA?**

Different qualitative methods were considered when thinking about the analysis of the data and included discourse analysis, grounded theory and narrative analysis. These three approaches will be discussed briefly regarding why they were not chosen as the analytic approach for the current study.

Discourse analysis (Willig, 2003, cited in Smith 2008) explores how language is used by participants in their constructions of knowledge, meaning and identity and focuses on naturally occurring text and conversations. Thus, it would have considered how language was used to construct discourses about HIV, as opposed to focusing on meaning making. Although they have been used in discursive research semi-structured interviews, tend to distort the natural discursive strategies used by individuals, due to the influence of the interviewer in co-creating the data (Willing, 2003). As a result, it was deemed to be inappropriate for the current study.

Grounded theory (Charmaz, 1995) focuses on theory generation using participant data. However, theory generation does not account for individual

experiences which were the primary focus of the current research, using IPA's idiographic focus. Grounded theory also draws on larger disparate samples to produce a generalisable theory. This is in contrast to the aims of the current research which sought to use a small homogenous sample of older Black African women living with HIV in the UK to tease out similarities and divergences in their idiosyncratic experiences.

Finally, narrative analysis explores how individuals construct stories and narratives to describe their experiences. The analysis focuses on the structure of participant narratives and uses a biographical approach to coding. Narrative was not chosen as a methodology of choice as the current study aimed to draw out the individual experiences of older Black African women living with HIV, as opposed to focusing on how they use stories to make interpretations of their experiences.

## **2.4 Epistemology**

Being qualitative the current study rejects the notion of a fixed reality that can be understood through hypothesis testing, objectivity and falsification. On the contrary, it tends to adopt an interpretive paradigm, which assumes that reality is based on and accessed via social constructions such as language, culture, consciousness and shared meanings (Larkin, Watts, & Clifton, 2006).

With this in mind, the current study adopted a social constructionist epistemology. IPA has a focus on meaning-making which fits with a social constructionist point of view, which has looks at how people construct reality and assign meaning to things through the use of language and within a social context. Also, as the study sought to explore the experiences of a largely underrepresented group in the literature, it was felt that a social constructionist view was fitting as it intends to move away from single account of reality and instead focuses on the varied nature of experience.

## **2.5 Design**

### **2.5.1 Context of the study.**

Participants were recruited from a specialist HIV unit serving two large Boroughs within London. The unit provides treatment and support services to over 1200 individuals living with HIV. The 2011 census data showed that both Boroughs have large Black African populations (11.4% and 9.83 %) when compared to the National average (1.7%) (Office of National Statistics, 2011a).

## **2.6 Participants.**

### **2.6.1 Recruitment.**

All participants were attending a London-based specialist HIV unit for men and women diagnosed with HIV. Initially, participants were recruited using purposive sampling to ensure a homogenous sample was achieved which is important for an IPA study. Before recruitment for the study, all potential participants were approached by a clinical psychologist at the HIV unit, who also acted as a field supervisor for the research. This person asked potential participants if they would be happy for the researcher to attend a user forum for older adults living with HIV, who were also attending the unit for treatment, to provide them with details of the study. This was discussed with service users who agreed to the researcher attending. During this forum, potential participants were provided with an information sheet (Appendix 3) detailing the nature of the study and were asked for their contact details if they were interested in taking part (telephone number and email addresses) or, requested to call the researcher directly if they preferred.

A total of ten participants expressed initial interest in the study and provided their contact details. The participants were then contacted a week later by the researcher to allow them enough time to consider the information. Participants were given the opportunity to ask questions and find out more about the study at this point. If they were happy to take part in the study, a meeting was arranged to conduct the interview. A total of three participants

agreed to take part using this method. The remaining participants were recruited using snowball sampling. The three participants who took part initially shared details of their involvement and the nature of the study with members of their support groups and social network, which resulted in a further four participants deciding to take part. These participants agreed for their contact details to be shared with the researcher.

Posters (Appendix 4) were also displayed in the unit waiting area, although no participants were recruited using this method.

### **2.6.2 Inclusion and exclusion criteria.**

The below inclusion and exclusion criteria were used to determine the eligibility of participants for the study and to ensure that a homogenous sample was obtained, which forms an important part of IPA research.

Inclusion criteria:

1. Women over the age of 50.
2. Women who defined themselves as Black African. According to the UK census (2011) the term Black African refers to individuals from sub-Saharan Africa including Nigeria, South Africa, Kenya, Zimbabwe, Somalia and Ghana.
3. Women living in the UK, regardless of immigration status.
4. Women with a diagnosis of HIV for at least five years which was important to ensure the sample was homogenous in having lived with HIV for a number of years.
5. Women able to speak English.

Exclusion criteria:

1. Women unable to meet the inclusion criteria.
2. Women unable to consent for themselves as outlined in the Mental Health Capacity Act
3. Women hospitalised due to severe physical health difficulties.

### **2.6.3 Sample.**

A total of seven women participated in the study. This was deemed a suitable sample as the number of participants recommended for an IPA study for a professional doctorate is between four to ten (Smith et al. 1999). Table 1.4 provides details of the participants. Names and in some situations possible identifiers (e.g. number of children, country of birth) were anonymised to ensure that participants are not identifiable.

## **2.7 Data collection**

### **2.7.1 Interviews.**

Participants were given a choice of where they preferred to be interviewed. One interview took place at a meeting room in the HIV unit. The remaining six interviews took place at the participants' homes. Interviews lasted between 45 to 75 minutes. Before conducting the interview, participants were fully informed about the study and given an opportunity to ask questions or raise any concerns. Written consent was obtained from all participants (Appendix 5). Background information was obtained from each participant (Appendix 6) which helped to provide a context in which to situate the individual interviews.

**Table 1.4: Participant details**

<b>Pseudonym</b>	<b>Age</b>	<b>Country of Heritage</b>	<b>Time in UK &amp; residential status</b>	<b>Years since diagnosis</b>	<b>Place of diagnosis</b>	<b>Employment</b>	<b>Religion</b>	<b>Marital status</b>	<b>children</b>
<b>Yvonne</b>	57	Zimbabwe	8 years, Refugee	8	UK	Unemployed	Christian	Widow	6
<b>Juliana</b>	51	Uganda	20 years, British	6	UK	Employed	Christian	Separated	5
<b>Brenda</b>	69	Zambia	14 years, Asylum Seeker	15	Zambia	Unemployed	Christian	Widow	8
<b>Maureen</b>	67	Uganda	15 years, British	15	UK	Unemployed	Muslim	Unstated	5
<b>Andella</b>	64	Zambia	14 years, residential permit	14	UK	Retired	Christian	Widow	3
<b>Esther</b>	60	Zimbabwe	15 years, discretionary leave	8	UK	Unemployed	Christian	Single	2
<b>Mercy</b>	55	Zimbabwe	15 years, Refugee	10	UK	Carer	Christian	Widow	2

### **2.7.2 Interview schedule.**

An interview schedule was used to conduct the interviews (Appendix 7). The interview schedule was informed by existing literature in the area as well as consultations with the field supervisor who has several years experience of working with individuals with HIV and the primary supervisor who has experience of conducting qualitative interviews. IPA encourages researchers to take a facilitative role when doing interviews to enable participants to narrate their experiences openly and freely. The interview schedule was deliberately loose and open-ended to recognise the complexity of the individual experiences of the women interviewed. Following each interview, the researcher kept a written record of reflections including thoughts, feelings and the overall flow of the interview. These notes formed an important part of the reflexive process and helped to achieve bracketing during the analysis process.

The interview schedule was created by drawing on guidelines on the use of intersectionality in qualitative research (Bowleg, 2008; Hunting, 2014). This felt particularly relevant for this study, which focused on exploring a complex array of features including HIV status, age, gender, residential status and culture and how they impact experience. Intersectionality is the notion that individuals social identities (e.g. gender, age, ethnicity, class) and inequalities (e.g. sexism, racism, ageism) are interdependent. In doing so, it moves beyond a single category of analysis, based on an 'additive' approach, such as exploring the experiences of 'older women living with HIV'. Instead, an intersectional technique to data collection recognises that individual identities can become more or less salient dependent upon their situation and context. As a result, it aims to capture the experiences of individuals while taking into consideration how their multiple social identities shape their experiences. The current study drew on intersectional techniques by asking 'how do older Black African women experience living with HIV in the UK?' In doing so, it aimed to explore how age, ethnicity, gender and migrant status interacted to shaped the women's experiences of HIV. Questions in the current study, adopted a similar intersectional approach, by privileging and acknowledging the women's multiple identities (e.g. 'Can you tell me about your life at the moment as an



older Black African women living with HIV in the UK?' This enabled the women to elaborate on those parts of their identity that were most important in the way they made sense of their experiences.

### **2.7.3 Service user involvement.**

A service user consultation committee run by the University of Hertfordshire was asked to review the participant information sheets, consent form, poster and interview schedule on 15/5/15. Please refer to Table A3 (Appendix 8) for review comments. These changes were incorporated before these documents were used as part of the study.

### **2.7.4 Transcription.**

The interviews were audiotaped and transcribed verbatim. Three interviews were transcribed by the researcher and four interviews were sent to a professional transcriber, who was recommended by the University of Hertfordshire. A contract was used (Appendix 9) to ensure confidentiality and protection of all data. All data remained password protected during the transportation.

## **2.8 Ethical considerations**

Full NHS ethical approval was granted by a Research Ethics Committee to recruit participants for the study (Appendix 10). Additionally, approval was obtained from the NHS Trust from which participants were recruited (Appendix 11). The University of Hertfordshire acted as sponsors of the researcher, for insurance and indemnity purposes (Appendix 12).

### **2.8.1 Informed consent.**

Participants were first approached by the field supervisor at the HIV unit. All participants were provided with verbal information outlining the nature of the study. The researcher then met with potential participants identified by the field supervisor at a user forum, where they were given information sheets

(Appendix ?) and an opportunity to learn more about the research. Participants were given at least a week to consider this information and were informed that their participation was entirely voluntary and their rights to health care would not be affected if they chose not to participate. Before the interviews, all participants signed a consent form (Appendix 3) and were informed that they could withdraw from the study at any point prior to data analysis. It was not possible to enable participants to withdraw once data analysis had begun as the analysis was dependent upon drawing connections across participant themes and therefore removal of data for one participant would have been detrimental to the entire analysis.

### **2.8.2 Data protection and confidentiality.**

The six key principles of the Caldicott Report (1997) concerning protecting personal identifiable information (PII) were adhered to at all times. All data from the interviews (electronic and paper transcripts) were anonymised using pseudonyms and stored securely in line with the Data Protection Act (1998). Data collected was only seen by the research team for data analysis purposes. All interview extracts were kept anonymous. Where quotes risked the anonymity of participants, particular identifiers were removed or changed to protect participants from being identified. Participants were also asked to give permission for the data collected to be used in publications and reports during the consent process (Appendix 5). In addition, all participants were given the opportunity to request that certain parts of the data not be used, during a debrief directly after the interviews were conducted.

### **2.8.3 Psychological Harm.**

No individuals were harmed during the research. As a Trainee Clinical Psychologist, I had experience of supporting people in distress. Steps were taken to ensure that any instances of psychological distress were managed in a sensitive manner. The emotive nature of the interviews meant that on some occasions participants became tearful when describing their experiences, particularly experiences of stigma. In these circumstances, individuals were given the opportunity to terminate the interview and provided with a break.

Although none of the participants requested to end the interview, one participant opted for a five-minute break as she became tearful when recalling a painful experience. During this time, the recording was stopped, and the participant was given a chance to talk about how she was feeling to ensure she was happy to continue. All participants were also connected with support groups which they were accessing on a weekly basis as well as support from the HIV unit from which they were recruited. They were also provided with details for Embrace UK and Positive UK if they required.

## **2.9 Data analysis**

The analysis used guidelines recommended by Smith et al. (2009) and involved seven key phases which are outlined below.

### **2.9.1 Phase 1: Reading, re-reading and re-listening.**

Before making any initial attempts to analyse the data, each transcript was re-read and re-listened to which enabled full engagement with the data. This also helped to put aside any previous knowledge from past interviews and analysis. Written notes were also kept of any initial thoughts and ideas which sprung to mind, during the process of re-engaging with the data, this ensured that pre-understandings were bracketed off (Finlay, 2008; Rolls & Relf, 2006).

### **2.9.2 Phase 2: Making initial notes.**

This stage of the analysis involved working directly with each transcript, and making notes of anything of interest in the right-hand column. The aim of this was to improve familiarity with the data, highlight key issues/concerns of the participant and create a detailed set of notes, which would aid the interpretative stage. Drawing on Smith et al.'s (2009) guidelines this stage involved looking out for:

- *Descriptive comments* (e.g. relationships, events and memories that appeared relevant to the participant).
- *Linguistic comments* (e.g. the use of language, in particular, pauses, laughter, repetition and metaphors).

### 2.9.3 Phase 3: Making interpretations.

Following the initial codes, the same transcript was re-analysed with a more interrogative focus, which involved thinking about why and how participants were making sense of their experiences in a certain way. This process involved the use of:

- *Personal insight:* Drawing on personal knowledge of being a clinical psychologist and having worked with individuals who have experienced health difficulties within a psychological therapeutic setting. It was also helpful to draw on personal experiences of belonging to an ethnic minority culture and having parents who had migrated to the UK.
- *Discussions with field supervisor:* This helped to gain first-hand experience of working with this group of people and better understanding the context in which participants were situated.
- *Questioning the data:* This allowed new understandings and perspectives to be opened up.
- *Drawing on the context of the participants:* This was particularly important given the complexity of many of the participants residential and disclosure statuses. Demographic data (Appendix 6) was collected prior to each interview which helped to set a context. This information was extremely helpful in ensuring that the participant was always held at the heart of any interpretations.
- *The relationship between the part and the whole:* This fits in with the concept of the hermeneutic circle and involved thinking about parts of the interview and how they related to the entire interview.

All interpretations were tied to the original data, and a worked transcript can be found in Appendix 13.

#### **2.9.4 Phase 4: Developing emergent themes.**

Drawing on certain parts of the data as well as consideration of the whole transcript, comments and interpretations, short themes which summarised the key features of the extract were noted in the left-hand column of the transcript.

#### **2.9.5 Phase 5: Finding connections between emergent themes.**

This step involved working with all the emerging themes identified from one transcript and searching for connections that brought them together. Each theme was cut out on paper and moved around until they seemed to cluster together to form master themes and sub-themes. Following this, a table was created identifying the master themes and sub-themes as well as extracts from the data which illustrated this interpretation. Sub-themes for each participant can be found in Appendix 14.

#### **2.9.6 Phase 6: Moving onto the next interview.**

The above steps were repeated for all seven interviews, individually.

#### **2.9.7 Phase 7: Looking for connections across participants.**

During this stage, all master themes and sub-themes from each interview were printed onto different coloured sheets of paper. They were cut and then moved around to find connections and patterns of relatedness between them (Appendix 15). This involved a similar process to that described in phase 5. Once master and sub-themes emerged, a table was created, and each theme was illustrated using quotes from all the participants (Appendix 16).

### **2.10 Quality measures**

The following section will explore how the validity and quality of the research were assessed. A number of guidelines have been proposed to establish the quality of qualitative research (Aguinaldo, 2004; Eakin & Mykhalovskiy, 2003; Patton, 1999; Spencer, Ritchie, Lewis & Dillon, 2003). Yardley (2000) proposed a set of criteria which has been deemed as suitable for use with qualitative research employing an IPA approach (Smith et al., 2009). Yardley (2000) proposes four criteria for evaluating qualitative research

which is sensitivity to context, commitment and rigour, transparency and coherence and impact and importance. Each of these criteria will now be explored in relation to the current study.

### **2.10.1 Sensitivity to context.**

Yardley (2000) states that qualitative research should consider the context in which the study was conducted, which can be achieved through consideration of the socio-cultural context of participations, review of existing literature and allowing participants to respond freely and openly about sensitive topics.

The current study considered the context of participants, by using IPA as a method to explore how they made sense of their experiences. The open-ended nature of IPA enabled participants to draw on numerous intersections (e.g. age, gender, culture, religion, sexuality, immigration status, social status) of their lives and reflect on how they felt they shaped their experiences.

A full review of the literature was conducted in Chapter 1 (Introduction) which provided details of the existing literature in the area and explained how the current study aimed to address a gap in the research. In addition, chapter 4 (Discussion) also draws on existing literature to create a context in which to make sense of the findings.

Finally, the reflexivity section later in this chapter draws attention to the part of the researcher and participants in the co-construction of multiple versions of reality. As the research takes a social constructionist epistemology, it is important to consider how experiences must be understood in the context in which they occurred (e.g. the research setting) and the fact that the researcher plays a role in shaping the data. This further draws on the researcher's subjectivity and perspectives and how they influence the way in which things were interpreted. Gadamer (as cited in Shaw, 2010) referred to this as 'horizons' which relates to one's presuppositions and beliefs, and how one must make their own horizons transparent in order to understand others horizons. Shaw (2010) further draws on these ideas and stresses the

importance of adopting reflexivity when conducting qualitative research as it is in keeping with hermeneutics and phenomenology both of which are central aspects of IPA.

### **2.10.2 Commitment and rigour.**

Commitment in relation to qualitative studies refers to the role of the researcher in engaging with participants and what they are sharing. Rigour relates to the thoroughness of how the research was conducted, for example regarding sample size and analysis.

Rigour was upheld in the current study through the use of guidelines on the analysis of data using an IPA approach (Smith et al., 2009). Although there are multiple ways of analysing data using IPA, these guidelines provided a helpful structure. In addition, triangulation involving more than one analyst was used. This process included the academic supervisor looking over two worked transcripts as well as the final themes, which resulted in discussions about the transparency of the analysis as well as conversations about reflexivity. In addition, one whole transcript was analysed independently by three other Herts trainees, who have experience of conducting IPA research. The results of this process can be found in Appendix 17. Drawing on social constructionist epistemology, the aim of analyst triangulation was to explore the multiple ways of viewing the data as opposed to searching for a consensus.

Secondly, seven participants were recruited for the study, which is thought to be an adequate sample size for an IPA doctoral study (Smith et al. 2009).

As a researcher, I was committed to engaging with participants, which I did by attending a forum initially to recruit participants as well as allowing participants plenty of opportunities to ask questions before taking part as well as after the interviews. The open-ended nature of the interview schedule allowed flexibility in terms of responding to the things raised by participants. This was achieved through the use of prompts, which focused on introspective questioning, which involved exploring the impact of other people on

participants' experiences as well as their own evaluations and explanations for why they made sense of things in a certain way. In addition, questions about the narrative aspects of participants accounts (e.g. stories), striking moments and imagery (e.g. descriptions of what an experience was like) were asked. Finally, during the analysis phase, it was important to hold in mind the participants' contexts and personal situations using the information they had shared during the interview, as well as questioning one's interpretations. Combined, this ensured that the research process was fully engaged with participants throughout.

Finally, the results of the research will be fed back at the same service user forum from which the participants were recruited, in the form of a written summary and verbal presentation.

### **2.10.3 Transparency and coherence.**

Transparency and coherence refer to the detail provided in each stage of the research process. The current chapter aims to provide clear and detailed information about each phase of the research from data collection through to analysis. In addition, a worked transcript and themes from all seven interviews can be found in the Appendices 13 and 14, to ensure the transparency of the data. In the results section findings have been illustrated by multiple quotes and additional supplementary quotes are provided in Appendix 16.

### **2.10.4 Impact and importance.**

The impact and importance of the research refer to the extent to which the findings are new and help elaborate on existing research. The current research fills a gap in the existing literature by providing an insight into the experiences of a group of people who have been largely underrepresented in the research. Further details of this can be found in chapter 4 (Discussion). Additionally, the findings of the thesis will be disseminated through publications in peer-reviewed journals, conference presentations and feedback to participants as well as the services from which they were recruited.



## 2.11 Reflexive Considerations

Reflexivity relates to the influence of the researcher on the collection and interpretation of the data (Willig, 2001). Transparency and consideration of one's own position are considered to be important aspects of the IPA process. Therefore, the following section provides details about my own reflections on my position, focusing on the beliefs, values and personal experiences that I brought to the research process. This will be written in present tense as it forms a reflective piece of writing.

The interviews took place during a time when migrants were receiving a significant amount of media attention. Often this attention was hostile, associating refugees, asylum seekers and migrants with terrorism (Stanton, 2016) and abuse of the social welfare system (Waugh, 2016). In addition, approximately a year prior to the interviews taking place, discourses about migrants as bringing disease into the UK were forming, especially in relation to HIV following the comments of UKIP leader Nigel Farage (Watt, 2014). They were also perceived as engaging in free health tourism: "we're working to control immigration by clamping down on health tourism...cracking down on the abuse of the immigration system by making much tougher or illegal immigrants to remain in the UK by restricting access to work, housing, benefits, healthcare, bank accounts and driving licenses" (The Conservative Party).

Therefore, I was very much aware of the complex political context in which the interviews were taking place and how these were likely to influence my own and the participants' attempts to make sense of their experiences. It was apparent that these experiences were impacting the women's sense making as more than one participant referred to Nigel Farage and appeared to defend their reasons for migration to the UK, which will be explored further in the results section.

My personal beliefs about migration have been heavily influenced by my own experiences of having family members who were migrants to the UK. My parents, for example, migrated from India to England during the 1970's. Conversations with my parents highlighted their struggles with acculturation, prejudice, discrimination and racism at the time. However, their stories were

also full of hope, prospect and opportunities which resulted in a great appreciation for England despite some negative encounters. Additionally, my paternal grandad was part of the mass migration during the partition of India during 1947, which led to him being displaced during the transition from Pakistan to India. My husband, also boarded the last plane to leave a country in conflict to come to England as a legal migrant in 1990. All of these experiences have informed my 'horizon' and in doing so constructed my own presuppositions about migration and ultimately given me an empathetic and open stance to this topic.

I also became aware of my fore-understandings of ageing, and when I heard the women talking about their cultural experiences, it highlighted our shared experiences. They described their cultures as promoting collectivist values, which focused on caregiving in the family by women, through the generations. However, they also spoke of how these values became diluted in their children when they moved to the UK. This resonated with my own experiences as a second generation British South Asian woman. My bi-cultural identity is often a source of confusion caused by the juxtaposition of two conflicting cultural values one which promotes interdependence and the other independence. As the women spoke of their isolation and loss of expectations in relation to caregiving in the family, I felt a sense of guilt, possibly due to my alignment with their children and the resonance with my own situation and thoughts about how my parents would be cared for as they enter old age.

As well as culture I was also interested in the shared commonalities we had as women from an ethnic minority community. I am aware that some of my questions were informed by this position. However, despite these shared identities, I found vast differences in our experiences. For example, the women often spoke of patriarchal systems in which they were located. However, in contrast to my own beliefs, they talked about these systems as something they stood for and held as an integral part of their lives. Their sense of womanhood also appeared to be shaped by their ability to be devoted caregivers and subservient wives. I recall my shock at this during the interviews which resulted in my silence as well as interjections such as 'wow' when these topics were raised. As I had not expected these issues to arise, they caught me off guard

and therefore formed part of the research process. I found myself intrigued by the women's experiences and asked follow-up questions to explore how their culture and systemic factors may have played a role in their beliefs.

The cumulative effect of the experiences I shared with the women led to the research becoming an emotional encounter. As a result, I became aware of the emotional impact the interviews and data analysis was having on me, due to the emotionally challenging nature of the topics. The interviews often left me feeling sadness and despair at the complex issues the women faced and the hopelessness of their situations.

I also became aware of my position of power, with respect to being a trainee clinical psychologist, a British citizen and being in a position of economic stability. The interviews highlighted my own privilege and although at the time felt this felt uncomfortable, on reflection it was an important part of my learning and interpretation of the data. During the interviews I continuously tried to adopt a curious stance, allowing the women to guide me through their experiences rather than me trying to enforce restricted questions upon them. It is likely that my position of power influenced the interviews, especially in relation to the women's narratives about service usage, and about being migrants to the UK.

Bracketing and reflexivity became an important aspect of the research process, and I drew on guidelines for the use of these techniques in qualitative data to adopt a reflexive stance to the data (Shaw, 2010). I used memos to write down observations and striking features of things that came up directly after the interviews. In addition, I made a note of my own feelings after the interviews as well as after listening to the audio recordings and re-reading the transcripts. I found that re-examining the interviews in the analysis stage was extremely emotionally challenging due to the cumulative effect of the distressing issues the women raised. Rolls and Relf (2006) state that researchers may adopt the sadness and despair of participants, especially when discussing highly emotive topics. As a result, I began to reflect on how my emotional response to the women's stories may have shaped the course of the interviews. For example, my body language, responses to distressing stories and questions asked are all likely to have formed part of the research

process. Bracketing off these intense emotional reactions through the use of memos and reflective journals helped to manage the intense emotions experienced. I also kept a reflexive journal at the start of the research process to keep a track of any preliminary ideas and thoughts I had about the research, including concerns about recruitment, hypotheses about potential findings and presumptions about the women and experiences of belonging to an ethnic minority group. Bringing these experiences into my awareness helped me to bracket them off and in doing so kept the participants at the heart of the analysis.

## Results

Following the data analysis, three master themes were created which were made up of sub-themes. These are shown in Table 1.5, as well as the representation of the themes across all seven participants. All participants contributed to the master themes, although their contribution to the sub-themes varied. Additional quotes can be found in Table A4 (Appendix 16) and the representation of the participants within each theme is outlined in Table A6 (Appendix 18). In keeping with a social constructionist stance, the results are a co-creation of the participant's narratives and the researcher's interpretations of the key issues raised.

**Table 1.5: Master themes and sub-themes following data analysis and the representation across participant's**

Master Theme	Subtheme	Representation across participants
Spoilt identities	<i>The contaminated self</i>	7
	<i>The shamed woman</i>	5
	<i>The self on trial</i>	5
	<i>The threatened body</i>	7
A present without light and a future without hope	<i>Suffering in silence</i>	4
	<i>Loneliness and longing</i>	6
	<i>Lost dreams</i>	4
	<i>Facing a life of imprisonment</i>	4
Escaping the labyrinth of distress and uncertainty	<i>The oasis of normality</i>	6
	<i>The gift of dreaming</i>	7
	<i>The search for acceptance and belonging</i>	6
	<i>Defending against distress</i>	6

Master theme one 'spoilt identities' focused on the overlapping forms of stigma and discrimination the women described experiencing. It highlighted how the interdependent relationships between the women's social identities (e.g. gender, ethnicity, migrant status and age) shaped their experiences of living with HIV. The second master theme 'a present without light and a future without hope' described the devastation the stigma and discrimination had on the women's lives. This led to distress, multiple relational losses, financial losses and uncertainty about what their future would hold. The final theme 'escaping the labyrinth of distress and uncertainty' revealed how the women

worked hard to escape and cope with the distress and destruction that consumed their lives.

The following section provides interpretative details illustrated by participant quotes for each master theme and its corresponding subthemes.

### **3.1 Master theme one: Spoilt identities**

The title 'spoilt identities' aims to capture the devastation that HIV appeared to cause to the women's multiple identities. The use of the word 'spoilt' reflects the ruination caused to their sense of self. It brings to mind the image of spoilt milk that has gone bad, which seemed to mirror the women's experiences of being seen as bad, contaminated, immoral and 'guilty' in the eyes of others.

The four sub-themes that make up this master theme which explore the interaction between HIV-associated stigma, ethnicity, gender, migrant status and age will now be described.

#### **3.1.1 The contaminated self.**

This subtheme conveys experiences of HIV-associated stigma, which labelled the women as dangerous, contaminated and disease spreading. The title aimed to demonstrate how the stigmatisation engulfed the women's lives and led to dehumanisation.

Esther described the disgust of a family member following her disclosure of being HIV-positive. The distress associated with the rejection she faced was evident in the fact that she became tearful when recalling the memory. Her repetition of the words 'every time' and 'bleach' reinforced the need for others to wipe away any traces of HIV she may have left behind during her visits. The word 'bleach' brings to mind the image of rigorous cleaning, disinfecting and sterilising as well as stirring up a smell of toxic fumes. This highlights that in the eyes of others, Esther was seen as a contaminant and that once diagnosed, appeared to embody HIV in every sense. Esther's description of having to sleep on the floor seems to have a disempowering effect, reinforcing that she was seen as an 'other' and not part of the family as she

used to be. Finally, the use of the word 'invading' suggests that she was seen as something intrusive and an unwelcome annoyance.

...(crying) every time I used the toilet she used to clean it with bleach, every time I bath she used to use bleach, and I used to sleep on the floor. She would open the window and one day she told me that I was invading her space (Esther)

During the interview with Brenda, an exploration of the reasons for rejection following disclosure were prompted. In the extract below, Brenda described becoming something dangerous that needed to be avoided. This reinforces the distance which HIV seems to create between Brenda and others, as it prevented her going 'near them'. She attributed this to the 'mentality' of others, suggesting that they hold misconceptions about the danger of HIV.

Researcher: Why are people afraid of being near you?

Brenda: They try to keep away from me because they've still got the same mentality that it is dangerous so they'll catch it if I go near them.

In addition, Mercy described her experience of 'becoming HIV'. She appears to try and distance herself from HIV, by referring to it as 'this problem' and thereby resisting ownership over it. However, this seems to be minimised by other people who reinforce the notion that she is 'HIV'. This suggests that the diagnosis may lead to an embodiment of HIV and consequently a loss of all other forms of identity in the eyes of others. "Even if I tell them that I've got this problem they say 'since you are HIV, it must be HIV', whatever you have is the HIV..." (Mercy)

For others, there was little resistance to being labelled as 'becoming HIV' and instead, there appeared to be a process of self-stigmatisation. For example, Juliana in the extract below seemed to have internalised negative stereotypes which made her view herself as a contaminant. As a result, her new sense of self appeared to be defined by HIV. This self-stigmatisation may have been protective, to the effect that it could have allowed Juliana to withdraw from human contact, thus reducing her chances of being stigmatised by other people. This is reinforced by her repetition of the word 'hide'. In comparison to

Esther, Juliana worked to distance herself from others, as opposed to them distancing themselves.

Yeah always a worry about (pause), you're aware of something or have you put on your gloves, have you washed your hands and I have this thing about toothbrushes. I hide my toothbrush (laughs) from my children... Yeah. I brush and then I hide, I hide it. What if I left it there and they used it or things like that. (Juliana)

Andella described experiencing multiple levels of rejection. She spoke of facing rejection from the African community attributed to her being considered 'untouchable' which may be linked to fears about danger as Brenda mentioned earlier. In addition, she felt perceived as 'bringing' HIV with her as a migrant. This reinforces these women were seen as contaminated and unwanted in the eyes of others. Finally, Andella talked of her emotional distress as she struggled to belong ('I don't know where I am') and have an identity beyond the highly stigmatised HIV and politicised migrant identity.

The rejection is so much. Come to Africa, you're untouchable, you can't even eat with them...and I've lived in Britain and the expectation is they think you bring it with you. And now I've no money, so emotionally I don't know where I am. (Andella)

This sub-theme highlights the overwhelming HIV-associated stigma these women experienced. Gender appeared to compound the situation further, by introducing another layer of stigmatisation, which will be looked at next.

### **3.1.2 The shamed woman.**

This subtheme relates to the shame associated with being a Black African woman living with HIV, encapsulating how gender compounded the stigma experienced by these women.

Brenda talked about the shame related to being thought of as somebody who had multiple sexual partners. She appeared to associate this shame with her age and gender, implying that the interaction between these two identities led to embarrassment. This passage also highlights the distressing nature of public discourses about HIV on Brenda's life.



...anyone suffering from HIV is thought to be somebody who sleeps with people, now an old woman like me having HIV there is that shame that I was doing this and that... (Brenda)

Brenda was prompted to explore further the nature of these public discourses and how they shaped her experiences of stigma. In the extract below she described the humiliation of HIV within Black African communities. Interestingly she makes a distinction between the constructions of the 'Black' community who she feels view the cause of transmission with 'prostitution' in comparison to the 'White community' which she believed link it with 'drugs and injections'. Both of these views appear to associate HIV with risky behaviours. As a result, Brenda reinforces how this makes her experience as a Black woman living with HIV 'harder' possibly due to the shame and humiliation she is forced to face as a result of being labelled as a prostitute.

Researcher: Something you said that sounds really important was being Black with HIV.

Brenda: Yes.

Researcher: Do you think it's different if you're Black with HIV?

Brenda: The Blacks are so humiliated (pause) It's harder.

Researcher: Why do you think that is?

Brenda: They think it's prostitution, while the White community says they had their drug habit with injections."

Participants seemed to protect their womanhood from the shame and humiliation of living with HIV. For example, in the extract below, Mercy described her uncertainty about how she may have contracted HIV, while doing so she appeared to defend herself by reinforcing that the HIV came from an external and possibly less stigmatised source such as a blood transfusion. In addition, she protected her identity as an honourable wife, highlighting her monogamy, which may serve to shield against the shame of being seen as having multiple partners as mentioned by earlier by Brenda.

I don't know how I got in contact with it because, my husband is not HIV and I've been with my husband all my life, and then when they asked about my history they said maybe, the blood transfusion back in Africa... it might be the thing, I know that I didn't do anything. (Mercy)

Yvonne highlighted the role of gender in HIV in Africa. She described the difference between the gender roles of men and women and framed this within the context of marriage. Similarly to Mercy, she spoke of the duty of wives to be monogamous to one husband. However, she suggested that it was expected and therefore accepted that African men were likely to engage in polygamous relationships.

...people were labelling us to say you are a prostitute, but as time went on people discovered the truth, like me, my husband was a soldier... six months, twelve months he's not home. I as a woman I can keep myself because I have got the entertainment of my children, we are brought up to say 'a woman has got one man' you know, you keep yourself. (Yvonne)

In keeping with this sense of duty, Yvonne did not blame her husband for transmitting the HIV to her but instead highlighted what she perceived to be his intention to protect her by refraining from sexual activity with her. Her narrative appears to highlight gender inequalities, which may label women living with HIV as 'prostitutes' who have transgressed moral sexual and behavioural ideologies of how women should be.

...even when my husband got ill he didn't tell me until he died and when I tried to say 'let's sleep' he was refusing, but it didn't click in my mind that this person is trying to support me...I can't blame him because of the situation with his work and being a man you know, especially our men in Africa they can't resist being six months, even two weeks (laughs) and you find out that he has got a girlfriend. (Yvonne)

Both Mercy and Andella's narratives suggest that the women lived within patriarchal systems, with men in positions of power, which left women being scapegoated for the transmission of HIV. As a result, it makes sense that the women would need to protect their own innocence, in the face of threats to their womanhood.

Finally, Juliana described the distress of living with HIV in such a shaming and humiliating context. This powerful reference to her relative described how for some women death was a better option than having to live with the shame of disclosing HIV. Her repetition of being 'wrapped up in knots'

symbolised the emotional impact of having to keep the diagnosis a secret. She also referred to the 'innocence' of most people living with HIV, counteracting the guilt that is often associated with them regarding engaging in immoral or promiscuous behaviours. The use of the word 'innocent' draws up images of criminality, something which will be explored in the next sub-theme.

Julianna: I was talking to one of umm my relatives, she was ill, and she was wrapped up, I think not telling the family, so everybody was worried about her, she was wrapped in knots, and it didn't help her, and she ended up dying yeah so it was too late.

Researcher: And what do you think made her not want to be open, what made it hard for her?

Julianna: I think it's in Umm,...mainly in Africa...like the shame, yeah, they were innocent most of them, HIV, you can get it anywhere, it could have been the husband, it could have been hospital equipment, it could have been anything, yeah so she puts the blame on herself yeah.

This subtheme stressed the role of gender in the experiences of the women which led to shame and humiliation. Despite living in the UK, the women's heritage cultures appeared to play a significant role in shaping how others interpreted and responded to their diagnosis. The next subtheme elaborates on the role of culture further by exploring African attitudes towards HIV and the impact of migration on the lived experience.

### **3.1.3 The self on trial.**

This sub-theme explores the complexity of living with the dual identities of having HIV and having a migrant status. The title 'the self on trial' seemed appropriate as the women described feeling like criminals due to the HIV diagnosis and their migrant status. In the extract below Andella described the response of her family and friends in Africa, who appeared to 'suspect' that she had contracted HIV. They voiced this suspicion indirectly by focusing on women living with HIV as being incapable mothers, which may link in with the sub-

theme 'the shamed woman' illustrating the significant stigma that comes with being an African woman living with HIV.

When I went home for the first time... people, they were gossiping about somebody and they want you to react, they say 'X person has got a baby, and she's not feeding the baby, and the milk is leaking, these people when they are found with HIV, they don't feed their babies!' So they know how to injure you because they are suspecting your condition! So they will talk about anything to bring your emotion down, to see the reaction or the body language whether you look guilty or not. (Andella)

For Andella this conversation appeared to be a deliberate attempt to coerce her into revealing the truth about the diagnosis. Her use of the words 'suspecting', 'body language' and 'guilty' give the illusion of being in a court trial as a defendant, who is being scrutinised by prosecution lawyers. This highlights the enormous emotional pressure the women faced in terms of living with HIV in such highly stigmatised contexts.

Mercy further reinforced the idea of being a 'suspect' in the extract below in which she referred to the work involved in trying to hide the guilt of having an HIV diagnosis. This appeared to be a constant source of worry and rumination as she remarked that it was always 'in the back of my mind'. As with Andella above, Mercy appeared to exist as a criminal which is highlighted by her concern that she would get 'caught', just like a criminal offender may worry about getting caught after committing a crime.

...even though I fool myself and say that my family doesn't know ...there's that thing in the back of my mind, there's a time when we talk about these things, I am afraid that I might get caught, I might answer in such a way that someone, my sister will say that 'ah these HIV people, this, this, this!!', so how are you going to answer that? It's very difficult (Mercy)

For some participants the idea of being 'guilty' of having HIV was further compounded by their migrant status, which appeared to increase their sense

of criminality. In the extract below Esther, whose legal status remained unclear within the UK, talked about her experiences of being placed in a detention facility. This excerpt highlighted her distress at being treated like a 'convict' and being put in a 'prison'. However, she appeared to question her crime by stating 'that she had not done anything'.

...it's not a good experience, you know I felt like a convict, I said I haven't done anything, all I want is to just lead a normal life, you know... It was just like a prison, you know you can't go anywhere, the gates are closed, you have to go through the security guard if you want to go to the shop, and you have to be back by a certain time, so they can check everybody is there and the wall is so high! Nobody can ever climb it and at night they come three or four times, and they open the door (Esther)

The reference to not having 'done anything', may be linked to her need to protect her womanhood from the shame of HIV, as was explored in the sub-theme 'the shamed woman' as well as her human rights to fair treatment as someone seeking refuge. In addition, Esther went on to refer to the political climate in which she found herself situated within the UK. In the extract below she referred to the comments of UKIP leader Nigel Farage who stated that the UK should close its borders to migrants with life-threatening illnesses <sup>4</sup>. Her reference to people living with HIV as 'human beings' appears to illustrate the powerlessness and dehumanisation of migrants living with HIV in the UK.

.... what Nigel Farage said about people with HIV, didn't feel good to me, I thought this is another human being, and you don't know what is waiting for you. (Esther)

Other participants appeared to defend against the idea that they may be perceived to have come to the UK with the intention of seeking healthcare by reinforcing that they had been diagnosed in the UK. For example, Yvonne, who was a refugee, talked about her journey to the UK to attend her mother's funeral as opposed to requiring medical attention. This appeared to resonate

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<sup>4</sup>During the 2015 Election Campaign: "You can come to Britain from anywhere in the world and get diagnosed with HIV and get the retroviral drugs that cost up to £25,000 per year per patient. I know there are some horrible things happening in many parts of the world, but what we need to is put the National Health Service there for British people and families who in many cases have paid into this system for decades."

with the other extracts reinforcing the need to prove one's innocence when feeling threatened or under suspicion. It is possible that my identity as a British citizen may have been a silent threat which triggered her need to reassure me of her innocence, as the reason for her travelling to the UK was not something that was specifically asked about.

I travelled to the UK for the memorial service so that we (family) will be together for the memorial service', not knowing that God had a plan, that I would fall ill here. (Yvonne)

The above subtheme showed how cultural and political factors shaped the women's experiences of having a migrant status living with HIV in the UK. Combined, a migrant status and HIV left women feeling like 'criminals', 'guilty' of the metaphorical 'crime' of carrying HIV. In addition, the women went on to speak about the impact of age on their experiences of living with HIV, which follows.

#### **3.1.4 The threatened body.**

This sub-theme reflects how the women made sense of ageing with HIV and most of the narratives emphasised the significant impact of HIV on the ageing body. For example, in the extract below Yvonne talked about the uncertainty associated with ageing with HIV. She referred to HIV and other illnesses as 'coming for us' illustrating a metaphorical sense of being chased and threatened by illnesses. This highlighted the unpredictable nature of growing older with HIV, which is likely to be a source of worry and anxiety. In addition, for Yvonne the boundary between ageing and HIV appeared to be blurred, making it harder to attribute her physical health difficulties to one or the other, which is likely to increase feelings of uncertainty.

...it's not only HIV that comes for us, there are other illnesses that come for us, like there's cancer, like my other friend she had her breast removed...it's really hard, me, it's only my arthritis and the eyesight, of course, is age, yeah, age plus the medication and how it affects the body also you know. So it's a bit, umm, hard to separate, when you get old. (Yvonne)

For Andella there appeared to be a clear link between HIV and a

deterioration in health. She described the constant worry that every day would bring with it new challenges in terms of physical health and she seemed to attribute this to the combined interaction between HIV and ageing: "I've got so many complications now which I think if I didn't have HIV I couldn't have those complications, but with HIV and with getting older every day it's another problem." (Andella)

For Juliana there also appeared to be a clear link between HIV and an accelerated weakening of the body. As a result, she focused on having to work to make sure her body was fit and healthy to counteract the impact of HIV. She referred to the worry of 'HIV heating up' which illustrated the unpredictable nature of HIV symptoms and reinforced the need to work to stay strong to resist the body being damaged. This may be a way of regaining some agency over the threatening and unpredictable nature of HIV.

It's good to keep up, go and do that and this, to make sure your body is ok because if the HIV heats up and other parts are weak, then you find more problems (Juliana)

Brenda distinguished between HIV and ageing as being two unrelated factors. For Brenda, ageing appeared to be more manageable than HIV, possibly due to the unpredictable prognosis of HIV as others mentioned above: '...it's different, they're two different things, getting older doesn't change anything at all, only the usual things but HIV changes your body'. (Brenda)

Interestingly, as with Juliana above, Brenda focused on the physical impact of HIV and ageing on the body. The importance of the body in the women's narratives may highlight the sociocultural representations of ageing, which focus on bodily changes that occur when one grows older. In addition, the descriptions may reflect the embodying nature of living with HIV as older women. For example, the uncertainty associated with ageing with HIV appeared to raise questions about what would happen to the body which may be a threat to the women's sense of self.

### **3.1.5 Summary of spoiled identities.**

Overall, the master theme 'spoiled identities' highlighted the significant overlapping forms of stigma and discrimination had on the women's lives and sense of self. The women attributed their experiences of HIV-associated stigma to an interaction between gender, ethnicity, migrant status and age. This highlights the importance of interdependent relationships between social identities in shaping the lived experiences of the women.

### **Theme 2: A present without light and a future without hope**

This master theme conveys the devastating impact stigma and discrimination had on the women's lives. The title 'a present with light and a future without hope', depicts the helplessness that followed the devastation. This theme highlights the distressing impact of non-disclosure due to fears about rejection as well as the relational losses attributed to the overlap between HIV, age and gender related stigma. The disruption HIV caused to the women's aspirations for the future, left them in a position where the worst possible outcome of going into a nursing home, seemed like an inevitability.

The four sub-themes that make up this master theme will now be described.

#### **3.2.1 Suffering in silence.**

This sub-theme relates to the decision of some women to withhold their HIV status from family and friends, due to concerns that they would face rejection. The title 'suffering in silence' sought to represent the powerlessness and distress that overwhelmed the women as a result of the overwhelming stigma they reported facing.

Yvonne described the inability of women living with HIV to disclose to family and friends, due to fears about stigmatisation and abandonment. She described the work of having to hide medication to keep the diagnosis secret. This may link in with the sub-theme 'the self on trial' where women talked about having to conceal the 'crime' of living with HIV:



I can speak out but others they can't speak out, you know like you live with your sister in the same house, but you put your tablets hidden in the cushion or your knitting or your sugar and you eat it when they have gone to work. (Yvonne)

In the extract below, Maureen highlighted the negative impact of disclosure. For Maureen, HIV was akin to being poisoned as it resulted in relational losses and abandonment. Thus, she chose to keep her diagnosis concealed and made reference to the emotional consequences which she felt 'killed' her in a metaphorical sense. This suggests that for Maureen although she continued to live with HIV, a part of her was 'killed', the part which thrived on being related to others. She referred to the HIV as being 'in me', giving the illusion that it was like a poison, working its way into her system as an invisible and silent killer.

Once they know they have got HIV you are just giving them poison because they know they are not going anywhere. No-one is going to look after them. They just kill themselves. So me I did also kill myself because I was keeping quiet. It was in me. (Maureen)

Both Yvonne and Esther referred to the inability to 'speak out' and having to keep 'quiet' about living with HIV, which reinforces a sense of powerlessness and external silence that succumbed the women following the diagnosis. This may relate to the sub-theme 'a shamed woman' which focused on the disempowering and gendered nature of HIV.

Keeping things hidden seemed to result in distress. For example, Mercy described the emotional turmoil of having to keep her diagnosis hidden. Similarly, to Maureen she referred to the HIV as being 'inside her', suggesting that it was something buried inside her and kept secret from other people, a secret that only she and the HIV knew about.

Because when I go out, or someone calls me, I answer rough and then at the end of it someone says 'why are you talking to me like that?' and they don't know what is inside me, what I'm going through. (Mercy)

This highlights the significant emotional impact of living a life of silence with respect to HIV. Following on from this many women described the subsequent isolation they faced which will be explored next.

### 3.3.2 Loneliness and Longing.

This sub-theme conveys the loneliness which appeared to engulf the everyday lives of the women and their longing to be connected with others.

Five of the seven women reported living alone, with limited support from their families due to stigmatisation. Many of them associated their loneliness with growing older. “There’s a change as I’m growing older, than before because most of the time I’m alone.” (Brenda) Brenda went on to attribute her loneliness to not being in an intimate relationship and a loss of family support as a result of them growing up and living their lives. She also alluded to a loss of African cultural traditions of caring for the elderly in a family unit within the context of the UK. As a result, she described the loneliness ‘adding up’ inferring that there is a progressive build-up of multiple relational losses as one grows older.

I think if umm, you had HIV, and you still had your husband life could be easy yeah, because you could have a friend who understands you, but where you start staying alone, it brings you a lot of loneliness, the children are grown up; all that loneliness adds up, and they are not like in the village where you say ‘oh go and stay with your grandma’ here, the grandchildren are only for the parents. So it’s really, really lonely.  
(Brenda)

Andella further reinforced the desire to be in an intimate relationship. For her, there was a longing to be accepted by a partner and to seek some form of social normality which was highlighted in her desire to be treated as a ‘human being’. She referred to the HIV as her ‘disablement’ possibly alluding to her inability to lead a regular life and reinforcing the dehumanisation she had faced as a consequence.

...somebody to talk to you see, somebody who understands my disablement and who can just take me as I am and say ‘you’re a human being, I’m a human being, let’s have a cup of tea let’s go to Southend’, things like that’. (Andella)

Esther also described a similar desire to be in an intimate relationship. However, she highlighted the struggle of dating within the HIV community, suggesting that men living with HIV are likely to hold more power and freedom

in the dating arena than women. This may tie in with the sub-theme 'the shamed women' and be associated with the role of gender in HIV, which leads to women being shamed and blamed as a result of the patriarchal systems in which they exist.

I am not having, not being, in any relationships, you know these men who are HIV-positive, who are the same as me, they want to use everybody, go around all the women. So I said to myself no, I'm not going to do it, I would rather stay alone (Esther)

It appears that the women experienced significant relational losses, which they attributed to the HIV and growing old. As a result, the future seemed uncertain regarding how they would be cared for in old age, which will be explored next.

### **3.2.3 Lost dreams**

The subtheme 'lost dreams' describes the disruption the HIV appeared to cause to the women's lives by preventing them from achieving goals, expectations and making plans for their future.

When asked about the future, all of the women described uncertainty regarding how they would be looked after. For Yvonne, this uncertainty was associated with financial losses, which were caused by her inability to continue to work due to physical health difficulties. This led to a questioning of what the future would hold for her: 'I am not working because of my mobility and all that and so financially that's where I can say 'what will happen to me?' (Yvonne)

For other women, the uncertainty was linked to an inability to plan for the future and to lost aspirations. For example, Brenda below talked about the HIV as disrupting her plans for her future. As a result, her independence appeared to be stripped away and replaced with a dependence on others to care for her. A future of being cared for featured heavily across all the participant narratives and appeared to reduce the autonomy and decision-making powers of the women.

Sighs...it's quite hard, when I was in health I had already started preparing my future now, that preparation was cut short because of my

health, you know, I didn't reach the goal that I had planned to reach, it was cut short by my sickness. Now, the only future that I have now is my children, and they are the only people who care for me and look after me, that's the only preparation I have done. (Brenda)

Esther further highlighted the loss of independence she experienced as she aged with the HIV. She described multiple losses associated with education and employment, which for Esther may be linked to her uncertain residential status in the UK. It also appears that the HIV had a 'disabling' impact on her life and her ability to be self-reliant, as it did with Andella mentioned previously. As a result, Esther appeared to be overwhelmed by uncertainty about her future which is illuminated in her repetition of the phrase 'I don't know', emphasising the distress of not being able to plan or control the future.

I don't have anything, nothing to my name, I can't go to school, I can't do anything. I would like to work, you know I have spent fourteen years not doing nothing, I don't have anything, I don't know what will happen to me, I don't know. You know you want to have something of your own, you want to be independent, you know it's not easy, I don't know, I don't know what will become of me. (Esther)

This subtheme illustrated the social and economic impact HIV had on the women's lives. As a result, they spoke of facing a future of uncertainty and being cared for, which is explored next.

### **3.2.4 Facing a life of imprisonment.**

This subtheme describes how women who had little support from family and friends, made sense of what the future would hold for them. They spoke of the prospect of living in British nursing homes, which they likened to 'prisons' and which consequently filled them with horror.

Andella described a worry about how she would be treated in a general nursing home. This may link in with the stigma the women mentioned in the master theme 'spoilt identities' which labelled them as 'promiscuous', 'contaminated' and of criminal standing. As a result, it is possible that this discriminatory public standpoint led to worries about going into a public welfare system, which the women feared may also discriminate against them.

When you come back in your house you are lonely, you are sad, it is very sad, and if you are in a nursing home, a general nursing home, it is even worse! Oh! I don't know! I don't know how they will treat me!  
(Andella)

For Brenda, the prospect of living in a nursing home was an uncomfortable one and seen as a last resort for 'desperate' circumstances. She reflected on her cultural values as playing an important role in shaping her views about nursing homes. It appears that she was influenced by collectivist values which emphasise the importance of caregiving within the family. She also alluded to the social stigma associated with going into a home.

I wouldn't even think of going into a home. No! People are not comfortable in a home, it is only if you are really desperate. You don't have no family, that's when the government comes in. It's not in our culture, to go into a home and be looked after by people you don't know. You miss the love of your family and in my country you think you are not loved by your children if they take you in a home. (Brenda)

The extract below further highlights the negative connotations the women had about British nursing homes. For instance, Mercy referred to nursing homes as 'prisons' which she related to her perception of them reducing one's independence. The thought of being imprisoned appears to resonate with the sub-theme 'The self on trial' which focused on the complexity of living with dual identities of having HIV and being migrants which led to women feeling like perpetrators and criminals. It is possible that the view of a nursing home as being prison interlinked with the women's feelings of being perceived as criminals due to their HIV/migrant statuses.

Researcher: So it feels like you're saying when people grow older, you don't put them in a nursing home?

Mercy: Put them in prison.

Researcher: Is that what it feels like?

Mercy: Prison, yes because you're not allowed to go out. I worked in a nursing home and umm, they're not allowed to go outside, so I don't want to live like that! You're confined in one place like the room here and the toilet

here and there's a routine, in the mornings, nine o'clock breakfast, lunch, then they toilet you.

### **3.2.5 Summary of a present without light and a future without hope**

This master theme illustrated the overwhelming disruption stigma and discrimination caused to the women's lives. It appeared to lead to a loss of voice, power and relational losses, which left the women living in isolation. As a result, they faced an uncertain and what seemed like helpless future.

### **Theme 3: Escaping the labyrinth of distress and uncertainty**

The previous two master themes highlighted the significant distress and uncertainty the women experienced in all facets of their lives, which seemed like an inescapable labyrinth. However, the current master theme, suggests that the women were not passive recipients of these experiences, but instead worked hard to escape the numerous challenges they encountered through normalisation, escapism, finding solace with their peers and avoidance.

The four sub-themes that make up this master theme will now be described.

#### **3.3.1 The oasis of normality.**

This subtheme describes how the women worked hard to introduce some normality to their lives which seemed to provide them with an oasis and escape from the distressing nature of their experiences. It also allowed them to reclaim parts of their 'spoilt identities', parts which were damaged by the HIV.

They did this by normalising their experiences of living with HIV by making comparisons to other long term illnesses which they perceived to be less stigmatised in the public arena, but which shared a similar prognosis with HIV. For example, in the extract below Yvonne, described the long-term nature of HIV, which for her resembled the same features as cancer. "This illness is just like any other long-term health condition, people are dying of cancer, people are dying of any other long term conditions" (Yvonne). Yvonne

emphasised the 'long term' nature of HIV thereby reinforcing its manageability which may be an attempt to resist negative discourses about HIV.

Often comparisons were made with cancer. Julianna, for example, talked about the relatedness of cancer and HIV as the same 'disease' leading to the same 'pain' and 'treatment'. Her repetition of the word 'same' appeared to be an attempt to resist being positioned as an 'other' or as 'different' as so many of the women described in the master theme 'spoilt identities'. "Let's not even talk about HIV, let's say a person had cancer, it's still the same disease, still the same. The pain is the same, the treatment is the same" (Julianna) However, this normalising appeared to minimise the social and political context in which HIV was situated (as described in the master theme 'spoilt identities'), which makes it distinguishable from other physical health conditions such as cancer.

For Brenda, there was less of a focus on making comparisons with other illnesses, but instead, she described the impact of medical advances which for her led to a shift in narratives about what it meant to live with HIV. For Brenda, medication improved perceptions about the manageability of the symptoms of HIV and as a result may have reinforced the notion of HIV as another chronic condition.

Living with HIV now is very easy and umm, not something you are worrying about all the time, before we used to worry a lot and we used to have a lot of problems like diarrhoea, coughing, TB and all that, but now I don't think a lot of people suffer from them, so like now medication is helping (Brenda)

However, this appears to neglect the numerous health concerns the women pointed out in the subtheme 'the threatened body' and the fluctuations in health that HIV and other chronic conditions are prone to. The focus on HIV as manageable and normative seemed to minimise the women's struggle associated with living with a long term condition including, unemployment, isolation and uncertainty as outlined in the master theme 'A present without light and a future without hope'. It is possible that minimisation allowed the women to regain a sense of control over what seemed like an overwhelmingly helpless situation.

Brenda further reinforces this idea by stating that medication leads to the HIV becoming invisible to other people and in doing so reduces the worries about stigma and rejection. However, as participants highlighted in the sub-theme 'suffering in silence' living with HIV in secret often leads to significant emotional distress and uncertainty, a burden which the women appeared to have to carry alone.

...with the medication that you are taking they don't notice anything, they know you are just an old woman and they are always ready to help you.  
(Brenda)

Despite this, focusing on normality, appeared to be protective and may have offered an oasis from the distress which seemed to feature so heavily in their accounts during the first two master themes. In addition to normality, the women also alluded to fantasies about a desired future life, a description of which follows.

### **3.3.2 The gift of dreaming.**

This subtheme related to the women's dreams and aspirations for the desired future life. This may have been a coping mechanism they employed to detach themselves from the distressful reality in which they lived, which was consumed by stigma, loneliness, imprisonment and social exclusion.

For example, Maureen described her plans to retire to Uganda and own a property in which to live. "I'm trying to plan where I'm going to be buried in Uganda, I'm trying to make it a nice place, look nice, with a small nice property" (Maureen). However, in a later part of her interview she went on to discuss the stark reality of her situation which left her dependent upon on life-saving medication, the medication that she would be unable to receive if she lived in Uganda: "I want to go back in Africa but where will I get the medication?" (Maureen)

Andella also described her desire to want to live in Africa and raise money for her children to look after her. However, drawing on her previous narratives in the sub-theme 'the self on trial', she referred to the stigma she experienced from family and friends in Africa, which left her feeling 'guilty' as if



she were a criminal. Therefore, there appears to be an incongruence between her reality and her dream for a future of being loved and cared for in Africa:

I wish to be able to raise a bit of money to go back to Africa umm if I have gone with small capital it means we can invest it into doing something or selling fish, and they would be able to love and care for me (Andella)

For other women, the dream was to hold simply onto a sense of normality and retain one's physical health. For example, Julianna described her desire to want to be the same person as she aged with HIV. However, this seemed unrealistic when compared to the women's earlier narratives alluding to the 'The threatened physical body'. "I think when maybe ten years time, I will still be the same, doing the same things yeah with medication, exercise and eating well, you can live happy" (Julianna)

Finally, for Esther, the dream was simply to grow old gracefully and in peace. However, she highlighted how even something as simplistic as this felt impossible given the numerous challenges she faced within her life. Although she tried to fantasise about a brighter future, the dream was short lived and instead she reinforced the nightmare of her reality which appeared to be hopeless and full of despair.

Esther: I would (pause) like to get old gracefully, you know.  
Interviewer: What would that look like?  
Esther: Just have peace of mind, you know, just have peace of mind.  
Interviewer: And what's the key thing that would give you that?  
Esther: I've got so many things that's worrying me, I don't know. This immigration issue one, you can't plan, you can't do anything you know you're just there. It's like you're useless, you know, you can't do anything.

Dreaming of a brighter future appeared to help protect the women from the hopelessness that seemed to overwhelm their lives. However, some women spoke of finding solace and comfort through the connections they made in support groups, which will be looked at next.

### **3.3.3 The search for acceptance and belonging.**

This subtheme conveys how support groups provided the women with a sense of belonging and acceptance through shared experiences of living with HIV as Black African women. For example, Brenda described the emotional relief associated with her membership to a support group and being in contact with 'friends' which seemed to give a sense of belonging. "When you find that there is also a group of women like you, the stress leaves your thoughts, and I think it (HIV) is just something that comes to everybody." (Brenda) Membership with support groups also appeared to serve to alleviate some of the women's existential concerns about freedom and isolation as it opened up the ability to work through these concerns together. "It gives you that hope, it gives you that excitement if that one can do it then you can do it" (Julianna)

Many of the women talked about a hope of having homes designed specifically for individuals living with HIV and run by those with HIV. This reinforces the need to have bared witness to the suffering and challenges of a life lived within the context of HIV to provide empathetic care and support. This focus on intergroup status may provide relief from the tarnished individual identities the women described in the master theme 'spoilt identities'. The use of the term 'us' when describing their group identity appeared to provide the women with a collective identity and one which enabled them to belong. This may have helped them to reclaim a sense of belonging and acceptance.

I wish there was like a place where we can have other people who are HIV, who can be there for us...who would be there for us because they know what it's like (Esther)

Support groups appeared to help the women find a sense of belonging amidst all of the exclusion and stigmas they experienced. However, for some women, the distress was managed through avoidance and will be looked at in the following section.

### **3.3.4 Defending against distress.**

This subtheme described how the women also worked to 'defend' themselves from emotional distress through avoidance. For example, Yvonne, described a process of sublimation whereby she avoided painful and

distressing emotions by engaging in social activities such as attending support groups and shopping. For Yvonne, there was a focus on staying away from the house, a place that is likely to have reinforced her sense of isolation and rejection.

I go anywhere where I am invited I just say 'ok I am out of the house' because I discovered that staying in the house it's something that will make you think and think and think and then at the end of the day you are not well, you know you will be thinking of things which can worry you (Yvonne)

Others talked about being worn down by the emotional strain of living with HIV. However, they described the need to distract oneself by engaging in other activities such as shopping.

You know...when it gets to you, it wears you out gradually, yeah (pause) it's just there, you can't do anything about it umm, when I have a problem, if I have money, I go shopping, and if I buy something I feel better, it keeps me going, you know, I try not to stay in the house (laughs). (Esther)

For others, there appeared to be a focus on the cognitive ways of managing distress by focusing on keeping positive and repressing distressing emotions. In a sense this reinforces the focus on avoiding distress and a difficulty with tolerating the emotional impact of living with HIV. "It's just psychological, you just think oh everything's going to be ok, just put it out, behind your back." (Julianna)

### **3.3.5 Summary of 'escaping the labyrinth of distress and uncertainty.'**

Overall, these sub-themes have highlighted how the strategies of normalisation, dreaming, connection with support groups and avoidance appeared to provide the women with emotional armour. This seemed to allow them to escape and distance themselves from the continuously distressing nature of their experiences.

### **3.4 Overall summary of the findings.**

The results revealed that age appeared to interact with HIV-status resulting in uncertainty and concerns about whether the body would assume a natural ageing process, or be complicated by illness. The women also experienced HIV-associated stigma which led to them being viewed as 'contaminated' and disease spreading. HIV-associated stigma interacted with gender which resulted in labels of 'prostitution' and left the participants having to defend their womanhood. Furthermore, the women spoke of feeling like 'criminals' due to the combined effect of their HIV-status and migrant status. Their experiences were consumed with suspicion as a result of people trying to reveal their HIV status and negative experiences of being in the British asylum system.

These intersectional experiences appeared to have significant effects on their social and economic functioning and quality of life. For example, they spoke of living in 'silence' due to fears of rejection as a result of disclosure. In addition, they lived in isolation, with limited opportunities for social contact beyond support groups or interactions with healthcare professionals. Combined, these experiences led to significant emotional distress and difficulties of planning financially for a future. This left them dependent upon others for future care, and many women spoke of the prospect of living in nursing homes which was met with resistance due to concerns about discrimination.

As a result, of these overwhelmingly negative experiences, the women appeared to have developed a variety of coping strategies. These focused on using normalisation, dreaming about the desired future and looking for acceptance amongst peers in support groups.

The following discussion will review these results in detail by exploring how they support, elaborate on and contradict existing literature in the field.

## Discussion

The following discussion will review the findings of the research as outlined in the results section in relation to the research aims, existing theory and literature. The discussion will also consider the clinical implications and limitations of the study, as well as make recommendations for further research.

The study explored the experiences of older Black African women living with HIV in the UK, to fill a gap in the existing literature. It had two main aims which were:

- Firstly, to explore how older Black African women's multiple intersecting identities (e.g. age, ethnicity, gender, migrant status) shape their experiences of living with HIV.
- Secondly, to discover how they manage the challenges of living with HIV on a day to day basis.

The following discussion will now review how the findings shed light on these two aims.

### **4.1 How do older Black African women's multiple intersecting identities (e.g. age, ethnicity, gender, migrant status) shape their experiences of living with HIV?**

The present study is the first to examine how several aspects of social identity shaped the lives of older Black African women living with HIV in the UK, which is in keeping with an intersectional approach. An intersectional approach was important as it explored how multiple layers of oppression and exclusion shaped experiences and meaning making. Participants spoke in detail about how interlocking barriers (e.g. HIV, migrant and gender associated stigma as well as ageism) shaped the way they made sense of their experiences.

The following discussion will review the findings of the current research from an intersectional perspective, exploring how the overlapping nature of social identity shaped women's experiences of living with HIV in the UK.

#### **4.1.1 The intersectional experience of HIV, ageing and uncertainty**

The master theme 'The threatened body' described how the women made sense of ageing with HIV, which resulted in uncertainty. Although research has explored the clinical implications of ageing with HIV, very few studies have investigated the lived experience of this phenomenon. The current study, however was able to provide insight into this. The women described HIV as a 'threat' against the body which they felt complicated the natural ageing process and led to significant uncertainty about their future physical health. The findings are in keeping with existing literature conducted in the United States which demonstrated that older adults, had concerns about premature ageing, difficulties attributing symptoms to HIV or natural ageing and concerns about the tolerance of medication (Rosenfield, Ridge & Von Lob 2014; Emlet et al. 2002; Psaros et al. 2012; Psaros et al., 2015).

The present study elaborates on the findings of the aforementioned research by highlighting the psychological distress the women experienced in the face of uncertainty about their future health. For example, HIV was seen as an imminent assault on the body which was reflected in their anxieties about the HIV 'heating up' or 'coming for us'. Very little is known about how uncertainty impacts the psychological well-being of individuals living with HIV, especially older adults. However, literature exploring uncertainty in chronic illnesses has suggested that it can lead to difficulties with adaptation, anger and depression (Wright, Afari & Zautra, 2009). These findings fit the narratives of the women in this study reinforcing their struggle to manage the unpredictable nature of HIV which made it harder for them to make sense of what the future would hold for them.

In order to cope with the psychological distress caused by uncertainty they engaged in preventative measures to defend their bodies against the 'threat' of HIV. These measures included staying one step ahead of HIV by doing things to keep fit and healthy. These findings are consistent with existing research conducted in the United States which has shown that both older men and women living with HIV focused on keeping well both physically and emotionally, which seemed to protect against isolation (Shrimshaw & Siegel,

2003; Psaros et al., 2015). These studies may help to understand why looking after themselves was an important feature for the women in the current study. As well as defending against the physical 'threat' of HIV, it is possible that looking after one's health enabled the women to hold onto their ability to look after themselves. This may have been important given the social exclusion they faced as a result of stigma and discrimination which will be explored next.

#### **4.1.2 The experience of intersectional stigmatisation and discrimination**

The master theme 'spoilt identities' described how the women's multiple social identities appeared to intersect and contribute to their experiences of being stigmatised. As a result, the findings revealed the need to move beyond viewing social identities as mutually exclusive but instead, consider how experience is shaped by the interlocking nature of identity. What follows is a review of how the intersection between age, gender, migrant status and HIV status combined, led to the women's experiences of multiple stigmatisations.

#### **4.1.3 The intersectional experience of HIV-associated stigma.**

In the sub theme 'the contaminated self' the women spoke of their experiences of being stigmatised as a result of their HIV-positive status. Much of this stigma was associated with other people's perceptions about the highly infectious and transferable nature of HIV. As a result, the women talked about about being viewed as 'contaminated' in the eyes of others, especially within the Black African community in the UK. This finding is supported by research conducted within sub-Saharan African contexts which has demonstrated that public discourses about HIV, focus on the contagious and polluting nature of the illness, which is often associated with a lack of awareness of the causes of transmission (Campbell, Nair, Maimane, & Nicholson, 2007; Simbayi et al., 2007). Further research appears to shed light onto the stigmatising nature of illness, by suggesting that losses to the physical body in chronic illness often lead to social identification and labelling of the body as being impaired which is thought to lead to stigmatisation (Bury, 1988; Goffman, 1963). This was evident

in the current study which highlighted that the women were perceived as being hazardous and dangerous.

As a result of stigmatising attitudes, the women in the present study spoke of the drastic steps people within their families took to protect themselves from infection, which led to discrimination. For example, they made powerful references to having to sleep on the floor and having the places and objects they touched cleaned with bleach when they visited family. These findings are supported by research conducted with Black African women living with HIV in the UK (Doyal & Anderson, 2004) which found that a third of their sample of Black African women reported facing direct rejection from family, having to have utensils washed after they had been used and being denied any contact with children for fear of the HIV being spread.

The current study extends these findings by suggesting that the women appeared to embody HIV as it consumed every part of their lives and 'spoilt' all aspects of their identity. As a result, they described being seen 'as HIV' by other people and nothing else. Some participants made attempts to externalise and view HIV as 'the problem' and in doing so attempted to create a separate identity for themselves which enabled them to distance themselves from HIV. However, despite these attempts, the narratives highlighted the disempowering nature of HIV stigma and the impact the diagnosis had on the women's identity. This demonstrates the all-consuming nature of HIV-related stigma on the women's lives and appears to be the first study to illustrate this with first-hand accounts of older Black African women.

The findings thus, reinforce the destructive impact HIV appeared to have on the women lives. This damage appeared to be compounded further as a result of gender which led to further stigmatisation.

#### **4.1.4 The intersectional experience of 'the role of gender and stigma.'**

The women's narratives highlighted how gender appeared to interact with HIV to shape their experiences of stigma. In the sub-theme 'the shamed



woman' the participants described negative attitudes towards Black African women living with HIV amongst the 'Black' community which labelled them as 'prostitutes' and having multiple partners. This finding fits previous research (Doyal & Anderson, 2004) which has revealed that Black African women living with HIV in London described being labelled as 'prostitutes' and engaging in sexually deviant behaviours. The current study elaborates on these findings reinforcing the importance of cultural gender norms, in shaping the stigmatisation of Black women living with HIV. For example, it highlighted the 'shame' and 'humiliation' of being seen as having multiple sexual partners amongst a community where monogamy is idealised amongst women.

Research conducted within a sub-Saharan context sheds light onto the role of gender in the constructions of HIV within an African context. Prevalence of HIV among women in Africa is thought to be double that of men and particularly high amongst sex workers (Human Science Research Council, HRSC 2014). Poverty and low-status of women is thought to be linked to this disparity (HRSC, 2014). The patriarchal systems in which African women exist may lead to scapegoating, which can result in them losing their homes, families, experiencing violence and facing social exclusion due to stigmatising attitudes (Petros et al., 2006). This often happens despite the fact that husbands, engaging in extramarital relationships are often a common cause of HIV transmission in women in Africa (Mbonu, van den Borne & De Vries, 2009). These findings may help explain why the women in the current study described the specific challenges they faced as being Black African women living with HIV, which labelled them as 'prostitutes'.

As a result of these gender specific challenges, the women appeared to protect their womanhood from the shame of having HIV, by offering alternative means of transmission (e.g. via blood transfusions) as well as locating the cause of transmission with their husbands who they stated engaged in extramarital relationships. Interestingly, none of the women blamed or spoke negatively of their husbands, despite them being the source of transmission which appeared to be linked to patriarchal systems. These appear to be novel and unique findings, which highlight the complex intersection

between HIV and gender, which seemed to be shaped by cultural constructions.

It appeared that despite living in the UK, the women in the current study were influenced by African cultural values and beliefs about HIV. It is important to note that cohort effects and the socio-historical context may have had an impact on the participants' experiences and understandings. For example, all of the women are likely to have witnessed the onset of the HIV epidemic in Africa during the 1980's. During this period HIV was linked to blood donors, pregnant women and sex workers (Thomas, 2015), which may explain the issues raised by the women in the sub-theme 'The shamed woman'. During the 1980's very little was known about HIV transmission which led to misconceptions that HIV could be transmitted through food and touch. As a result of the limited knowledge about HIV transmission, there were no cures and instead preventative strategies were used to manage the prevalence of HIV. These measures included the promotion of safe sex using condoms, monogamy and sterilisation of medical equipment (Thomas, 2015, World Health Organisation, 1989). These preventive measures however had little impact on the figures and during the 1990's the prevalence of HIV in Africa continued to rise. For example, in 1993 nine million people were infected with HIV in Sub-Saharan Africa. 1996 saw the introduction of HAART treatments in the west, however these drugs were not rolled out in Africa until the early 2000's (Simelela & Venter, 2014), due to them being too costly. Consideration of this context is important when considering the results and it is possible that these factors may have influenced the women narratives, despite them not being directly spoken about. The experience of being an African migrant living within the UK is something which the women reported led to further stigmatisation and will be explored next.

### **The intersectional experience of 'minority group stigma'.**

Very little research has explored the link between HIV and migrant status and how these two identities interlock to shape experiences of illness-related stigma. However, the sub-theme 'the self on trial' helped shed light onto this underexplored area.

Participants spoke of their negative experiences of the British asylum system, which left them feeling powerless in detained facilities. These experiences seemed to leave the women feeling like 'criminals' and contributed to their experiences of stigmatisation. This perception of being treated like 'criminals' in 'prison' appeared to be linked to their concerns that the UK public viewed African migrants as engaging in 'treatment tourism'. For example, one woman spoke of the comments of the UKIP leader Nigel Farage, during the 2015 election campaign.

As a result, it seemed that hostile attitudes such as those above may have reinforced the women's notions of being seen as 'criminals'. A recent report by The Migration Observatory at the University of Oxford (2013) provides further support for this view, demonstrating the prevalence of negative discourses in relation to immigrants within Britain. The research analysed the language used by twenty British national newspapers, from 2010-2012. The results showed that the most commonly used descriptors for stories referring to immigrants and asylum seekers across all newspapers were 'illegal' and 'criminals'. This data may explain the women's concerns of being viewed as criminals due to their migrant status and highlights the influence of the social and political context in their experiences of stigmatisation.

As a result, some of the women in the current study reinforced the reasons for their move to the UK as being unrelated to the need for HIV treatment. Many of them spoke of realising that they had contracted HIV only once after having lived in the UK for several months. This appeared to be a way for the women to prevent themselves as being blamed for bringing HIV with them into the UK and may tie in with societal discourses about HIV. These findings fit with research conducted by the Terrence Higgins Trust (2003) which showed that most individuals accessing their services in the UK, had been diagnosed nine months after entering the UK, which they imply provides little evidence for 'treatment tourism'. These findings provide a unique insight into the lived experience of being a migrant with HIV in the UK. It appears that this is one of the first studies to have examined this issues in such qualitative detail.

The discussion so far has demonstrated how the women's multiple intersecting identities appeared to shaped their experiences of stigma, which in return influenced their experiences of social exclusion and quality of life. The following section of the discussion will examine how the intersectional experience of stigmatisation led to isolation, uncertainty and social disadvantage.

## **4.2 The social and economic impact of intersectional stigmatisation**

The master theme 'a present without light and a future without hope' described how intersectional experiences of stigmatisation negatively affected the social aspects of the women's lives. As a result, they described experiencing isolation, loneliness, a loss of aspirations, unemployment and distress about the uncertainty with which they faced the challenges of growing older. The following sub-sections will explore these challenges in relation to existing literature.

### **4.2.1 Living in secrecy and isolation.**

The sub-theme 'suffering in silence' described the women's experiences of keeping their diagnosis hidden from family and friends. Non-disclosure appeared to protect them from rejection and abandonment, findings which are supported by research amongst Black African individuals living with HIV in the UK (Chinouya & Reynolds, 2001; Sigma Research, 2004). The current study however, suggests that the women did not completely refrain from disclosing their status, but instead appeared to have disclosed to health professionals and their peers within HIV support groups. These findings may tie in with research which states that individuals tend to weigh up the 'costs of disclosure' prior to making a decision about whom and when to disclose (Flowers et al., 2006). Thus, for women in the current study the 'costs of disclosure' to health professionals and their peers may have led to increased support and healthcare which outweighed the costs associated with disclosure to family and friends, that could have resulted in rejection.

Non-disclosure seemed to leave the women vulnerable to the suspicions of others. They felt people wanted to catch them out and reveal their 'suspected' HIV-positive status, once again leaving them feeling like 'criminals'. Although the current research is one of the first to reveal ideas about the 'criminality' of the lived experience of HIV, other studies have illustrated numerous concerns around non-disclosure and fears about confidentiality. For example, Foster and Gaskins (2009) showed a reluctance to disclose amongst African American men living with HIV due to concerns about privacy. Emlert (2008) further proposed that common experiences of 'involuntary disclosure', resulting in HIV-statuses being revealed by other people, lead to a breaches of confidentiality. These results fit the findings of the present study which identified accounts of being 'suspected' or 'guilty' of having HIV, which ties in with the notion of criminality and the need to be exposed. Research from an African context further revealed common experiences of 'gossiping' and 'rumours' amongst communities in relation to those who are suspected to have died of AIDs (Stadler, 2003). Again this research provides possible explanations for the women's narratives alluding to suspicion and guilt.

Further adding to the literature on disclosure, the current research highlighted that the women experienced a loss of voice and power, which may have made it harder for them to disclose to family and friends. One participant described the inability to 'speak out' which resulted in the HIV status having to be kept hidden. It appears that only two studies conducted within the United States have described similar results pointing towards 'self-silencing' amongst African American women living with HIV (DeMarco & Stokes, 2010; DeMarco & Lanier, 2014). The authors suggest that 'self-silencing' leads to a restriction of thoughts and feelings amongst women who experience multiple forms of oppression and discrimination. This may help to explain the loss of voice the women in the present study described as it suggests that the multiple forms of stigma and discrimination they experienced may have to lead to a loss of power and consequently a loss of voice.

The process of having to stay silent about their disclosure led to significant emotional distress for the women, which was depicted in the theme 'suffering in silence'. A number of studies have stated that nondisclosure can

inhibit individuals from accessing health and social care, applying for work, accessing community and social activities, leading to multi-faceted social exclusion which can cause significant distress (Terrence Higgins Trust, 2001a; 2001b). The current study reinforces the distressing nature of non-disclosure by highlighting the embodied nature of psychological distress the women experienced. This was shown through the use of powerful metaphors implying that living in silence was like being 'poisoned' and having something painful hidden 'inside them'.

The distressing nature of nondisclosure was further complicated by the women's experience of isolation. Research has demonstrated that isolation is highly prevalent amongst older adults living with HIV and is thought to be linked to HIV-associated stigma as well as age related losses in companions (Owen & Catalan, 2012; Schrimshaw & Siegel, 2003; Elmet 2007). For the women in the current study, HIV-related stigma appeared to be the primary cause of isolation as it seemed to lead to a loss of family and friends and difficulties engaging in intimate relationships. These findings are consistent with other research which has shown that older women living with HIV are less likely to be in intimate relationships due to concerns about being judged negatively as a result of their HIV positive status (Psaros et al., 2012). The results of the current study elaborate on these findings by suggesting that gender roles and stereotypes may have made it harder for the women to engage in intimate relationships. For example, some participants described having dated men who had multiple partners, which led to feelings of being used and made it harder for them to engage in monogamous relationships.

Another novel finding of the research, were the women's descriptions of the loss of their traditional African caregiving values, which promoted interdependence and a reliance on family members for support, due to the influence of western social values which promote independence. For example, the women spoke of African traditions of grandchildren providing care to the elderly. However, they stated that such traditions were lost in the UK, due to western cultural practices which meant that grandchildren were busy with their own lives. This appeared to be a great source of distress which as well as

increasing their feelings of isolation led to uncertainty about how they would be cared for in the future.

#### **4.2.3 The uncertainty of being cared for.**

Currently, there appears to be very little research exploring the caregiving patterns of Black African communities within the UK. One study exploring caregiving in dementia found that there is an expectation amongst Black African families to provide care within the family unit (Lawrence, Murray, Samsi & Banerjee, 2008). Additionally, research exploring caregiving in African migrants living with HIV in the UK, proposes an emphasis on caregiving by young carers who are part of an extended family network. (Evans, 2011). However, the current findings go against these results and instead, highlighted the overwhelming isolation in which the women lived which led to an unpredictable future. Many of the women lived alone and received very little, if any support from friends and families. These findings are in keeping with UK census data which has revealed that of all the ethnic minority groups, a significantly larger proportion of African elders live alone than any other group (Office of National Statistic, 2011b). Thus, the research highlights the importance of a non-assumptive stance when thinking about the needs of Black African communities and the impact of acculturation of traditional views such as caregiving.

As a result, the participants did not appear to have any firm plans about how they would be looked after in the future. When reflecting on their future possibilities in the UK, some of the women spoke with dread about the prospect of going into nursing homes. This appeared to be due to concerns that they would be discriminated against and experience a loss of freedom and quality of life. Studies exploring service usage amongst Black African individuals living with HIV in the UK have revealed that concerns about HIV-associated stigma and discrimination, confidentiality, migration status and lack of information about services were barriers to service usage (Erwin et al, 2002; Burns, et al., 2007). These findings may help to understand the women's concerns about nursing home usage described in the current study, considering that stigma and discrimination was a significant part of their lived experience.

In addition to uncertainties about future care the women also spoke of facing significant social disadvantage which further increased their concerns about the future.

#### **4.2.2 Facing social disadvantage.**

When thinking about the future, many of the participating women reflected on lost dreams and aspirations. Some associated these losses with HIV and the deterioration in physical health. Literature exploring the impact of chronic illness, suggests that individuals may face 'disruptions' in their lives as a consequence of illness, which can lead to multiple losses including aspirations and finances (Bury 1991, Charmaz, 1983). The women in the current study appeared to face 'disruptions' in their lives, as a result of having their future plans 'cut short' and consequently being unable to meet financial provisions for their future. As a result, they appeared to experience a significant loss of independence and were rendered dependent upon others to care for them in the future. These results, are in keeping with qualitative research (Charmaz,1983) which suggests that the lives of individuals living with chronic health conditions may become restricted due to a loss of functioning and impairments, which can lead to a loss of self-identity and feelings of being a burden. This seemed to be true for the women in the present study who experienced numerous restrictions to their ability to work and study, which contributed to a loss of control and uncertainty about what the future would hold. Consequently, it is likely that they experienced a loss of a former identity which was full hope and expectations for the future, whilst at the same time struggling to find themselves a new identity amidst such an unpredictable and uncertain future.

Undefined residential status further added to the complexity of the situation and led to an overwhelming loss of independence and uncertainty about what the future would hold. These results are consistent with research which has demonstrated that asylum seekers and refugees experience significant levels of poverty which can impact their ability to plan for the future, and cause an increased dependency on others (Taylor, 2009; Phillimore,



2011). Furthermore, research has shown that they are likely to face enduring poverty due to their reliance on benefits and no right to work as a result of being held in the British asylum system (Refugee Action, 2006).

The addition of HIV to the migrant status appears to further add to social disadvantage. For example, Flowers et al. (2006) revealed that pending decisions about immigration status, led to significant distress and worry for individuals living with HIV in the UK and often outweighed the stress associated with HIV. This was similar for the women in the current study who revealed that the combination of the HIV-positive and uncertain migrant status limited opportunities to work and save money. This consequently added to their distress when thinking about the future. As a result, their situations seemed to be helpless and the women appeared to be immobilised by the combined effects of HIV and immigration-associated work restrictions.

#### **4.3 How do older Black African women manage the challenges of living with HIV on a day to day basis?**

As outlined in the literature review the stress vulnerability model (Zubin & Spring, 1977) proposes that individuals develop vulnerabilities to experiencing mental health difficulties as a result of multiple 'risk factors'. The current study identified several risk factors which may have increased the women's susceptibility to psychological distress including intersectional experiences of stigma and discrimination, social exclusion, isolation, powerlessness and nondisclosure, social disadvantage and uncertainties about future care. However, the results revealed that they were not passive recipients of these challenges. Instead the women developed their own ways of coping with the significant distress they faced, which appeared to employ both cognitive and relational strategies and will be explored next.

##### **4.3.1 Cognitive coping strategies.**

The women in the current study appeared to use normalisation and escapism as a way of managing the psychological distress of living with HIV. For example, the sub-theme 'the oasis of normality' revealed how they normalised the HIV by referring to it as a 'long term' condition similar to cancer

which seemed to reinforce its manageability and thereby reduce its disruptive impact on their lives. This appeared to downplay the overwhelming impact HIV had on their lives. Research on chronic conditions in older adults has found that normalisation is commonly used as a coping technique in the context of diabetes and stroke management (Kelleher, 1988; Pound, Gompertz, & Ebrahim, 1998). Furthermore, Bury (1991) suggests that normalisation may be used as a cognitive coping strategy by individuals experiencing stressful events as a means of managing and 'bracketing off' the impact of an illness. This may explain why normalisation was a coping strategy employed by the women in the present study as it may have enabled them to distance themselves from stigmatisation and the overwhelming uncertainty they faced as they grew older with HIV.

As well as coping, normalisation also seemed to provide the women with an opportunity to fantasise about a future desired life as was described in the sub-theme the 'gift of dreaming'. In psychological terms fantasising may be referred to as 'wishful thinking', a concept which has been used in coping assessments which conceptualise it as 'imaging or dreaming about desired states' (Lazarus & Folkman, 1985). Research involving adults living with HIV has demonstrated that they tend to adopt avoidant coping strategies (Vosvick et al., 2002; Gore-Felton et al., 2006). For the women in the current study, wishful thinking may have offered a form of avoidance in enabling them to escape the numerous stressors they faced of living with HIV on a daily basis. This also appears to link with the sub-theme 'defending against distress' in which they spoke of distraction and keeping busy in order to protect themselves from distress. Although some of the dreams such as retiring or setting up a business 'back home', in Africa appeared to be out of reach given the numerous social and economic challenges they faced, the 'gift of dreaming' seemed to allow the women to hold onto to hope. The concept of escapism is a unique finding and something which has not been explored in the HIV literature to date.

#### **4.3.2 Relational coping strategies.**

The sub-theme 'the search for acceptance and belonging' demonstrated the significance of other people in the lives of the women. As a

result of the losses in family support, it appeared that many of the women accessed support groups. These groups seemed to enable the women to achieve a sense of acceptance and belonging, allowing them to reclaim parts of their identity that had been tarnished by stigma.

Research has revealed that group identification through support groups can provide highly stigmatised individuals with collective coping strategies, which helped to resist stigma and stereotypes (Crabtree & Haslam, 2010; Molero, Fuster, Jetten & Moriano, 2011). A study exploring service usage amongst Black Africans in the UK (Erwin, et al., 2002) revealed that women were more likely to access support groups and voluntary services for support following diagnosis, further corroborating the current findings which highlight the significance of this resource. Studies exploring community-based interventions amongst African American women living with HIV have shown that group-based interventions are associated with multiple benefits. These include increasing perceived social support, collective problem solving and offering an opportunity for women to confide in each other regarding difficult issues such as loss of sexuality, disclosure and isolation (Emlet et al., 2002; DeMarco & Lanier, 2014). These findings are in keeping with the current research suggesting that support groups offered the women comfort from distress in the form of solidarity and companionship. Membership to support groups acted as a buffer against social exclusion and psychological distress and provided the women with an alternative form of inclusion through identification with a largely excluded group.

Overall, these findings suggest that despite the significant distress the women experienced in all aspects of their lives, they creatively used resources and coping strategies to tolerate the difficulties they encountered. This highlights the incredible strength and resilience these women possessed in being able to do this in the face of such enormous adversity.

#### **4.4 Overall summary and key findings**

The results of this study provide a unique insight into the experiences of older Black African women living in the UK with HIV, an area that has not been looked at previously. The findings revealed the experiences of

overlapping forms of stigma and discrimination on the women's lives. HIV-associated stigma formed a significant part of their narratives and appeared to interact with gender, ethnicity, migrant status and age. Thus highlighting the importance of interdependent identities in shaping the lived experience of HIV.

Stigma and discrimination seemed to devastate the women's lives, causing fears about disclosure and a consequent loss of power and voice. As well as relational losses resulting in overwhelming isolation.

The women also described uncertainties of growing older with HIV regarding the impact to the physical body as well as concerns about how they would be looked after in the future. Of particular concern was the prospect of going into a nursing home, due to fears about further stigma and discrimination.

Finally, the women drew on coping strategies to enable them to manage the numerous challenges they faced. These included normalisation, escapism, support groups and avoidance.

#### **4.5 Clinical Implications**

The next section of the discussion will explore how the findings can be applied to think about clinical implications for service providers working not just with Black African women living with HIV, but with other vulnerable groups who may be at risk of marginalisation based on aspects of their identity.

##### **4.5.1 Considering the intersectionality of experience.**

The research highlighted the need for interventions to explore how stigma, age, gender, HIV, migrant status, culture, socio-economic status and exclusion interact to shape the experiences of Black African women living with HIV in the UK. As a result, it is important that interventions consider the complexity of these experiences while at the same time considering the uniqueness of individual experiences. Therefore, it seems important for clinicians to honour the complexity of experiences raised by the women. For example, by conducting assessments and formulations which consider the political and cultural context in which service users are situated.

#### **4.5.2 Advocating the need for support groups.**

The results highlight the significance of resources such as support groups in the lives of the women. As a result, it may be important for professionals working within health contexts to advocate the need for continued funding for such services. This is especially important in the current economic climate due to drastic funding cuts to HIV services. For example, charitable organisations supporting individuals with HIV, such as the Terrence Higgins Trust have had their funding reduced by half. This is an area where clinicians and service providers can draw on their leadership skills to stand in solidarity with service users and advocate on behalf of their needs.

Given the significant stigma the women in the current study reported experiencing it would be helpful for such support groups to be located in discrete buildings (e.g. non-hospital sites). In addition, support groups tend to be located within community settings, however considering the study revealed that the community were linked with stigmatising views, it may be helpful to consider alternative locations. Discussions with service users about these issues would help to ensure that their needs are taken into consideration.

#### **4.5.3 Narrative based approaches**

Narrative approaches (White, 1998) identify how dominant societal narratives contribute to stigmatisation, social exclusion and powerlessness, experiences identified by the women in the current study. Narrative approaches view individuals as experts in their own lives and work by drawing on the stories people tell about their experiences in order to help them co-create new alternatives stories for themselves (re-authoring). Narrative approaches could therefore enable individuals to break free of stigmatising labels such as being seen as 'criminals' or 'contagious' and instead create alternative stories about themselves. Such therapies could help to harness the stories of stigmatised individuals living with HIV in relation to resiliency, strength and determination which were highlighted in the narratives of the participants in this study.

As support groups were shown to promote a sense of belonging and acceptance, it is possible that groups based interventions could help Black African women and other excluded groups to overcome the psychological distress of living with HIV. Adopting an empowering approach to train individuals living with HIV to run such group based interventions, could be one way of enabling them to find meaning in their lives beyond being 'seen as HIV'.

In addition, peer-based interventions could help tackle issues of loneliness and isolation. This may be particularly helpful for older adults, for whom the uncertainties of living with HIV and isolation appear to be overwhelming.

#### **4.5.4 Managing uncertainty.**

The research highlighted that many of the women reported anxiety and distress associated with uncertainty about how they would age with HIV and about how they would be looked after in old age as a result of relational losses. It may, therefore, be important for clinicians working with service users to provide psycho-education about the possible physical interactions between HIV and the ageing body. By adopting a collaborative approach, clinicians can help empower women to stay informed about treatment plans as well as contributing to reducing anxiety about the future. In addition, support from social care providers to plan for the future in terms of care, housing and finances may help to reduce distress and uncertainty further.

The women in the current study also viewed the HIV as a long term condition and spoke about lost goals and aspirations for their future. As a result, clinicians may help women by engaging in conversations about the practical and emotional aspects of living with a chronic illness. As a result, therapeutic interventions aimed at creating new identities, expectations and goals for the future may be helpful in enabling the women to achieve a quality of life.

#### **4.6 Limitations**

IPA is an idiographic approach which attempts to explore the detailed and subjective lived experiences of a small number of people about a particular

phenomenon. As a result, it is unable to make generalisations from the results. Generalisations are also difficult to make due to the fact that women recruited were accessing support in the form of healthcare services and support groups. Consequently, it is likely that the experiences of women receiving less support may be different. In addition, some participants were recruited using a snowball sample, which involved women who had participated in the study sharing details with their friends. As a result, this may have led to certain types of women coming forward to take part, and it is possible that these women shared conversations about the research process and what the interview involved. Consequently, they may have already begun to make sense of their experiences prior to the interview being conducted. Although this may be advantageous in the sense that it allowed for more structured answers, it is possible it impacted the free and open nature of the interview which is important for IPA.

Unfortunately, it was not possible to gain full details of the participants' residential status and it is possible that differences in migration status may have impacted the results. For example, one participant described themselves as having lived in the UK for 14 years and having a residential permit and another as living in UK for 15 years and having discretionary leave. It was not possible to uncover the reasons for the temporary nature of their residence despite their lengthy stay in the UK. This felt like a sensitive topic and it was decided that this questions would not be asked of the participants due to fears that it would cause unnecessary distress during the interview process.

The results were based on one interpretation which is likely to have been influenced by the researcher's background, experiences and beliefs. As a result, it is possible that a different researcher would have highlighted different features in the participant's narratives and interpreted them in an alternative way. Despite this, attempts were made to ensure the research process was rigorous and transparent, by asking two other researchers to review a transcript to ensure there was some consistency in the data which was deemed most salient (Appendix 17). Also, to ensure transparency of the analysis process, a full transcribed script can be found in Appendix 13 Another way of checking the analysis process would have been through member validation, which involves participants reviewing the themes following the initial analysis to ensure they

are in keeping with how they made sense of things. Although this technique helps to reduce misinterpretations of data, it implies that there is a fixed truth, which goes against the social constructionist epistemology of the research. In addition, Yardley (2008) proposes that such checks can be confusing for participants, as themes and quotes used out of the context of the original interview can be un-relatable.

A key challenge of this research was the blurred lines between my role as a researcher and clinical psychologist. Wagstaff et al. (2014) describe the “temptation to revert to a clinician/therapist stance during the interview process” (p.5), and the potential ethical and methodological dilemmas that this may bring. An advantage of my dual identity was that my skills as a clinical psychologist enabled me to engage in a deeper exploration of the issues raised by the women which led to richer data. However, it also meant that on some occasions, the interviews went off to explore divergent topics and as a result I found myself having to be aware of this and bring the interview back to its focus. Also, although the research has the advantage of adopting an intersectional lens, in reality, the process of interviewing using an intersectional approach was a challenge. It meant that the women raised issues about different aspects of their social identities and on some occasions this happened simultaneously, which meant that during the research process we had to choose which identity to privilege. I often approached this dilemma, by reflecting the two positions back to the women and in doing so offering them the opportunity to select which identity they felt was most poignant in relation to what they were discussing.

#### **4.7 Future research.**

The participant's in the current research were Black African women, however, the women migrated from a range of different sub-Saharan African countries such as Uganda, Zimbabwe and Zambia. It may be beneficial for future research to explore whether the country of heritage influences the way the women make sense of their experiences of living with HIV. It is possible that different countries are affected by different attitudes and beliefs about HIV, which may impact the lived experiences of HIV. In addition, future studies may want to study a group of older women (80+) to provide an insight into what the future may potentially hold for Black African women as they age with HIV, as



well as identifying their specific needs at this later stage of life. Finally, it may be helpful to examine the experiences of older women who have been recently diagnosed, which may reveal issues around coming to terms with diagnosis as an older woman.

In addition, to there being no literature exploring the experiences of older Black African women, there also appears to be no research examining the experiences of older Black African men living with HIV in the UK. Furthermore, it may be interesting to make comparisons between men and women to further explore the role of gender in stigmatisation, as highlighted in the current study. This research may benefit from adopting an intersectional approach, as the current research has demonstrated how it can recognise the complexity of the lives of minority groups.

Given the significance of support groups to the women's lives in terms of enabling them to cope with and manage the numerous difficulties they faced, it may be important for future research to explore outcomes of support groups. One way of doing this would be to conduct quantitative research using quality of life, coping and resilience measures to explore the benefits of support group participation. In addition, quantitative outcome studies may also help to contribute to the evidence base about the efficacy of support groups and in doing so may help to secure much needed funding for such important resources.

Finally, it may be helpful to involve participants in every stage of future research projects, including the design, collection and analysis of data. In doing so, it ensures that questions of importance to the population being studied are explored and meaningful. It also works to remove power differentials that may arise when studies are led by an 'expert' researcher.

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## **Appendices**



**Appendix 1: Table A1, critical appraisal of the eighteen papers identified in the literature review**

Article and Author(s)	Aims	Context and sample (e.g. n, age, Gender, ethnicity)	Method of data collection & analysis	Key Findings	Critical Review
<p>The concept of "silencing the self" in low-income, aging, HIV-infected African American women: A 10-year community-based participatory program of research with results</p> <p>DeMarco &amp; Lanier (2014)</p>	<p>Exploring the use of community-based approaches and structured writing interventions to give aging African American living with HIV women a voice and increase safe=sex behaviours and attitudes</p>	<p><b>Context:</b> USA  <b>n=</b> 120  <b>Average Age =</b> 40+  <b>Gender:</b> F  <b>Ethnicity =</b> African American &amp; Black (African, Caribbean, Central and South American)</p>	<p>Quantitative using the silencing self-measure                      Uncertain analysis- no description provided</p>	<ul style="list-style-type: none"> <li>• Structured writing led to increased social support and shared experiences</li> </ul>	<ul style="list-style-type: none"> <li>• First study in the area to adopt a community approach &amp; use service user involvement across design</li> <li>• Attention to context of study, including demographic information about recruitment geographical location</li> <li>• Limited exploration of analysis procedures</li> </ul>
<p>A feminist approach to practice in working with midlife and older women with HIV/AIDS</p> <p>Emler, Tangenberg &amp; Siverson, 2002</p>	<p>To explore the needs of midlife and older women living with HIV/AIDS regarding service provision, using feminist theory</p>	<p><b>Context:</b> USA  <b>n=</b>7  <b>Age:</b> 45-56  <b>Gender:</b> F  <b>Ethnicity:</b> African American, Latina, White</p>	<p>Focus group conducted by the researcher. No information provided about recruitment strategy (e.g. how, when &amp; by whom).</p>	<ul style="list-style-type: none"> <li>• Uncertainty about growing older with HIV</li> <li>• Increased isolation</li> <li>• The importance of accepting the diagnosis</li> <li>• Experiences of depression related to 4 risk factors</li> <li>• Negative impact of HIV diagnosis of sexuality</li> </ul>	<ul style="list-style-type: none"> <li>• First study in the area to explore multiple intersections of identity and HIV</li> <li>• Discussion of researcher reflexivity issues</li> <li>• Difficulties with transparency due to limited details of recruitment and analysis</li> </ul>

<p>Experiences of stigma in older adults living with HIV/AIDS: A mixed methods analysis</p> <p>Emlet (2007)</p>	<p>To examine the experiences of HIV-related stigma in older adults living with HIV/AIDS</p>	<p><b>Context:</b> USA  <b>N:</b> 25  <b>Gender:</b> M&amp;F  <b>Ethnicity:</b> African America &amp; White</p>	<p>Semi-structured interviews</p>	<ul style="list-style-type: none"> <li>• Positive Correlation between stigma and depression</li> <li>• Increased stigma amongst African American participants</li> <li>• Personalised stigma, negative self-image, fears about disclosure and discriminatory public attitudes</li> </ul>	<ul style="list-style-type: none"> <li>• Possible bias due to staff involvement in recruitment and payments were given for participation</li> <li>• Small sample size reduced quantitative analysis and introduced the need for nonparametric tests</li> <li>• No casual links were established between stigma and depression</li> </ul>
<p>Truth and consequences: A qualitative exploration of HIV disclosure in older adults</p> <p>Emlet (2008)</p>	<p>To explore the factors impacting disclosure in older adults living with HIV</p>	<p><b>Context:</b> USA  <b>N:</b> 25  <b>Age:</b> 50-72  <b>Gender:</b> M&amp;F  <b>Ethnicity:</b> African American &amp; White</p>	<p>Semi-structured interviews. Open coding.</p>	<ul style="list-style-type: none"> <li>• A model of disclosure was proposed consisting of 4 types of disclosure (protective silence, anticipatory and unintended disclosure confidentiality breach)</li> <li>• Similar reasons for disclosure amongst older and younger adults</li> <li>• Generativity and sharing experience important for older adults</li> </ul>	<ul style="list-style-type: none"> <li>• Proposes a model for understanding factors impacting disclosure amongst older adults living with HIV which supports existing research</li> <li>• Little consideration of gender or ethnic variations in disclosure</li> </ul>

<p>I'm not going to die from AIDS: Resilience in aging with HIV disease</p> <p>Emlet, Tozay &amp; Raveis (2010)</p>	<p>To examine strength and resilience in older adults living with HIV</p>	<p><b>Context:</b> USA <b>N:</b> 25 <b>Age:</b> <b>Gender:</b> M &amp; F <b>Ethnicity:</b> African American, White, Latina</p>	<p>Semi-structured interviews. Constant comparative analysis</p>	<ul style="list-style-type: none"> <li>Seven key factors associated with resilience in older adults which were: self-acceptance, optimism, will to live, generativity, self-management, relationships &amp; independence</li> </ul>	<ul style="list-style-type: none"> <li>No data about the time since diagnosis which may have impacted resilience</li> <li>No consideration of ethnic variations in resiliency or how education or socio-economic variables may have impacted this phenomenon.</li> </ul>
<p>Older African Americans' management of HIV/AIDS stigma</p> <p>Foster &amp; Gaskins (2009)</p>	<p>To explore the experiences of HIV/AIDS-related stigma in older African Americans living with HIV</p>	<p><b>Context:</b> USA <b>Age:</b> 50-76 <b>Gender:</b> M&amp;F <b>Ethnicity:</b> African American</p>	<p>Focus groups &amp; surveys. Constant comparative analysis &amp; descriptive statistic</p>	<ul style="list-style-type: none"> <li>Four key themes were identified in relation to stigma: disclosure, experiences of stigma, lack of education &amp; acceptance</li> </ul>	<ul style="list-style-type: none"> <li>A broad range of time since diagnosis may have influenced perceptions about stigma due to the reconceptualisation of HIV</li> <li>Little consideration of differences across gender</li> </ul>
<p>Loneliness and HIV-related stigma explain depression among older HIV-positive adults</p> <p>Grov, Golubb, Parsons, Brennane &amp; Karpiak (2010)</p>	<p>To explore the impact of disclosure and social support amongst older adults living with HIV</p>	<p><b>Context:</b> USA <b>N:</b> 914 <b>Age:</b> 50-78 <b>Gender:</b> M <b>Ethnicity:</b> African American, White, Latina &amp; Other</p>	<p>Structured interviews, logistic regression</p>	<ul style="list-style-type: none"> <li>Older adults reported higher levels of perceived stigma and loneliness which may be linked to levels of depression</li> </ul>	<ul style="list-style-type: none"> <li>Cross-sectional design introduces possibility of bidirectional results</li> <li>Sample linked to service which may have introduced a bias and improved coping</li> </ul>

<p>Heckman et al., (2000)</p>	<p>To examine racial differences in stress, coping, social support and psychological distress amongst older men living with AIDS/HIV</p>	<p><b>Context:</b> USA <b>N:</b> <b>Age:</b> 48-66 <b>Gender:</b> M <b>Ethnicity:</b> African American, White</p>	<p>Quantitative measures. Multivariate analysis</p>	<ul style="list-style-type: none"> <li>• Both groups highlighted high levels of HIV-related discrimination, financial strain, lack of information and relationship difficulties</li> <li>• African American individuals demonstrated more adaptive coping and increased social support</li> </ul>	<ul style="list-style-type: none"> <li>• One of the few studies to explore older African men's experiences, an underrepresented group in literature</li> <li>• Individuals received support from services which may have impacted coping</li> <li>• Questions around the ethnic validity of the measures used</li> <li>• Cross-sectional design which limited causation</li> </ul>
<p>How older Black women perceive the effects of stigma and social support on engagement in HIV care</p> <p>McDoom, Bokhour, Sullivan &amp; Drainoni (2015)</p>	<p>To understand how older Black women perceive their experiences with stigma and social support and how this impacts engagement with HIV care</p>	<p><b>Context:</b> USA <b>N:</b> 20 <b>Age:</b> 56.60 mean <b>Gender:</b> women <b>Ethnicity:</b> Black/African American</p>	<p>Qualitative semi-structured interviews</p>	<ul style="list-style-type: none"> <li>• Stigma reduced engagement with care</li> <li>• Social support increased engagement with care</li> <li>• HIV-related stigma led to reluctance to disclose positive status</li> </ul>	<ul style="list-style-type: none"> <li>• Advantage of exploring divergent attitudes</li> <li>• Possible setting bias due to interviews being conducted in a clinic</li> <li>• Little consideration of researcher reflexivity issues</li> <li>• Focus on women engaged in care as opposed to those with little healthcare support</li> </ul>
<p>Mental health problems in older adults with HIV referred to a</p>	<p>To compare older and younger individuals living with HIV</p>	<p><b>Context:</b> London, UK</p> <p><b>N=</b> 52</p>	<p>Data collected from individuals referred to a psychological clinic. Not specific details about how</p>	<ul style="list-style-type: none"> <li>• Older adults were less likely to have received previous psychiatric involvement</li> </ul>	<ul style="list-style-type: none"> <li>• Limited details about the recruitment and analysis of data</li> <li>• No consideration of how ethnicity may</li> </ul>

<p>psychological medicine unit</p> <p>Meadows, Le Marechal &amp; Catalan, 1998</p>	<p>regarding psychological well-being.</p>	<p><b>Age</b> = &gt;54 and &lt;54  <b>Gender</b> = M &amp; F  <b>Ethnicity</b> = not specified</p>	<p>and when this data was collected.</p>	<ul style="list-style-type: none"> <li>• Most common reason for referral amongst both groups were mood disorders</li> <li>• Older adults were more likely to experience isolation, which was influenced by poverty and physical health difficulties</li> </ul>	<p>have influences presentations-information not collected</p> <ul style="list-style-type: none"> <li>• No matching of younger and older samples</li> </ul>
<p>We never expected this to happen: narratives of ageing with HIV among gay men living in London</p> <p>Owen &amp; Catalan, 2012</p>	<p>To identify factors that impact on the experience of aging with HIV in gay men living with HIV in London</p>	<p><b>Context:</b> London, UK  <b>N:</b>10  <b>Gender:</b> M  <b>Ethnicity:</b> White, White Other &amp; Black Caribbean</p>	<p>Open-ended questions using a biographical narrative approach.</p>	<ul style="list-style-type: none"> <li>• Divergent attitudes about the impact of ageing with HIV (progressive towards life values v's oppressive)</li> <li>• Uncertainties about ageing with HIV</li> <li>• Coping by living in the moment</li> <li>• Social isolation</li> </ul>	<ul style="list-style-type: none"> <li>• Consideration of social history of HIV</li> <li>• Clear rationale for study</li> <li>• Limited information about recruitment strategy</li> <li>• Issues around homogeneity of sample due to ethnic differences being unaccounted for</li> </ul>
<p>Intimacy and sexual decision making: Exploring the perspective of HIV-positive women over 50</p> <p>Psaros, Barinas, Robbins, Bedoya,</p>	<p>To explore factors that impacted intimate partner relationships in women over 50 living with HIV</p>	<p><b>Context:</b> USA  <b>N:</b>19  <b>Gender:</b> F  <b>Ethnicity:</b> American Indian, Asian, Black or African, White &amp; Latina</p>	<p>Qualitative Semi - structured interviews, Grounded Theory</p>	<ul style="list-style-type: none"> <li>• Hopelessness about being in intimate relationships</li> <li>• Experiences of stigma, poor body image and fears about disclosure</li> </ul>	<ul style="list-style-type: none"> <li>• Pilot testing of interview schedule</li> <li>• Limited details about context of study and participants</li> <li>• Little consideration of ethnic variations in experiences</li> </ul>

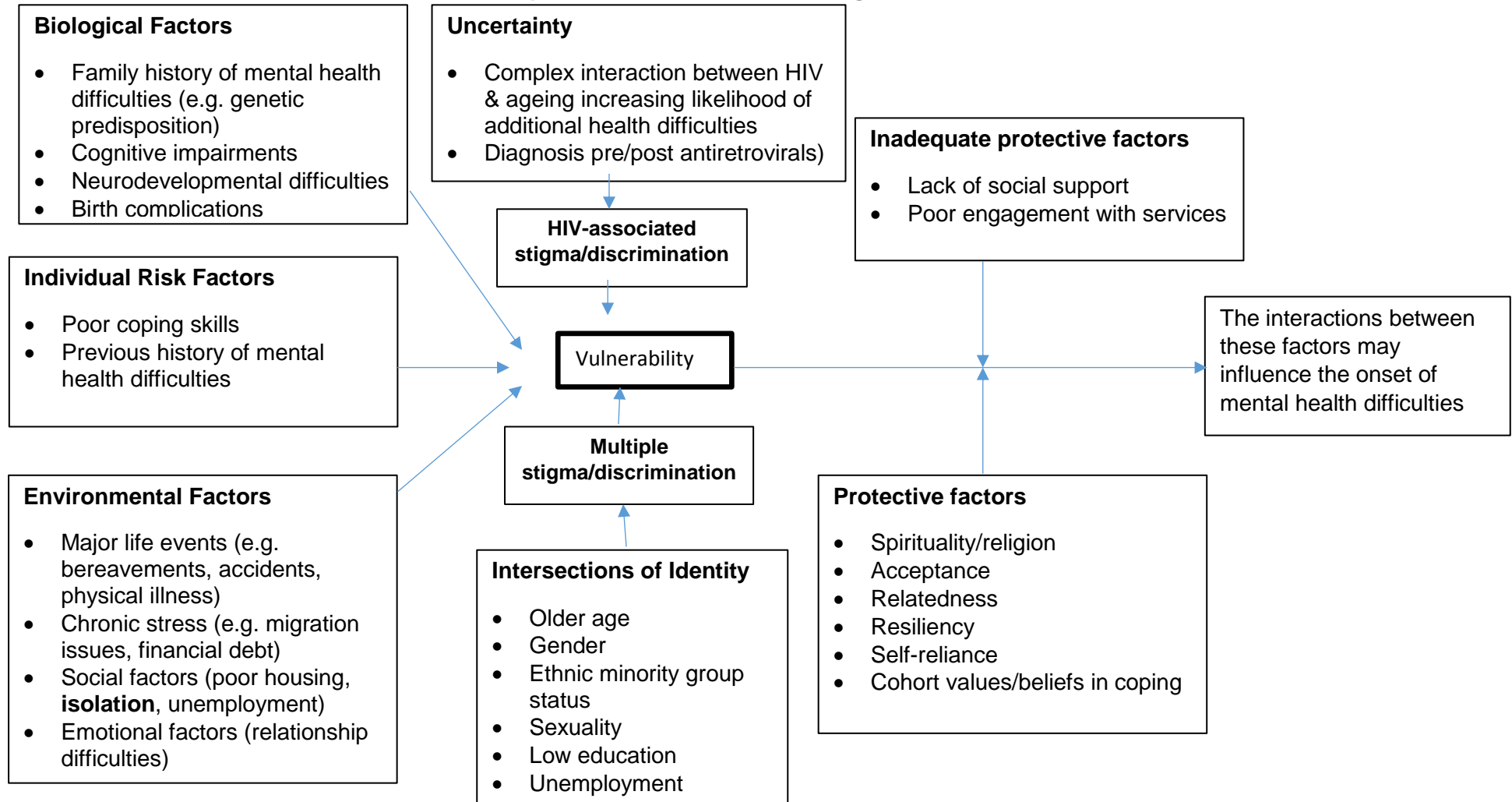
Safren, & Park, (2012).					
Reflections on living with HIV over time: exploring the perspective of HIV-infected women over 50  Psaros et al. (2015)	To explore the experiences of older women living with HIV to understand how they make sense of the diagnosis and cope with HIV over time	<b>Context: USA</b> <b>N: 19</b> <b>Age: Mean 59.79</b> <b>Gender: F</b> <b>Ethnicity: Black/African, White</b>	Semi-structured Interviews, Grounded Theory	<ul style="list-style-type: none"> <li>• Positive adjustment and acceptance over time</li> <li>• Strategies to live well included a focus on positivity and gaining meaning through support groups</li> <li>• Uncertainty about health</li> </ul>	<ul style="list-style-type: none"> <li>• Explored an underrepresented group in the research</li> <li>• Shed light into women's experiences of ageing with HIV specifically</li> <li>• Analysis process detailed and quotes provided</li> <li>• Demographic variables (e.g. education, socio-economic factors) not considered</li> <li>• Little information about recruitment methods</li> </ul>
The perceived benefits of religious and spiritual coping among older adults living with HIV/AIDS.  Siegel & Schrimshaw, 2002	To explore the benefits if religious and spirituality in relation to psychological distress in older adults living with HIV	<b>Context: USA</b> <b>N: 63</b> <b>Age: 50-88</b> <b>Gender: M&amp;F</b> <b>Ethnicity: African American, White &amp; Latina</b>	Semi-structured interviews. Thematic analysis	<ul style="list-style-type: none"> <li>• Benefits of religious/spirituality included helped regulate emotions, provided a sense of control, improved acceptance and reduces uncertainty.</li> </ul>	<ul style="list-style-type: none"> <li>• Some consideration of differences in how religion and spirituality are used across ethnicities.</li> <li>• Further exploration of differences in younger and older adults in relation to use of these strategies would be helpful to determine if it unique to older adults</li> </ul>



<p>Perceived barriers to social support from family and friends among older adults with HIV/AIDS</p> <p>Schrimshaw &amp; Siegel, 2003</p>	<p>To explore the perceived barriers to emotional and practical support from family and friends amongst older adults living with HIV.</p>	<p><b>Context:</b> USA  <b>N=</b> 63  <b>Age=</b> 50-68  <b>Gender:</b> M&amp;F  <b>Ethnicity:</b> African American, Puerto Rican &amp; White</p>	<p>Semi-structured interviews. Sample recruited from community-based services (both HIV and Non-HIV specific organisations). Self-referrals through flyers.</p>	<ul style="list-style-type: none"> <li>• Concerns about the disclosure of HIV/AIDS</li> <li>• Stigmatising attitudes</li> <li>• Desire to be self-reliant and refusal to seek support</li> <li>• Fears of being seen as a burden</li> <li>• Unavailability of support due to limited family and friends</li> <li>• Experiences of more negative attitudes towards older people with HIV in comparison to younger people</li> </ul>	<ul style="list-style-type: none"> <li>• Many of the barriers identified are present in all age groups of people living with HIV</li> <li>• Focus on narratives of gay men</li> <li>• Little consideration of ethnic variation in barriers to support</li> </ul>
<p>Vital scientific puzzle or lived uncertainty? Professional and lived approaches to the uncertainties of ageing with HIV</p> <p>Rosenfield, Ridge &amp; Von Lob, 2014</p>	<p>To explore how stakeholders and people living with HIV make sense of growing older with HIV</p>	<p><b>Context:</b> UK  <b>N=</b> 17  <b>stakeholders</b> (e.g. health professionals, academics, policy makers, advocates)</p> <p>Age = 50-86  Gender= M &amp; F  Ethnicity = White &amp; Black African</p>	<p>Semi-structured interviews</p>	<ul style="list-style-type: none"> <li>• Stakeholder narratives focused on treatment advances in reducing uncertainties about aging with HIV</li> <li>• Advocate and people living with HIV focused on the uncertainties around the future which were tied up with uncertainties about mortality, premature aging and trying to distinguish what aspects of growing older were attributed to age and which to HIV</li> </ul>	<ul style="list-style-type: none"> <li>• Explored a range of perspectives from health professionals to service users, which highlighted divergent views</li> <li>• Little consideration of ethnic differences in uncertainty</li> <li>• Broad range of age groups and time since diagnosis may have impacted experiences described but were not accounted for</li> </ul>

<p>Age, stress, and isolation in older adults living with HIV</p> <p>Webel et al. (2014)</p>	<p>To explore if age and gender in people living with HIV is associated with psychological distress stress and isolation</p>	<p><b>Context:</b> USA  <b>N:</b> 107  <b>Average age:</b> mean 48  <b>Gender:</b> M&amp;F  <b>Ethnicity:</b> African American &amp; Other</p>	<p>Quantitative measures using a range of psychological distress stress and isolation measures.</p> <p>Multivariate regression analysis</p>	<ul style="list-style-type: none"> <li>• Younger people living with HIV were shown to be at increased risk of social isolation</li> </ul>	<ul style="list-style-type: none"> <li>• Further exploration of longitudinal relationship between causes of stress and isolation across the lifespan</li> <li>• No mention of age-specific discrimination</li> <li>• A majority African American sample, however little mention of how ethnicity impacts isolation</li> </ul>
<p>The association between depressive symptoms, anger, and perceived support resources among underserved older HIV-positive Black/African American adults</p> <p>Whitehead, Hearn &amp; Burrell (2014)</p>	<p>To examine the relationship between depressive symptoms and anger on perceived social support. To further examine whether life stressors moderate this relationship.</p>	<p><b>Context:</b> USA  <b>n</b> = 95  <b>Average Age</b> = 55.78  <b>Gender</b> = M &amp; F living with HIV  <b>Ethnicity</b> = African American  <b>Time since diagnosis</b> = 14.83 years</p>	<p><i>Quantitative measures included:</i> Life burden scale, Strait-Trait Anger Expression Inventory, Beck Depression Inventory and Enhancing Recovery in Coronary heart Disease Social Support Inventory</p>	<ul style="list-style-type: none"> <li>• Inverse relationship between depression and anger and perceived social support</li> <li>• Life stressors did not have moderating effect on this relationship</li> <li>• Life stressors associated with decreased perceived social support.</li> </ul>	<ul style="list-style-type: none"> <li>• First study to explore phenomena in older adults living with HIV</li> <li>• Did not account for confounding variables (e.g. age, gender, socio-economic status)</li> <li>• Correlational design limits causal relationships</li> </ul>

**Appendix 2: Figure A1 The application of the stress vulnerability coping model (ref) to understanding the experiences of older adults living with HIV**



### **Appendix 3: Participant Information Sheet**



Title of Project: How do older Black African women living in the UK experience and make sense of living with HIV?

Researcher: Kuljit Heer

We would like to invite you to take part in a research project that is being done as part of an educational qualification. Before you decide if you would like to take part you need to understand why this project is being done and what it would involve for you. Please read through this information sheet carefully. If there is anything that is not clear or if you would like more information you can talk to the researcher.

#### **Why is this research being done?**

The research aims to find out about the experiences of Black African women, aged 50 years and over, living with HIV in the UK. This is an area that has not been looked at in much detail. It is hoped that the research will help services and professionals to better understand the needs of these people in order to develop services which can support their needs.

#### **Why have I been invited to take part?**

You have been invited to take part because you are a Black African woman, aged 50 years or over, who is living in the UK and have had a diagnosis of HIV for over 5 years. In this research the term Black African refers to anyone from sub-Saharan African including countries such as Nigeria, South Africa, Kenya, Zimbabwe, Somalia and Ghana as well as others.

#### **Do I have to take part?**

It is up to you if you want to take part. If you do decide to take part the researcher will either contact you or you may prefer to contact them yourself. If you do not want to take part, please let the researcher know and she will not contact you again. This will not affect any care or treatments you may be receiving in any way. If you do decide to take part we will ask you if you are happy for us to let your GP know that you are involved in the research. I will also ask you to sign a consent form and if you are happy to give permission to use direct quotes from the interview to write up reports and papers. If there is anything you would not like me to include in these reports you can let me know.

#### **What would be involved?**

I would like to ask you some questions about what it is like living with HIV. For example, things that might worry you, what helps and does not help you to cope, how other people have responded to you and what your expectations are for your future. We can arrange a time and place that is best for you to meet. I can talk to you at your home or at an NHS meeting room or at a local support group building. It will take no longer than 2 hours. After the interview is finished you will have the chance to ask me questions and tell me how you found it.

#### **What will happen after that?**

If you don't mind I will record what you say using an audio recorder. I will also type out a copy of what you say. I can show you this copy if you would like to see it. The data I collect will be kept for up to five years before it is destroyed. I will then write a report. I can send you a summary copy of the report if you would like to see it. I also want to write articles and give presentations. The data collected may be used to support research in the future, and may be shared anonymously with other researchers.

#### **Will the things I say be kept private?**

I may want to use some things you say in my project report, articles and presentations. I will not use your name. Anything I include in my report will be fully anonymised so that no-one will be able to identify you as an individual. Only I will know your real names. If you tell me that there is a possibility of you harming yourself or others I may have to tell other professionals about this.

### **I do not speak English can I still take part?**

Unfortunately, if you do not speak English it is not possible for you to take part because we do not have any translators or interpreters in the research team.

### **Are there any risks involved?**

You may become upset when talking about your experiences. If this happens you can ask to stop. You will be able to have as many breaks as you wish during the interview or you can choose to stop completely. If you find the process upsetting or need extra mental and/or physical support, you will be provided with details of people who can help such as your GP or psychology services.

### **What will happen if I do not want to carry on?**

You can stop being involved in the research up to one month after the interview and until the data is not included in the analysis. You do not have to give me a reason to stop. It is up to you. If you want to stop I will not use anything you say in the project. Unfortunately, after one month it will not be possible to stop taking part as the analysis of your data will have started.

### **Expenses**

You will be refunded any expenses like travel and childcare costs up to the amount of £10.

### **Who is the researcher?**

My name is Kuljit Heer. I am a doctoral researcher at the University of Hertfordshire. I have a Criminal Records Bureau check which says I can work with children and vulnerable adults. This project is being done with Dr Helen Ellis-Caird, who works at the University of Hertfordshire. The research is also being supported by Dr Elizabeth Shaw, Clinical Psychologist at North Middlesex University Hospital NHS Trust. If you would like information about the research you may also contact Dr Lizette Nolte ([l.nolte@herts.ac.uk](mailto:l.nolte@herts.ac.uk)/ 01707 284486) who is aware of the research but not directly involved in it.

### **Who has reviewed the study?**

The East of Scotland Research Ethics Service REC 2, which has responsibility for scrutinising all proposals for medical research on humans, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from The University of Hertfordshire and North Middlesex University Hospital NHS Trust, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

### **Other important information**

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through the University of Hertfordshire who are acting as the research sponsor. Details about this are available from the research team. Also, as a patient of the NHS, you have the right to pursue a complaint through the usual NHS process. To do so, you can submit a written complaint to the Patient Liaison Manager, XXXXXXXXXX, XXXXXXXX). Note that the NHS has no legal liability for non-negligent harm. However, if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against XXXXXXXX XXXXXX but you may have to pay your legal costs. Thank you for reading this information. You can contact me to talk about the research. We can talk on the telephone, via email or face to face if you would prefer this.

**Contact details for researcher: Mrs Kuljit Heer / Email: [k.heer@herts.ac.uk](mailto:k.heer@herts.ac.uk)/ 07873 947282**

**Appendix 4: Poster used for recruitment of participants**



Are you a **Black African woman aged 50 years or over living with HIV** for the past five years?

Would you be willing to talk about your experiences of living with HIV?

Then please consider joining our research project looking at the experiences and needs of Black African women (aged 50 years and over) living with HIV in the UK

**What will it involve?**

- **Talking about your experiences** of living with HIV such as: what it is like living with HIV; what helps and does not help you to cope and what your expectations are for your future.
- We can talk to you at your home or at an NHS meeting room or at a local support group building.
- You will be refunded any expenses like travel and childcare costs up to the amount of £10.

If you would like more information please contact:

**Mrs Kuljit Heer** (Trainee Clinical Psychologist) or **Dr XXXXXX** (Clinical Psychologist)

**[k.heer@herts.ac.uk](mailto:k.heer@herts.ac.uk)** Tel: **07873 947282**

**Appendix 5: Consent Form**



Participant Identification Number for this trial:

Title of Project: How do older Black African women living in the UK experience and make sense of living with HIV?

Name of Researcher: Mrs Kuljit Heer (Trainee Clinical Psychologist, University of Hertfordshire)

Please  
initial  
boxes

- 1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw until up to one month after taking part without giving any reason, without my medical care or legal rights being affected.
- 3. I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Hertfordshire or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- 4. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.
- 5. I agree that information and resultant data collected, including direct quotes may be published providing it remains anonymous.
- 6. I give permission to audio record my interview.
- 7. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking  
consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Appendix 6: Table A2, Demographic Information collected during the interviews**

<b>Participant ID</b>	
<b>Age</b>	
<b>Country of heritage</b>	
<b>Time living in UK</b>	
<b>Residential status</b>	
<b>Employment</b>	
<b>Education</b>	
<b>Religion</b>	
<b>Marital status</b>	
<b>Children</b>	
<b>Physical Health problems</b>	
<b>Mental health problems</b>	
<b>Length of time since diagnosis</b>	
<b>Place of diagnosis</b>	
<b>Groups attended/volunteering/services received</b>	



## **Appendix 7: Interview Schedule**

### **Living with HIV**

Can you tell me about your life at the moment as an older Black African women living with HIV in the UK?

Prompts: *Tell me about what is important in your life? What a typical day looks like?*

What place does HIV have in your life at the moment?

Prompts: *What does it mean to have HIV?; Does HIV make anything easier / harder?*

Prompts: *Do you consider yourself to be "older"? What does being "older" mean to you? What does being older with HIV mean to you?*

### **Current worries**

What are the things that worry you most in your life at the moment as an older Black African women living with HIV in the UK?

Prompts: *What are the things that worry you on a daily basis?; How do you feel about things like finances, relationships, physical health or mental health? Which of these worry you the most/least?*

### **Support/coping**

How do your age, gender, ethnicity and migrant status impact how you cope with these worries /challenges?

Prompt: *What helps you to cope?; Are there things other people say or do which help?; Are there things that make it harder to cope? Are there things other people say / do which do not help?*

### **Other people's attitudes**

Have you told anyone about the HIV? (does age, gender, ethnicity, migrant status play any role in your decision to disclose/not to disclose?)

Prompts: *Does anybody (e.g. family or friends) know that you have HIV?; Why did you choose to tell / not tell them? What would happen if you told them? Do you think you may tell them at some point?*

What do you think people / society think about older Black African women living with HIV in the UK?

Prompts: *What have your experiences been of other people's reactions to HIV?; Can you think of any positive / negative examples? Do you think people's views are negative or positive?*

What role does your own culture have to say about these issues?

### **Looking to the Future**

Looking at the next 5-10 years ahead, what do you see for yourself as an older Black African women living with HIV in the UK?

Prompts: *What are your expectations/hopes/worries?; Have you made any plans for your future? Do you think making plans is important? How achievable do you think these plans are?*

**Appendix 8: Table A3, University of Hertfordshire Service User Consultation Feedback**

Project: Older Black African Women’s experiences of living with HIV in the UK

Researcher: Kuly Heer

Number of reviewers: 2

Date of review discussion: 15.5.15

Document Reviewed	Review Comments	Changes made
Poster	<ul style="list-style-type: none"> <li>• Well laid out and easy to read. Enough information to make an informed decision.</li> <li>• The title needs to stand out more, by highlighting it in black</li> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• The title has been highlighted using black and underlined font.</li> </ul>
Interview Schedule	<ul style="list-style-type: none"> <li>• Positive comments about the range of questions asked</li> <li>• To include questions about the impact of culture on individual’s experiences</li> <li>• To where a person acquired HIV, (e.g. whether this was in the UK or in their home countries)</li> <li>• To use the term “older” with care, as certain individuals aged 50 may not consider themselves as old. To explore the participants perceptions of their age and to be guided by this.</li> </ul>	<ul style="list-style-type: none"> <li>• A questions regarding culture has been added to the interview schedule.</li> <li>• When asking about participants demographics to ask where HIV was acquired if this feels appropriate at the time.</li> <li>• To be guided by the participants personal interpretations of their age throughout the interview. Prompts have been included in the interview schedule to allow for this.</li> </ul>
Information Sheet	<ul style="list-style-type: none"> <li>• To make the nature of the study and what the participants involvement will involve more explicit</li> </ul>	<ul style="list-style-type: none"> <li>• Further details have been added to the information sheet under the what will be involved section</li> </ul>
Consent Form	<ul style="list-style-type: none"> <li>• Easy to read and understand</li> <li>• To ensure that all participants have the opportunity to receive a summary of the results, of they would like to, by asking them during the consent process.</li> </ul>	<ul style="list-style-type: none"> <li>• All participants will be asked if they would like to receive feedback and how (e.g. post, email)</li> </ul>

**Appendix 9: Transcription Contract**

University of  
Hertfordshire



**Doctorate in Clinical Psychology**

**University of Hertfordshire**

**Transcription confidentiality/ non-disclosure agreement**

**This non-disclosure agreement is in reference to the following parties:**

**X ('the discloser')**

**And**

***Transcription service* ('the recipient')**

**The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.**

**The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.**

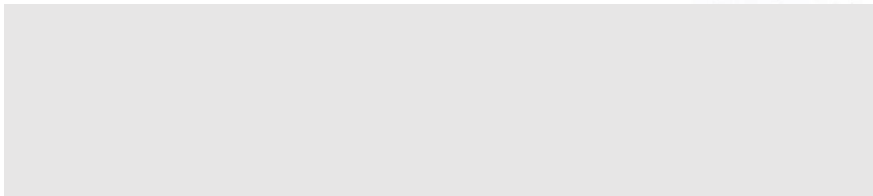
**The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.**

**Signed:.....**

**Name:.....**

**Date:.....**

### Appendix 10: REC Approval



Date: 30.09.15

#### NHS PERMISSION FOR RESEARCH (R&D Approval)

Dear Colleague/s

IRAS ID: 601  
REC Ref: 15/ES/0119  
NMH RAP: 601

**Study Title:** How do older Black African women living in the UK experience and make sense of living with HIV?

NHS permission for the above research has been granted for the following NHS Trusts and/or Independent Contractors:

Trust/Independent Contractor	Name of PI / LC	Date of Permission
[Redacted]	[Redacted]	30 September 2015

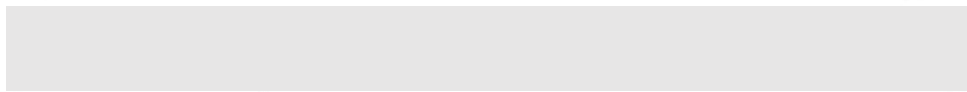
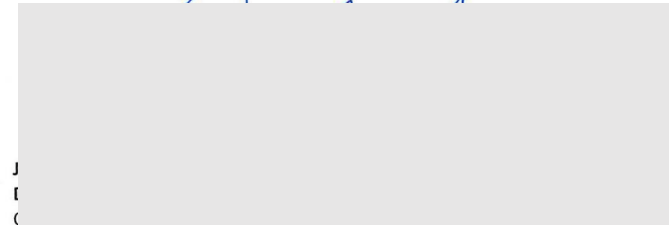
Permission is based on the REC favourable opinion given on 03 September 2015.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP, and the policies and procedures of the Trust/s [<http://www.crn.nihr.ac.uk/resources/trusts-covered-by-crn-north-thames/?h=42> ].

Permission is only granted for the activities for which a favourable opinion has been given by the REC [and which have been authorised by the MHRA].

Specific Conditions of Permissions (if applicable)
[Redacted]

Yours Sincerely,



## **Appendix 11: NHS Ethical Approval**



**East of Scotland Research Ethics Service (*EoSRES*)**

**Research Ethics Service**

Tayside medical Science Centre  
Residency Block Level 3  
George Pirie Way  
Ninewells Hospital and Medical School  
Dundee DD1 9SY

Dr Helen Ellis-Caird  
Doctorate in Clinical Psychology  
University of Hertfordshire  
College Lane  
Hatfield  
AL10 9AB

Date: 03 September 2015  
Your Ref:  
Our Ref: LR/15/ES/0119  
Enquiries to: Mrs Lorraine Reilly  
Direct Line: 01382 383878  
Email: [eosres.tayside@nhs.net](mailto:eosres.tayside@nhs.net)

Dear Dr Ellis-Caird

**Study Title:** How do older Black African women living in the UK experience and make sense of living with HIV?  
**REC reference:** 15/ES/0119  
**Protocol number:** LMS/PG/NHS/00416  
**IRAS project ID:** 181095

Thank you for your emails of the 28 August 2015 & 03 September 2015, 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 and designated Committee members.

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 favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Mrs Lorraine Reilly, [eosres.tayside@nhs.net](mailto:eosres.tayside@nhs.net). Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

### **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.



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

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

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

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 request a deferral for study registration within the required timeframe, they should contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

**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
Copies of advertisement materials for research participants	2	03 September 2015
Covering letter on headed paper [Covering Letter & Response]	1	28 July 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of UH Sponsorship]		06 July 2015
GP/consultant information sheets or letters [Letter to GP]	1	24 August 2015
Interview schedules or topic guides for participants [Interview Schedule]	1	02 July 2015
IRAS Checklist XML [Checklist_28082015]		28 August 2015
Letter from sponsor [Sponsorship Letter]	1	06 July 2015
Other [Letter of insurance from University Insurance]	1	04 August 2015
Other [GCP Certificate]	1	31 July 2015
Other [Transcription Contract]	1	24 August 2015
Participant consent form [Consent Form]	2	24 August 2015
Participant information sheet (PIS) [Participant Information Sheet]	2	24 August 2015
REC Application Form [REC_Form_14072015]		14 July 2015
Referee's report or other scientific critique report [Academic Review of Proposal]		
Research protocol or project proposal [Research Protocol]	2	24 August 2015
Response to Request for Further Information		03 September 2015
Summary CV for Chief Investigator (CI) [Dr Helen Ellis-Caird ]	1	01 January 2015
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	2	21 August 2015
Summary CV for student [CV student Kuljit Heer]		
Summary CV for supervisor (student research) [CV Academic Supervisor Dr Shaw ]		

### 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/>

15/ES/0119

Please quote this number on all correspondence

Yours sincerely



pp  
**Ms Tara Graham**  
**Chair**

Email: eosres.tayside@nhs.net

Enclosures: "After ethical review – guidance for researchers"



## **Appendix 12: University of Hertfordshire sponsorship**



Dr Helen Ellis-Caird &  
Ms K Heer  
Department of Psychology  
School of Life and Medical Sciences

University of Hertfordshire  
Hatfield  
AL10 9AB  
UK

tel +44 (0)1707 284000  
fax +44 (0)1707 284115  
herts.ac.uk

6 July 2015

Dear Dr Ellis-Caird and Ms Heer,

**Re: UNIVERSITY OF HERTFORDSHIRE SPONSORSHIP IN PRINCIPLE for the following:**  
**RESEARCH STUDY TITLE:** How do older Black African women living in the UH experience and make sense of living with HIV?  
**NAME OF CHIEF INVESTIGATOR (Supervisor):** Dr Helen Ellis-Caird  
**NAME OF INVESTIGATOR (Student):** Kuljit Heer  
**UNIVERSITY OF HERTFORDSHIRE ETHICS PROTOCOL NUMBER:** LMS/PG/NHS/00416

This letter is to confirm your research study detailed above has been reviewed and accepted, and I agree to give University of Hertfordshire sponsorship in principle.

Before you commence your research you must be in full compliance with all NHS Governance requirements. You must also secure full University of Hertfordshire sponsorship, for which you will need to have supplied the following documentation:

- Final version of the submitted IRAS form (pdf)
- Approval from the relevant NRES (NHS) Research Ethics Committee (REC) as well as confirmation of favourable opinion of any amendments
- Evidence of relevant NHS Permissions (eg Research Passport) and NHS Trust Management Permissions (previously known as R&D Approval) as they are received
- The final version of the protocol
- The final versions of the patient information leaflet and informed consent form
- One page summary CV for the Chief Investigator (CI) as submitted to IRAS
- Any other regulatory permissions required for your research, eg from the National Information Governance Board (NIGB), under the Human Tissue Act or the Ionising Radiation (Medical Exposure) Regulations
- If applicable, copies of any contracts/agreements with external organisations (eg funders, collaborators, co-sponsors) involved in your research study

As a condition of receiving full sponsorship, it is the responsibility of the Chief Investigator to inform the Sponsor of any changes to the duration or funding of the project, changes of investigators, changes to the protocol and any future amendments, or deviations from the protocol, which may require re-evaluation of the sponsorship arrangements. It is also the responsibility of the Chief Investigator to inform the funder, the NRES (NHS) Research Ethics Committee (REC) and the relevant University of Hertfordshire Ethics Committee with Delegated Authority (ECDA) and any other relevant authority of any of these changes.

I look forward to receiving the above documents before you commence your research. Please email these to [research-sponsorship@herts.ac.uk](mailto:research-sponsorship@herts.ac.uk) so the University can confirm sponsorship. In the meantime, we wish you well in pursuing this interesting research study.

Yours sincerely,

Professor J M Senior  
Pro Vice-Chancellor (Research and International)

*Encl: Insurance certificate*



A Charity Exempt from Registration under the  
Second Schedule of the Charities Act 1993

**Appendix 13: Worked Transcript for Brenda**

	<p>I: Ok so just before we start on the interviews I just wanted to ask you a few questions? So how old are you?</p> <p>B: I'm 69 and I'll soon be 70 on X XXXXXXXX.</p> <p>I: And is it ok to ask your origin country?</p> <p>B: I come from Zambia.</p> <p>I: Ok and how long have you been here?</p> <p>B: Fourteen years.</p> <p>I: And what's your residential status?</p> <p>B: Asylum seeker.</p> <p>I: What level are you educated to?</p> <p>B: In my country, I went to secondary, I became a teacher.</p> <p>I: You became a teacher? What did you teach?</p> <p>B: I taught English, I taught a lot of subjects.</p> <p>I: Ok, and was that secondary school or primary?</p> <p>B: I was teaching in a primary school, but I went to secondary school.</p>	<p><i>69</i></p> <p><i>Zambia</i></p> <p><i>14 year's resident</i></p> <p><i>Asylum seeker</i></p> <p><i>In my country- identifies as 'my country'-</i></p>
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<p><b>The physical impact of ageing</b></p> <p><b>The physical impact of ageing</b></p> <p><b>The physical impact of ageing</b></p>	<p>I: Ok, and do you have a religion?</p> <p>B: Yeh, I'm a Christian.</p> <p>I: Ok, is there a certain type of Christianity or...</p> <p>B: Umm, freechurch, which is a ?(placebatarian)? church.</p> <p>I: And umm, your marital status?</p> <p>B: I'm a widow.</p> <p>I: Ok, I'm sorry, and do you have any children?</p> <p>B: Yes I have children, I had eight children, I lost three and am remaining with five. Two men and three women.</p> <p>I: Ok ...and how's your physical health? Have you got any difficulties, any pains, aches or...</p> <p>B: Yes, I've got a lot of aches in my body.</p> <p>I: Can you tell me a bit about them?</p> <p>B: I've got a hip replacement which still bothers me.</p> <p>I: OK.</p>	<p><i>Christian</i></p> <p><i>Widow, factual, numb, coping with loss, adult, 8 children, lost 3- loss to HIV and husband?</i></p> <p><i>Aches in body-physical, growing older?</i></p> <p><i>Hip replacement- bothers her, ongoing</i></p> <p><i>Leg pain, pains all over body, takes painkillers- 'out of nowhere' sudden, unexplained- repetition of pain-</i></p>
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<p><b>The physical impact of ageing</b></p>	<p>B: And sometimes the legs start paining from nowhere. Right now I've got a pain in my shoulders, so painful, just been taking painkiller, aches all over the body.</p> <p>I: Ok and when did you have your hip replacement?</p> <p>B: In...what was it...2000 and er, 8.</p> <p>I: Ok, anything else?</p> <p>B: Yeh, I'm starting to have lots of memory problems.</p> <p>I: Ok and when did you notice that?</p> <p>B: Umm, it's almost five years now. I can't remember, even if I have read a story, I can't retain it again.</p> <p>I: Ok, have you had any tests for that?</p>	<p><i>need to witness the pain? Pain represents something emotional? Hip replacement pain?</i></p> <p><i>Memory problems</i></p> <p><i>Concept of time? How long been?</i></p> <p><i>5 years onset of memory difficulties, can't retain stories, HRBI, - Doctor says she has HIV dementia</i></p>
<p><b>The psychological impact of loneliness</b></p>	<p>B: My doctor is saying that I am having dementia. HIV dementia.</p> <p>I: Ok, and how about your mood?</p> <p>B: My mood is OK, I don't get angry easily.</p> <p>I: Ok, do you ever feel low, or sad or anxious?</p> <p>B: Not really anxious, but I'm a bit low.</p> <p>I: Ok, is that generally, every day or does it go up and down?</p>	<p><i>Anxious sometimes, low</i></p> <p><i>Mood changes as grows older, alone a lot more, being alone leads to mood fluctuations-alone most of time-more time to worry/worry about loneliness? Rejection?</i></p>

<p>??</p> <p><b>The importance of staying connected</b></p>	<p>B: There's a change as I'm growing older, than before, almost every time, because most of the time I'm alone.</p> <p>I: Ok, so it's when you're alone you notice it more?</p> <p>B: Yes.</p> <p>I: Ok, so how long has it been since you've been diagnosed?</p> <p>B: Umm, 1995, yeh twenty one years now.</p> <p>I: Ok, was that here in the UK?</p> <p>B: No it was back in Africa.</p> <p>I: Ok and do you attend any support groups?</p> <p>B: I attend a lot of support groups. I also get help from social services.</p> <p>I: Ok, so that's the background bit done. Now I'll ask you some questions about your experiences. So can you tell me a bit about your life right now? What's important in your life at the moment?</p> <p>B: It's my life, it's life itself.</p> <p>I: It's life itself, OK and what makes your life important, what are the things that contribute?</p>	<p><i>21 years since diagnosis</i></p> <p><i>Diagnosed in Africa</i></p> <p><i>Life itself is important. Life as needing to be valued? Could have died? Thinking about life- death hanging over you</i></p> <p><i>Desire to live, to see children/grandchildren, pass through expected development? 'wanted' questioning if it will happen?</i></p> <p><i>Doesn't do much with day, socialises, groups, church, visit people- meets with people-important- reductive-</i></p>
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	<p>B: Umm, I wanted to live and see my children, see my grandchildren and er meet new friends.</p>	<p><i>not what she wants to do-people and God, - after life/death</i></p>
<p><b>HIV as a ‘long illness’</b></p>	<p>I: Ok, so it sounds like people are really important in your life?</p>	
<p><b>The long term duration of HIV</b></p>	<p>B: Yes.</p>	<p><i>HIV as a ‘long illness’ – tiring, long time, tired?</i></p>
<p><b>The accepting self</b></p>	<p>I: Ok and what other things make up your life on a daily basis?</p>	<p><i>‘Long illness’ will stay with her for the rest of her life- attached, can’t escape</i></p>
<p><b>The questioning self (die or live)</b></p>	<p>B: I don’t have really a lot of things that I do apart from going to socialise with friends in different groups, going to church on Sundays, to meet friends at the church and then sometimes I visit relatives.</p>	<p><i>Long illness, had impact, but part of life, acceptance, accommodate it?- medication has become part of her life, adaptations, long illness affects all of life, - mind preoccupied with the question of whether she will live or die, constant worry, rumination. 2 parts of life, pre and post diagnosis- death hanging over every decision- death always present?</i></p>
	<p>I: So it sounds like people and your faith are important to you?</p>	
	<p>B: Yes, yes.</p>	
	<p>I: Ok, so in your life, what role does HIV, do you call it HIV or something else?</p>	<p><i>Constantly questioning herself- no certainty, just uncertainty about life- HIV controls life- in its hands Always questioning if she will die, death related to age, as grows older the question of death more prominent? ‘suffering’- does she want it to end? Waiting &amp; watching&gt; passive- answer?</i></p>
<p><b>The questioning self (die or live, HIV controls life)</b></p>	<p>B: It’s a long illness.</p>	
	<p>I: It’s a long illness? Why?</p>	
	<p>B: Because it will remain with me for the rest of my life.</p>	<p><i>Not old mentally, but recognises she is old in numerical terms. Age just a number? Resistant being</i></p>

<p><b>Resisting ageing</b></p>	<p>I: OK, so what role does the long illness have in your life?</p> <p>B: It has had a lot of impact on me but which has become part of my life now because I have to think of medication every day. I have to think that [I: hmm] I am having that long illness all the time, so it affects my life, different than before. [I:mhm]. Sometimes I say maybe if I do this I will die soon or maybe this is it, today is the end of me. So my mind is always with it, is there death? Or is it that I am still alive?</p> <p>I: Hmm, yeh.</p> <p>B: You know, I am questioning myself all the time.</p>	<p><i>old, another label? Being older raises more questions about death? Makes life less certain? Double death sentence- HIV and ageing. Contrast of numbers vs feelings- youthful inside vs ageing outside&gt; shell separate from feelings</i></p> <p><i>Looks after herself physically</i></p>
<p><b>Living with loss</b></p>	<p>I: So you're questioning yourself, am I going to die or am I going to live?</p> <p>B: Yeh, is this the end of it? If maybe sometimes I become sick I think is this the end of it? That I am suffering now? That I am old and getting older.</p>	<p><i>HIV changed things in a bad way- was supposed to die, lived because of medication and UK. Catch 22, could live due to medication but separated from family. Hiv as 'it' externalising, choice, illness related sacrifices</i></p> <p><i>'it' (HIV) bought her to UK, no choice, but can't get right to stay- important needs it in order to go home? – affected emotionally by this worry- can't tolerate certain emotions- removed from 'it' – detachment-</i></p>
<p><b>Living with uncertainty</b></p>	<p>I: Ok, and so you're 69 years old, do you consider yourself to be older?</p> <p>B: No. The thing is I don't feel that I am old, mentally [I: Ok] but age wise I know I'm old because of I keep counting every year and I'm going up and up and up (both laugh). But physically, I can look after myself, sometimes with some help, to compare myself to be seventy next month.</p>	<p><i>Loss- of previous life, family, what she was doing</i></p> <p><i>Contrast to dementia</i></p>

<p><b>Living with loss</b></p>	<p>I: Ok, so it sounds like you're mentally younger...</p> <p>B: Yes, I am younger than seventy years! (both laugh)</p> <p>I: And even physically?</p> <p>B: Yes, physically I am looking after myself, yes.</p> <p>I: Ok, and you said that HIV is part of your life now, do you think that it's made things harder or has it changed things in another way?</p>	<p><i>Better to be diagnosed later in life- have had children, they won't get it, was able to be a mother, wife? Role expectations, family- important in her culture- relief. Gratitude.</i></p> <p><i>Having it older means you've had your life</i></p>
<p><b>The grateful self</b></p>	<p>B: No, it has changed in a bad way because I'm not supposed to be here, I'm here because I'm having some better medication and if I was home I would've been dead by now, but it has separated me from part of my family.</p> <p>I: Hmm, so back in Zambia?</p> <p>B: Back in Zambia, yes. So it has really bought me to the UK, but I have problems in securing my remain here, every time you go to the home office to report, so all this affects me.</p>	<p><i>Nothing to hide, open about status, was married, 'husband reckless'- he died of HIV, knew she'd got it in her- waiting for it to get her. Was married, so no shame for her? – husband bought it to her- could defend herself in community; HIV in marriage less taboo-protective publicly – inevitability- Men- brothers noticed something wrong with her. Got tested. Brothers controlled/made decisions? Husband had another women, - both died, she lived- ok for men to do that? Public identity chosen for her only one living? How does she make sense of that? Wasn't reckless?</i></p>
<p><b>Resisting shame as a woman</b></p>	<p>I: So it sounds like you've [lost...</p> <p>B: I've lost] my family, I've lost whatever I was doing before.</p>	<p><i>People trying to avoid HIV, discourse in Africa, worked in butcher, people didn't want to buy meat- stigma, outcast. 'fear'- others would catch it. Ignorance/lack of education. People outside of family stigmatised, in family provided practical support- but not emotional- don't talk about it-shame? Silent support-colludes with stigma? Untouchable, hierarchy, leper&gt; avoidance publicly, she avoids, family</i></p>



<p><b>Men as decision makers</b></p>	<p>I: And it sounds like things are unstable [because you don't know about your status</p>	<p><i>avoids emotions. Physical pain-body talking for her- feelings</i></p>
<p><b>Resisting shame as a woman</b></p>	<p>B: Don't know, yes, yes].</p>	<p><i>Physical impact of HIV- become thin, people notice physical change due to HIV- people 'desert' you – abandoned.</i></p>
<p><b>The rejected self</b></p>	<p>I: Ok, so you were diagnosed about twenty one years ago, so you would've been...sorry my maths isn't great, umm...fifty?</p>	<p><i>Faced some discrimination in the UK when first arrived, but education has helped and support groups. 'easy' – global stigma- in UK.</i></p>
<p><b>Being feared</b></p>	<p>B: Yeh, yeh, I was forty nine I think.</p>	<p><i>In the UK professionals have allowed her to talk about HIV- before it was hidden, silent, seen but not spoken about-because of shame? Stigma? Not dangerous, talking reduces danger/fear- alternative stories- about having HIV, 'us'</i></p>
<p><b>Receiving 'silent' support</b></p>	<p>I: Forty nine, yeh ok, sorry, do you think age makes a difference in terms of diagnosis? Do you think if you were maybe younger, say in your twenties as opposed to almost fifty when you found out would that have made a difference?</p>	<p><i>Older people with HIV more serious-take meds, want diagnosis to live. Younger people they don't want diagnosis because it stops you living, achieving a normal life. Younger people hide, avoid, run away, trying to escape it-it's after their life—huge impact, grateful it happened in later life? Impact of diagnosis and age. Wanting to live v's wanting to be alive. YOLO culture. Avoidance of sickness.</i></p>
<p><b>HIV as a visible condition</b></p>	<p>B: Yes, I think umm...not a comfortable one, because if I was diagnosed when I was young I would've affected my children, but thank goodness it happened after I stopped having children. So...it was going to be a bad thing if I had it when I was young.</p>	<p><i>Older people with HIV more serious-take meds, want diagnosis to live. Younger people they don't want diagnosis because it stops you living, achieving a normal life. Younger people hide, avoid, run away, trying to escape it-it's after their life—huge impact, grateful it happened in later life? Impact of diagnosis and age. Wanting to live v's wanting to be alive. YOLO culture. Avoidance of sickness.</i></p>
<p><b>The abandoned self</b></p>	<p>I: So there's an advantage to getting it later?</p>	<p><i>Older people with HIV more serious-take meds, want diagnosis to live. Younger people they don't want diagnosis because it stops you living, achieving a normal life. Younger people hide, avoid, run away, trying to escape it-it's after their life—huge impact, grateful it happened in later life? Impact of diagnosis and age. Wanting to live v's wanting to be alive. YOLO culture. Avoidance of sickness.</i></p>
	<p>B: Yes, at least you have had your life.</p>	
	<p>I: OK, and when you found out did you decide to tell people or not?</p>	

<p><b>Education as a means of making things 'easy'</b></p>	<p>B: Umm, it wasn't something to hide, because I was a married person and umm, my husband was a reckless one. Now, when he was diagnosed, I knew I was also going to have HIV, so when he died I was still very healthy but I had it in me and after some five years I started becoming sick.</p>	<p><i>Older people without HIV, isolate themselves from those who are 'sick' HIV is a 'sickness'</i></p> <p><i>People more care free with HIV in UK, can take medication, access to healthcare, can have a 'don't care' attitude- for younger people.</i></p>
<p><b>Talking about the unspoken</b></p>	<p>I: Ok, so five years after your husband passed?</p> <p>B: Yes. Then my brothers noticed that something was wrong with me so they decided to take me to a doctor to have me tested, then I was founded to be positive. So everybody knew, because my husband died of HIV, so, and he had another woman, another wife, second wife, who also passed away, the same problem, so I was, I am the only one living.</p>	<p><i>People avoid her because 'it's dangerous' – worried they'll catch it- like a cold- not educated. Older stories- different public narratives 'hiv' dangerous</i></p>
<p><b>Diagnosis and a lost life</b></p>	<p>I: Right ok, so for you it wasn't a decision, everybody just [knew</p> <p>B: Knew that now] she has it, yeh.</p> <p>I: And how did people respond?</p> <p>B: By then HIV was something which people were trying to avoid you once you are diagnosed and er, by then I was running a business which people didn't even want me to touch the meat that I was selling in the butcher [I: In Zambia?] In Zambia, yes and by then there was er... a lot of fear that somebody would catch HIV from me,</p>	<p><i>Worried about medication and impact it will have on her as she grows older- wants a cure, wants to have it taken away- gives more certainty as opposed to uncertainty? How HIV meds will interact with growing older? 'us' part of something- identifying- talking about what she wants.- group helps that?</i></p> <p><i>If had husband life would be easier- would be understood, friend, companionship, HIV brings loneliness, children grown up leading lives, Not like</i></p>

<p><b>Medication as a life line??</b></p>	<p>from the cups, from whatever, even if I sit on the toilet and all that. This was the people outside of my family, but with my family nobody did that to me and nobody talked about it, they all just cared trying to help me get medication, that's all.</p> <p>I: Hmm, so you, so there were people that [wanted to help</p> <p>B: My family] yes but er, you know when you have HIV you start becoming thin, now people started noticing, so this is what happens and then they start deserting you, that you are sick.</p> <p>I: And is it the same here, when you're in the UK?</p>	<p><i>back home, where grandchildren would stay with her- in UK grandchildren stay with parents- loneliness adds up, overtime, gets worse. Loss of cultural support in UK, alone, have to be proactive and socialise in order to avoid loneliness. Wants to be back home- life lost – different cultural approach to treatment- being supported.</i></p> <p><i>Publicly people can't come for her- public stigma</i></p> <p><i>Loneliness is 'too much'= can't have b/f – because of illness if they know you're 'sick' don't want you- woman rejected if sick</i></p>
<p><b>Being feared</b></p>	<p>B: Yes, sometimes, before but now when I just came in 2003 it wasn't as er, comfortable as it is now. Yeh there was still this discrimination and all that, but I don't know about other people who have been diagnosed but I think getting lectures from professional people in the support groups they have made it easy.</p> <p>I: What has made it easy?</p>	<p><i>Thinks can't have b/f never tried herself-why? Afraid of rejection? Men with HIV prefer to be alone and not with women who are sick? Why?</i></p> <p><i>Shame/stigma/prostitutes? Women with HIV face more stigma, reciprocal role</i></p>
<p><b>Ageing with uncertainty</b></p>	<p>B: I think it is the people, who are talking to us, doctors, professionals, they are finding ways to help us and it's not as dangerous as it was before so somebody can talk about it. Yeh, it's easier to talk about it, yeh.</p>	<p><i>Young men don't want older women- women needed for children, they can't provide it. Men with HIV die quicker than women- hence more older women. Not valuable because she's older and has HIV.</i></p>

<p><b>The lonely self</b></p>	<p>I: And do you think there's a difference between older generations and younger generations in terms of how they see HIV or how they think about it?</p>	<p><i>Needs help or faces 'difficult' future, worries who will look after her when she can't herself. Comparison of African culture where she'd be looked after, in the UK much more uncertain</i></p>
<p><b>The loss of expectations</b></p>	<p>B: I think so, older people are more serious you know? They buy their medication and they are wanting to be diagnosed, but the way I look at the young ones they don't want to be diagnosed because of life. They feel if they know about it, 'oh I won't have a boyfriend', 'oh I won't have a girlfriend' so they tried to hide it. They think if I go for diagnosing and they know I am sick 'oh I will lose life, my friends will run away from me once they see me taking medication' so they try to avoid it.</p>	<p><i>Prepare to go into home- mentally and financially? Worries about buying herself a resting place- can't afford it- as grow older better to be at home- 'easier' in terms of being cared for and financially. Comparisons to UK and Africa- what could've been. In UK much uncertainty. Loss of control. Death as unifying? Brings you back together again.</i></p>
<p><b>The loss of expectations</b> <b>The lonely self</b></p>	<p>I: So there's more, it's more hidden?</p>	<p><i>Poor family in Africa- compounded with her lack of finances- needs to give family in Africa money to look after her. Cost of living and dying- where does it leave you? Financial burden</i></p>
<p><b>The lonely self</b></p>	<p>B: In younger ones yes.</p>	
	<p>I: And what about when you have older people who don't have HIV, umm, what are their perspectives?</p>	
<p><b>The gendered nature of HIV</b></p>	<p>B: It's the opposite I think, older ones who don't have HIV are more, they isolate themselves more from sick people than the young ones, yeh, young ones I don't think they even care.</p>	<p><i>When she was 'in health' had made preparations for future but cut short- surprise, not expected. Didn't reach her 'goal' only future is with children- that's the only preparation she can do. Loss of goals/aspirations- HIV took life and goals.</i></p>
<p><b>The gendered nature of HIV</b></p>	<p>I: Why do you think that is, why do older people who don't have [HIV... B: Because] of good living here and it doesn't come that serious as HIV is in the villages where diet is poor,</p>	<p><i>Goal to be comfortable.</i></p>

<p><b>The gendered nature of HIV</b></p>	<p>medication is poor, so they don't feel it, dangerous that it is that bad and the other thing, they know 'ah we here this medication, when I become sick, I'll start taking medication so I don't care'.</p> <p>I: For the younger people?</p> <p>B: Yes, for the younger people.</p> <p>I: Whereas with the older [ones...</p> <p>B: They try] to keep away from me because they've still got the same mentality that it is dangerous so they'll catch it if I go near them. Yes, they don't have that education about it.</p>	<p><i>Doesn't want to be a 'beggar' – beg for money/help- pride- working hard for comfortable retirement- waiting to live as older adult- independent</i></p> <p><i>Worried about dementia- how far it will take her- danger of dementia like HIV? lots of dangerous illness in her life. Left stove gas leak- worried she'll die if it happens again- alone- needs people- more reliant/dependent in old age? Hierarchy of danger&gt; physical&gt; cognitive stuff. Self doubt.</i></p> <p><i>Worry/rumination</i></p>
<p><b>An uncertain future</b> <b>The loss of expectations</b></p>	<p>I: Hmm, that makes sense. And how do you feel about, let's say in ten years time or five years time, what are your expectations, what would you like to be doing or like to be happening?</p>	<p><i>Don't tell people she is 'sick' Hiv as sickness? Medication makes illness invisible, makes you a normal 'old woman'- hidden secret- people come and help you. Societies views of helping the elderly, but different if old with HIV. Need to be seen as 'old woman' not 'HIV sufferer' stigma, exclusion, discrepancy, identity.</i></p>
<p><b>Preparing for a home</b> <b>The loss of expectations</b></p>	<p>B: All of us feel we should find the cure for that because we have lived with it now, we don't know where this medication will take us. Maybe the side effects we are feeling all the time, aches in the body, maybe we are having problem with your eyes and all that. I mean if there was a cure, I think this could help us.</p> <p>I: Hmm, and how do you feel about having the long term illness and growing older?</p>	<p><i>Strength from people friends, daughter</i></p>

<p><b>Facing financial uncertainty</b></p>	<p>B: It, I think if umm..., you grew, you had HIV and you still had your husband life could be easy yeh, because you could have a friend who understands you better, but whereby you start staying alone it brings you a lot of loneliness, children are grown up and you are away from your children, all that loneliness adds up and they are not like in the village where you say 'oh go and stay with your grandma' here, the grandchildren are only for the parents, they want them also. So it's really, really lonely.</p>	<p><i>Daughter provides physical support, expects it from others HIV? fellow 'long illness sufferers' - belonging</i></p>
<p><b>Loss of goals/aspirations</b></p>	<p>I: So it sounds like the cultures different?</p>	<p><i>Hope in friends like her</i></p>
<p><b>An uncertain future The dependent self</b></p>	<p>B: Yes, back in Zambia there is more looking after, but here it's worse here because you are always alone, if you don't go to socialise you are always alone.</p> <p>I: Hmm, so the [loneliness</p> <p>B: Yeh, it's too] much and you are old, you can't have a boyfriend and if they know you are sick they can't come for you.</p>	<p><i>Stigma- someone with HIV is a prostitute, older person with HIV- shame amplified, to think she was promiscuous, HIV as something that comes to everybody- normalising. Friends- women, helps her to feel normal, less stigmatised, ashamed, sense of belonging, identity, normality, resisting, reclaiming. Women- gendered nature of HIV stigma. Witnessing different stories.</i></p>
<p><b>Facing financial uncertainty</b></p>	<p>I: So are you saying because you are sick it makes it harder for you to have a partner or a boyfriend?</p> <p>B: I think so, I think so although I have never tried myself. [I: Hmm, Ok]. They way I look at it, is that where we go in the groups there is a lot of young ones which don't get married who have been staying alone just like me, an old woman so I think it's just HIV and men who try to refrain from women who are sick and that's why they</p>	<p><i>Feels 'easy'- doesn't worry about HIV when around other women like her, not a 'bad' person, - invisible disease, didn't choose to have it, pick and eat reference to biblical Adam and Eve? – women seen as bad ones? Invisible, can't see it, predict, dangerous, uncontrollable- more than just HIV?</i></p>

<p><b>The dependent self</b></p> <p><b>Ageing with uncertainty</b></p> <p><b>Worry/rumination</b></p> <p><b>Resisting rejection</b></p> <p><b>An invisible illness</b></p> <p><b>The multiply stigmatised self</b></p>	<p>are lonely. Yeh, unless those who understand it, they don't mind whether you have HIV as long as your health, you are on your medication, there are a lot of men who are negative but they do go for positive women, yeh so.</p> <p>I: Ok, so it sounds like there's a possibility.</p> <p>B: Yes, yes, yes.</p> <p>I: But sometimes there's things that make it hard.</p> <p>B: Yes, and sometimes it's worse with the old ones because ... you are already old. They won't, they won't need children from you and most of the old ones, many die much, much much quicker with HIV than women like me, I'm still living but my husband died twenty one years ago.</p> <p>I: Hmm, that makes sense and what about your physical health what do you think will happen to that in the future?</p> <p>B: ...If I don't have anyone to help more it, my future will be very difficult, very much when I am unable to look after myself, yeh but ...in Africa it is easy, we have got extended families, if you have brothers who have got missus for you or maybe your sisters got children, they'll come to assist you.</p>	<p><i>Living with HIV 'easy' less to worry about- physical side of things well managed by medication- medication provides physical normality- living physically is easier &gt; easy? Protective? Can't say it's hard? Not allowed to say it's hard? HIV or woman can't complain?</i></p> <p><i>Growing older harder, strength drains out you- mental and physical? Interaction between ageing and Hiv. Connected to growing old- separation taken away can be just old.</i></p> <p><i>Medication makes her feel like she is a normal women ageing, without HIV- meds take HIV physical side away- makes it invisible</i></p> <p><i>Ageing as a natural process of decline in strength- not HIV related would happen anyway</i></p>
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<p><b>The dependent self</b></p> <p><b>Wanting belonging and acceptance</b></p> <p><b>Shame</b></p> <p><b>Finding a sense of belonging and acceptance</b></p> <p><b>Resisting rejection</b></p> <p><b>The gendered nature of HIV</b></p>	<p>I: But here it's different?</p> <p>B: Here it is quite different, you have to prepare yourself to go in a home, 'how do I go in a home? I don't even have an account here!' and I'm old already, I don't even work, to accumulate money to buy myself my err, resting place. So...at home they will go and dig somewhere, bury <u>me where they bury everybody</u>, even if I have to pay, I won't pay as much as they pay here and which my poor relatives can afford.</p> <p>I: Hmm, so it sounds like there's a few worries there, including a worry that you won't be looked after by your family [B: Yes] so you may have to go to a nursing home, but how will you pay for that so there's a money worry as well [B: Yes] and also [how will you...</p> <p>B: I, I know] I will be looked after by my family, but my family is poor, that's the problem, if I had money, my family could be happy to look after me because they will be comfortable to feed me from my money.</p> <p>I: Ok so the hardship is that they money isn't there to [look after you].</p> <p>B: [yes, to look after me].</p> <p>I: Have you done anything to help think about the future?</p>	<p><i>Desire to Have a house in the future and be looked after. Financially give children money to prepare for funeral</i></p> <p><i>Worries about discrimination, by children in the UK- feels they don't want to look after her like they would have in Africa- their duty. Disappointed, says in Africa they would look after that's why she had children. Didn't fulfil their part in her expectations. – in the UK, they put you in home- abandon/reject- growing older awful in UK. Needs not met- cultural difference- HIV made her come to UK, impacted all aspects of life. Intolerable to think about it&gt; can't think about cultural values that could be so different.</i></p> <p><i>Doesn't want to go to home- only if desperate</i></p> <p><i>If don't have family go to home</i></p>
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<p><b>The 'normal' self</b></p>	<p>B: Sighs...it's quite hard, as I was in health I had already started preparing my future [I: Hmm]. Now, that preparation was cut short because of my health of which...I didn't reach the goal that I had planned to reach, it was cut short by my sickness [I: Hmm]. Now, the only future that I have now is my children, the ones I have had and they are the only people who care for me and look after me, that's the only preparation I have done.</p>	<p><i>Will miss love of family—people don't understand you-worries about home</i></p> <p><i>Think she's no loved by children if put in home- other people in Africa will gossip/shame</i></p>
<p><b>The physical impact of ageing</b></p>	<p>I: OK, is it OK to ask what your goal was?</p> <p>B: I wanted to be comfortable, hmm.</p> <p>I: What would that have looked like, what would being comfortable look like?</p>	<p><i>Difference between having HIV in UK and Africa</i></p>
<p><b>The 'normal' self</b></p>	<p>B: I don't become a beggar...I don't...have umm, poor, I didn't want to be poor and I was working always, very hard for the future so that I could retire and rest comfortably.</p> <p>I: Hmm, so working hard to get money to secure [B: Yes] your future and that sounds hard at the moment. Do you ever worry about ... umm kind of, I suppose your mental health or your mood?</p> <p>B: Yes, I become a bit worried because of the dementia in my report, I don't know how far it will take me [I: Hmm] because I really forget and it might be dangerous for me ... because sometime, for sometime back I had left</p>	<p><i>Wants to be back home but fears rejection, stigma, lack of finances, meds uncertainty about UK and Africa- weighing up which is better? Worries people will not look after her- change in Africa in relation to HIV?</i></p> <p><i>People have wrong thoughts about you.</i></p>

<p><b>The physical impact of ageing</b></p> <p>??</p> <p><b>The rejected self</b></p> <p><b>The loss of expectations</b></p> <p><b>Avoiding a home</b></p>	<p>the gas stove leaking, I couldn't smell it, then I just had people coming to my door, knocking so loud! Because they had reported that there is some gas going on here, so... next time if I am not able, or they are not able to dictate what is going wrong in my place I might die in there.</p> <p>I: So there's a worry about that as well.</p> <p>B: Yes, I've got a worry about that.</p> <p>I: Yes, ... do you think society of people do you think they, they respond differently when you're older with HIV?</p> <p>B: No, because we don't broadcast that we are sick, so people who look at you with the medication that you are taking they don't notice anything, they know you are just an old woman and they are always ready to help you. Once you fall down, you will see the group that comes running for you, so... I don't think there's any problem growing old with HIV if you are among people who look at you as an old woman, not as an HIV sufferer.</p> <p>I: So is it easier to be older [than have HIV?</p> <p>B: Yes, yes it is yes.]</p> <p>I: So when you do have worries about the future, how do you get through them? [How do you cope?</p>	<p><i>Restricted narratives in culture not being acceptable because of HIV, talking about two different cultures.</i></p>
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<p><b>Avoiding a home</b></p>          <p><b>The shame of growing older without family support</b></p>	<p>B: Umm, I get my strength] from friends, as well as from my daughter.</p> <p>I: and what is it that they do, how do they give you the strength?</p> <p>B: Like my daughter helps me when I'm sick, she's there for me, physically and when I'm in need she helps me, maybe clothes and taking me for a holiday and all that yeh. [I: Ok so practical help?] Yeh they are helping me and friends, very much from church and also fellow long illness sufferers.</p> <p>I: When you look at your friends who are the same age as you how does that make you feel...?</p> <p>B: More hopeful.</p> <p>I: Hmm, in what way? What...</p> <p>B: Umm, you know before anyone suffering from HIV was thought to be somebody who sleeps with people, now an old person like me having HIV there was that shame to know that they was thinking that I was doing this and that, now when you find that there is also a group of you women, it leaves your thoughts, you say 'ah, what about my friend, what about my friends?' and I think it is just something that comes to everybody.</p>	
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	<p>I: Hmm, so there's a coming together because there's a group of you who share the illness that makes you feel...</p> <p>B: Easy, it's not something that I should be worried about yeh of course, 'here's my friend who is older than me' it doesn't mean that I am a bad person. No! you look at somebody as just a Christian lady, [section inaudible] it's just something that comes from different ways, it's not something that you pick and eat, that you have seen this thing is dangerous, it is something invisible, we don't even know.</p> <p>I: So it sounds like you're saying you look at the person, but not the illness.</p> <p>B: No.</p> <p>I: Do you think umm, you know when you were diagnosed when you were 49, and if you compare it to now are there somethings that are harder about living with HIV that are harder now?</p> <p>B: Living with HIV now is very easy and umm, not something you are worrying about all the time than before, before we used to worry a lot and we used to have a lot of problems like diarrhoea, coughing, TB and all that for now, I don't think a lot of people suffer from them and before there was no medication, that was helping so like now medication is helping,</p>	
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	<p>there is advanced knowledge from doctors who know how to treat it, if anything goes wrong with you so it is easier living with HIV now.</p> <p>I: So living with it is easier?</p> <p>B: Yes, it's easier to live with but it's just the growing older, your strength drains out, it's just the strength that goes out.</p> <p>I: You know how you said the strength goes out, do you think the HIV makes that worse, so if you didn't have HIV would you have more strength now?</p> <p>B: I don't think so, I would have been the same because if I didn't have this medication, this good medication it's the same as if I am just healthy without my long illness because I don't have diarrhoea, I don't vomit, I just live with it like that.</p> <p>I: Hmm, so the change of medication...</p> <p>B: Yeh, has improved the whole thing, thoughts wise and health wise.</p> <p>I: So for you even if you didn't have the illness, [you would still be the same now.</p> <p>B: I would have been, yes.]</p>	
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	<p>I: SO it sounds like the illness doesn't really impact how you grow old?</p> <p>B: No, no, because even at the age of 49 I wasn't as strong as I was when I was 22.</p> <p>I: Hmm, so it's natural?</p> <p>B: It's a natural thing, hmm.</p> <p>I: So finally, what kind of things do you think can help you in the future? What can services, people around you or you do?</p> <p>B: Umm...I have a house, where I can stay whoever is looking after me can stay and look after me, that is what I have prepared already, yeh then I know my children are better off to provide my coffin and live in until I die.</p> <p>I: Ok, I just wanted to come back to something you mentioned earlier which was your worries about going into a nursing home and you said it was about the costs involved...</p> <p>B: Yes, if I was here, but if I was back in my country there are no homes because if my children take me to a home here, they will discriminate me. [I: The home will discriminate?]. No my children are discriminate me,</p>	
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	<p>they don't want to look after me. They are supposed to look after me in my old age, that's why you have children in Africa, whereas it is different for me here, to grow old your children will put you in a home! And they will visit you maybe once a week or once a month but in Africa it is their duty to be on my bedside when I am dying, to be there when I need food, to be there whenever I am in need of anything.</p> <p>I: Hmm, and how would you feel if you went into a nursing home?</p> <p>B: I wouldn't even think of going into a home.</p> <p>I: It's not an option for you?</p> <p>B: No. People are not comfortable in a home, it is only if you are really desperate.</p> <p>I: What would make them desperate?</p> <p>B: You don't have no family, that's when the government comes in.</p> <p>I: Is there anything else about living in a home that feels uncomfortable?</p> <p>B: Your family will understand you, but maybe not others. It's not in our culture, to go into a home and be looked after people you don't know. You miss the love of your family.</p>	
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	<p>I: So is there a shame in it?</p> <p>B: No not really, but in my country you think you are not loved by your children if they take you in a home.</p> <p>I: Yeh, that makes sense. Thank you so much for sharing was there anything else you wanted to add about your experiences that you think I might have missed or you feel is important?</p> <p>B: Umm .... It's the only culture I could talk about and this interview we are having in a country which has got a different culture from mine so it is difficult for me to fit in culture about having HIV in Africa and about having HIV here.</p> <p>I: So there's a difference between the two?</p> <p>B: Yes, yes, yeh.</p> <p>I: and from what you were saying it sounded like there's a real, there's a, almost wish that you were back home?</p> <p>B: Yeh, there's a wish that I was back home but at the same time there's fear.</p> <p>I: Can I ask what the fear is?</p>	
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	<p>B: The fear is that people might not look at you, they don't have the education that we have here, yeh so they might be like the old ages like what HIV was years ago.</p> <p>I: So it sounds tricky because back in Zambia you've got your family and they're gonna look after you but [then other people</p> <p>B: They have got wrong] thoughts about you.</p>	
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### **Appendix 14: Initial codes from the seven transcripts**

**Yvonne:** Initial Themes generated from analysis of transcript

Deteriorating health	The former hard working self
Forgetfulness	The regressing self
Avoiding emotional distress	Self-talk
Resisting illness	The uncertainty and distress of looking into the future
Protecting the public self-identity	Ageing self and visible frailty
Bearing witness to emotional distress through physical pain	Wanting to be self-reliant
Belonging to a group of suffers	The fragility of the ageing body
Externalising the illness	Waiting for illness
Comparison to less fortunate	Externalising illness
Family values about illness	The distinction between HIV and ageing
Acceptance	Finding a sense of belonging with others
Carrying a burden	Others as suspecting
Living by faith in the face of uncertainty	The self as a criminal
Resisting negative discourses about migrants	The contaminated self
Normalising HIV- just an illness	Wanting a sense of belonging with others
Being something other than HIV	Resisting stigma/protecting womanhood through denial
Keeping distracted	Protecting the self from rejection
The importance of help seeking	Preparing for death
Avoiding emotional distress	The hidden stories of emotional pain
A period of questioning following diagnosis	The fairy-tale of wanting to live forever
The importance of connecting with others	Avoiding emotional distress
The stigmatised self	
Resisting stigma through faith	
Holding onto the former self	
Keeping things hidden	
HIV and a death narrative	
HIV as a promiscuous illness	
Protecting one's womanhood	
Submitting to husband	
Gender differences in sexuality	
The emphasis on being normal	
Being happy	
Resisting shame/stigma	
The work of appearing visibly normal	
The dependent self	
Worry/rumination about future/uncertainty	
Looking after the body in the face of uncertainty	
Responsibility as a mother/worry	
Questioning – uncertainty/death	
Witnessing the struggles of ageing friends	
Facing the reality of ageing	

**Julianna:** Initial Themes generated from analysis of transcript

Viewing the self as a 'carrier'  
Guilt/shame of being a 'carrier'  
Constant worry  
Being seen as a different person  
The self as disease spreading-self blame  
Low mood following diagnosis  
The strain of diagnosis  
The fear of accessing support  
Fears about coming out  
Facing isolation in the UK  
Relational losses due to disclosure  
The importance of being connected  
Having to bear witness to HIV  
Support in the form of professionals  
Resisting loneliness  
Focus on getting better  
Searching for normality  
Protecting the public identity-keeping it hidden;  
Minimizing the impact to feel normal  
Protecting the self by normalising;  
Normalising 'like cancer'  
Holding multiple identities  
Protecting one's womanhood  
Resisting being seen as a bad person  
Staying one step ahead of HIV  
Becoming weak  
Feeling old  
Ageing associated with weakness  
The ageing body  
Hope in the form of ageing friends  
Planning for a future  
Working towards normality  
preventing weakness  
Uncertainty about illness progression  
Unpredictability of illness  
Avoiding emotional distress  
Focus on being happy-avoidance  
Thinking positive  
The work of staying positive  
Family work values-work hard

**Maureen:** Initial Themes generated from analysis of transcript

Feeling grateful for the UK  
Resisting migrant stigma  
Becoming part of the healthcare system  
The different between UK and Uganda  
Family as deceiving  
HIV as a complication/burden  
Facing Complications-physical  
The sick self  
Searching for an explanation  
HIV as maddening  
HIV as a 'problem'  
Emphasising emotional impact of HIV  
Resigning to death  
Denying diagnosis  
The certainty of death prior to medication  
Keeping quiet  
Others as suspecting  
Being on trial  
Keeping quiet or dying alone  
Living with a secret  
The contaminated self  
Facing rejection  
Avoiding isolation/emotions  
The house as an 'enemy'  
Avoiding the home/Isolation  
Staying connected  
Relational needs  
Isolation and no companionship  
Ageing and the weakening body  
Mobility limitations  
Facing financial struggle  
Medication and pain  
The work of taking meds  
Physical pain as overwhelming  
Avoiding a home  
Loss of cultural expectations of caregiving  
in the family  
Making plans for a future back home  
The uncertainty about the future  
A home for HIV sufferers  
Planning a burial  
Living in a home vs dying  
Wanting to be reunited with a former self in  
death  
A plan to die back home

**Brenda:** Initial Themes generated from analysis of transcript

Ageing with uncertainty  
The loss of expectations  
The dependent self  
An uncertain future  
Preparing for a home  
Facing financial uncertainty  
Loss of goals/aspirations  
The questioning self  
Living with uncertainty  
The physical impact of ageing  
HIV as a 'long illness'  
The rejected self  
Being feared  
HIV as a visible condition  
Receiving 'silent' support  
Talking about the unspoken  
Resisting shame as a woman  
Men as decision makers  
The multiply stigmatised self  
Resisting ageing  
The shame of growing older without family support  
The psychological impact of loneliness  
The abandoned self  
The lonely self  
Shame  
The gendered nature of HIV  
The importance of staying connected  
Resisting rejection  
Wanting belonging and acceptance  
An invisible illness  
The 'normal' self  
Medication as a life line  
The accepting self  
Living with loss  
Diagnosis and a lost life  
Worry/rumination  
Avoiding a home

**Andella:** Initial Themes generated from analysis of transcript

The sick self  
My HIV  
Low mood  
Being thankful to God  
Facing isolation  
The sick self  
Financial & emotional burden of being sick  
A loss of control  
Distracting the mind  
Working the self into sickness  
The emotional strain of working hard  
Failing to acknowledge the weakening body  
The importance of having a plan  
Ageing as a physical process  
HIV is an ageing condition  
Worries about ageing with the condition  
Wanting belonging & acceptance  
Sadness & loneliness  
Facing stigma from health professionals  
No sense of belonging/lost identity  
The multiply rejected self  
The psychological burden of rejection  
A humiliated community  
The criminal self (not innocent/here for meds)  
Being stripped of dignity  
Facing 'back lash' from the community  
Relational losses  
Losing hope in others  
Regret over disclosure  
Being stripped of dignity  
Facing 'back lash' from the community  
Relational losses  
Losing hope in others  
Regret over disclosure  
feeling threatened  
Loss of dreams  
Facing a life of isolation or poverty  
HIV as a woman's 'problem'  
Wanting acceptance & belonging  
Being anonymous  
Sickness & isolation  
Emotionally draining  
Distracting the mind  
Wanting time away from the condition  
Wanting acceptance & belonging  
Keeping busy  
The impact of ageing as a woman on intimacy & relationships  
Avoiding isolation  
Wanting a saviour/rescuing  
The disabled self

**Esther:** Initial Themes generated from analysis of transcript

Uncertainty-immigration?

Being restricted

A past life

Loss of functioning following stroke

Psychological burden associated with uncertainty

Helplessness over a long term problem

The house is not a home

Avoiding isolation

A commitment to staying connected with others

Finding a sense of belonging with others

Connecting with others

Externalising the illness

Constant worry/rumination

Trying to make sense of rejection

Trying to make sense of the unspoken

Having decisions taken away?

Deconstructing HIV

Looking normal on the outside

Being seen as infectious

The sick self

Wanting acceptance and belonging

Finding support with others

Facing rejection from family members

HIV makes you a bad person

'HIV drives people away'

Gender differences & HIV

The psychological impact of isolation

The universality of loneliness

The practical reality of loneliness

The struggle to be resilient when faced with uncertainty

Wanting peace of mind

Facing multiples worries

Helplessness

Psychological burden associated with uncertainty

Sharing stories of rejection

A life consumed by medication

Grief over a life consumed by illness/medication

Facing multiple losses

Facing multiple health difficulties

Feeling like a convict in the UK

Being imprisoned in the UK

Relying on others for legal purposes

Not being seen as a human being

Protecting the self from shame

Feeling grateful

Facing racial disparities in treatment

Connecting with others

Psychological burden associated with uncertainty

Resisting being old

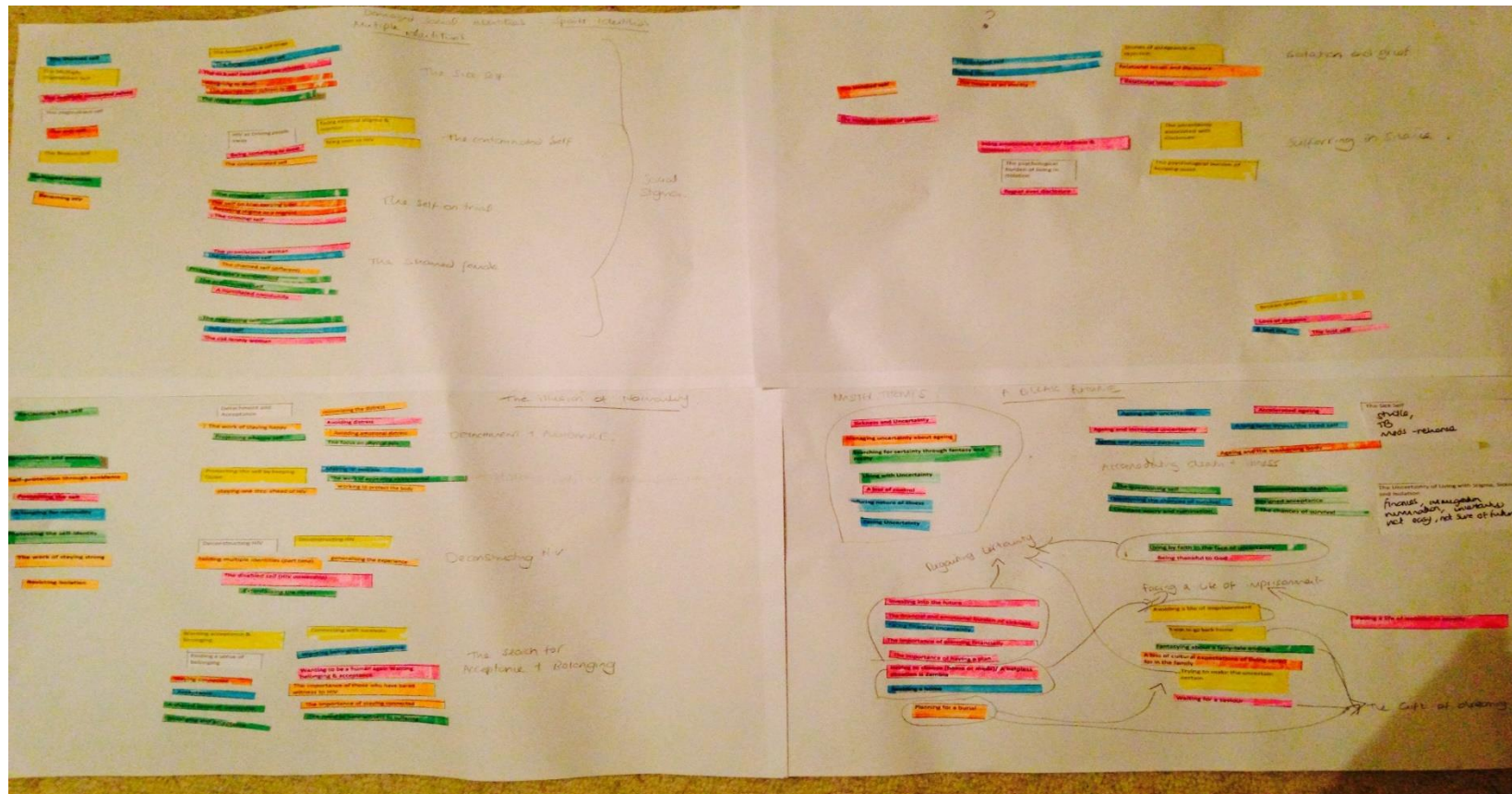
The struggle to be resilient when faced with uncertainty

### **Mercy: Initial themes generated from analysis of transcript**

Almost broken by diagnosis  
Facing death & hopelessness  
HIV as a sickness  
Protecting the self from shame/blame  
Wanting to die  
The broken self-image  
Finding hope in medication  
Finding hope with survivors  
Mending self-image through connections with survivors  
Medication as a life line  
Facing external stigma & rejection  
Being labelled as HIV  
Stigma and uncertainty about the future  
The broken body  
Self-avoidance/fear of HIV  
Resisting being labelled  
Fears about stigma & rejection  
Others-avoidance/fear of HIV  
Being seen as a carrier of disease  
Being seen as untrustworthy  
Losses associated with disclosure  
Stories of acceptance vs rejection  
Disclosure and uncertainty  
The impact of rejection  
Disclosure, uncertainty & distress  
Keeping quiet to avoid rejection  
Being something other than HIV  
Anger, Low mood  
Worries that things will not be kept quiet for long  
Disclosure, uncertainty & avoidance  
Withdrawal & low mood  
The psychological burden of keeping things hidden  
Avoiding rejection  
Loss of aspirations  
Sadness at losses  
Trying to make the uncertain certain  
Urgency and time pressure  
A culture of caregiving in the Family  
Avoiding a life of imprisonment  
Prayer as a way of tolerating distress  
The fear of being exposed  
Stigma towards others with HIV from within the family  
The guilt of keeping secrets  
Grateful for early treatment  
Facing multiple layers of discrimination  
Discrimination as distressing  
Feeling unsupported  
Fighting for support  
Keeping quiet to avoid rejection  
The burden associated with disclosure



### Appendix 15: The analysis phase, bringing themes together across participants



**Appendix 16: Table A4, Master themes, sub-themes and representatives quotes across participants**

Master theme	Sub theme	Participant	Quote
<b>Spoilt Identities</b>	<b>The contaminated self</b>	<b>Yvonne</b>	We are not liars who will bite anyone, you know, of course there are some who still have the bad mentality of 'why did I get it? I have got to spread it'. Yeah, because some think that by touching you or by washing in the same bath with you they will get it. They have little understanding of the situation.
		<b>Juliana</b>	I used to help in school, one example, yeah and now that I know I have HIV I just, you feel oh 'what's going to happen'. If you are playing with the kid and they touch, you touch that kid and then things like that, yeah it's not normal Yeah I stopped playing xxxxx because I thought there is that as I say, there's that in me, 'oh what's going to happen' (laughs) yeah, mixing up with other people, cos it's a physical contact, yeah so things like that yeah. ...I would like to first aid but I couldn't do first aid because like if you're giving mouth to mouth, umm things like that yeah so there are things really that, that hinder you from doing certain things."
		<b>Brenda</b>	By then HIV was something which people were trying to avoid you, once you are diagnosed and er, by then I was running a business which people didn't even want me to touch the meat that I was selling in the butcher and er... a lot of fear that somebody would catch HIV from me, from the cups, from whatever, even if I sit on the toilet and all that." When you have HIV you start becoming thin, now people started noticing, so this is what happens and then they start deserting you, that you are sick." They try to keep away from me because they've still got the same mentality that it is dangerous so they'll catch it if I go near them. Yes, they don't have that education about it.
		<b>Maureen</b>	At the time, I didn't tell them that I've got HIV but I went to their place, it's my brother, my stepbrother in XXXXX and they started saying that they don't want me to use their toilets! They think if I use their toilet I'm hurting them.
		<b>Andella</b>	So even in the hospital I'm going there, the gynaecologist will say 'do you have any other conditions?' so I had to say it because, I said well 'I've been living with HIV', he said 'Oh!' and these are professional doctors who are but they are not friendly with, with er the thing you know." Yes, being in a community who is black, even when you go to things like flu jab, people will not sit with you, if you cough a little bit"
		<b>Esther</b>	I have, have my sisters and brothers, here and my nephews and nieces but you know [pause] they don't

			<p>want to use the cup that you use so I tend not to go there, yeah.”</p> <p>Yeah, what my sister did to me, you know I never expected her to treat me that way, yeah, you know so...I do and visit but it's just in me, you know?</p> <p>The nurses said 'you're infectious' and they said 'you can't sit there' like I'm sitting with you, so she would be sitting like you see outside in the garden that chair, she'd be sitting there and you'd have to shout. You know, now that I have HIV and all these other illnesses [pause] umm, if I didn't have HIV maybe people would be closer to me but now it's like they're driven away, you know?</p>
		<b>Mercy</b>	<p>Yeah when we are on training they say 'when you are working put on your gloves, don't transfer disease to someone else' but it's not um transferrable any way...”</p> <p>...if they know someone is HIV even at work they wouldn't trust you that you look after yourself better and you wouldn't transfer it to a client.</p> <p>There are some nurses who doesn't know. who just go and take our blood and others who look uncomfortable and don't know anything about the condition.</p> <p>Because all of a sudden everybody's just so afraid...but I don't think it's contagious because you put gloves on everything...</p>
	<b>The shamed woman</b>	<b>Yvonne</b>	<p>They would deny them! They would deny them, mmm or they would live with them and they treat you like you have been mischievous in your life, they don't understand that you can be a good person and you got it from someone who is not good. “</p>
		<b>Juliana</b>	<p>Quotes used in results section</p>
		<b>Brenda</b>	<p>So everybody knew, because my husband died of HIV, so, and he had another woman, another wife, second wife, who also passed away, the same problem, so I was, I am the only one living.</p> <p>It doesn't mean that I am a bad person. No! you look at somebody as just a Christian lady, it's just something that comes from different ways, it's not something that you pick and eat, that you have seen this thing is dangerous, it is something invisible, we don't even know. “</p>
		<b>Andella</b>	<p>Yes, being in a community who is black, even when you go to things like flu jab, people will not sit with you, if you cough a little bit</p> <p>I don't know how to tell to them that, 'how do you know it's wrong'? I've had so much many injections and blood transfusions for malaria. When you are anaemic I may have come with it out of that but you can't express yourself.</p>
		<b>Esther</b>	<p>In the support groups you hear people telling their stories, what happened to them and with their relatives. They are treated so badly, yeah. You know even if I want to have a relationship it is not easy. You know like one time I met somebody and I told him, because people see you and they won't know but you know I thought I'd open up and tell him and he ran away! He was out of that door! [laughs] so it's not easy.”</p>

	<b>The self on trial</b>	<b>Yvonne</b>	...some people they say 'ah! If my people see me going to the hospital they will know what I am going for'" Such an illness they just google your tablets and they start behaving different. Like this lady who had stroke and is one of us, they started being funny and when she told me I said 'do you know what I am suspecting something went on, it's either the agency told them about you"
		<b>Maureen</b>	For us in Uganda you get sick you don't go to the doctor cos you don't have Say no, no here it's ok. Ok if they're going to pay it's ok. And then he told me you can even go and get some money and buy some good clothes to put on so where I would get it. Go and ask they will tell you. They gave you money free of charge. Say what they will give you... I couldn't understand how you get free money like that. I kept quiet, but my brother who is following me say 'no, no, no something's wrong'. He was trying to tell stories. I said it was just nothing.
		<b>Andella</b>	Maybe I met the wrong person thinking he'd look after me and we'd stay in Britain and marry, now I'm sick because they didn't test me and that was my issue even back home, to tell who, because when I left home I was a dignified person, now I'm er, they think I am careless. I don't have anybody here, they live abroad. I came here when I lost my daughter who was strangled and the boys who done it were saying 'you may just be locked up but I will make sure you know us better' so I came like a running refugee or asylum. Our culture, we live in a wider family so when you see someone sneering and being curious to say, 'what is she doing in Britain?' Last time we went she went to the hospital. What is she suffering from? You know and the world knows what is going on so..."
		<b>Esther</b>	Used quotes in results
		<b>Mercy</b>	Used quotes in results
	<b>The threatened body</b>	<b>Yvonne</b>	Mmm, I would say from the shoulders going down. Mmm, my eyesight is becoming a problem, I can see from far away but not close and also a tooth problem (ageing) Yes, because I have seen so many people get worse, I have seen so many people, like my friend who wanted to do your interview, just because she is getting old, she's now over sixty, I can see how much she is struggling now and [pause] I don't know whether it is because of getting old or overworked, but I also overworked before I was diagnosed. ...if not for the arthritis I would be going to other countries and open my shop and selling, but because of the mobility... the eyesight of course is age, yeah, age plus the medication and how it affects the body also you know. So it's a bit, umm, hard to separate, when you get old.
		<b>Juliana</b>	Yeah that's, the body wears out (laughs) with it having taken medication every, I don't think my body will still be the same as it was when I was healthy.

			<p>I think my low point was because I was ill and because I was admitted... It was my lungs, my lungs were weak. Then I had pneumonia then yeah I was ok, yeah that sets you back doesn't it yeah, But then it came back, I was ok, then it goes back again yeah</p> <p>I think some things you forget as you get old (laughs), as you grow older you forget things easily don't you? So that might be the problem that weakness as well.</p> <p>Yeah because like recently I've made an appointment to see eye specialist to see, to go back and see if you worry or what about my ears or my eyes, things like that. Other things, yeah and um HIV makes you aware to check for that, check for that, check for that yeah, yeah.</p> <p>I think definitely put a big impact on someone yeah especially if you're weak, some of them might um as you say the physical impact, they might not be able to do their hair, they might not be able to commute where they used to go shopping, where they, that puts...</p>
		<b>Brenda</b>	<p>Yes, I've got a lot of aches in my body... I've got a hip replacement which still bothers me.... And sometimes the legs start paining from nowhere. Right now I've got a pain in my shoulders, so painful, just been taking painkiller, aches all over the body.</p> <p>Yeh, I'm starting to have lots of memory problems... Umm, it's almost five years now. I can't remember, even if I have read a story, I can't retain it again... My doctor is saying that I am having dementia. HIV dementia.</p>
		<b>Maureen</b>	<p>Knees, knees are still.....killing me. Yeah they hurt too much. It's hard to walk yeah. When it's cold it becomes too much...because of age, bones they shrink</p> <p>When the doctor told me 'your CD doesn't go up', I said 'what can I do now'? So now I ask him, I'm taking some medication so when I wake up in the morning my eyes are red.</p>
		<b>Andella</b>	<p>...my bones are aching, my tummy, my lower belly's in pain, there's query anything for my uterus, they said it has enlarged by six inch so those are my health conditions apart from my HIV which I was diagnosed in 2004.</p> <p>I have memory loss and sight, I can't read, I er, I have to read distance reading, I put on glasses. So both the mind was working and the HIV was also doing its banking in me, I was frequently taking medication in time I think I was working too hard then, I should have done as a person with the condition of my situation,</p> <p>So my, mentally and emotionally, I am ok but if the physical body says we are drawing you into your real age, then that's where the issue is</p>
		<b>Esther</b>	<p>Umm...that...since er...when did they write to me? Cos I went for a bone density test before and then er, I think last, last year? That's when they said I had osteoporosis and osteoarthritis and I also have a back problem.</p>

			<p>I had a mild stroke in March this year and I was in hospital for one week, three days. Yeh... sighs, you know it's the things we take for granted, I couldn't brush my teeth! I kept missing it, I couldn't write, you know, even know I, my writing hasn't come back. It affected my right side, so at times when I'm walking it's not the same and I tend to use my left hand instead when I'm doing housework.</p> <p>You know what, I told myself err, because I used to cough a lot, I used to just cough, cough, cough and when I was back home I went to the hospital and they did x-rays, I think I went about five times, nothing!</p>
		<b>Mercy</b>	<p>Yeah because I've got, what do they call it, low blood, blood immune what, system is weak because of HIV, that's why I've got this and that, they said that.</p>
<b>A present without light and a future without hope</b>	<b>Suffering in silence</b>	<b>Yvonne</b>	<p>I am one of the luckiest people with this illness because I think the acceptance which I had about it has helped me</p>
		<b>Juliana</b>	<p>You wouldn't go on the streets in let's say for example where I live, and then you say 'oh I'm HIV positive' or things like that!</p> <p>I don't think, maybe I don't think about it (laughs), yeah. It's easier not to think about it, if you put it in your head every day, you wouldn't, I wouldn't live, yeah, especially when you have family yeah.</p> <p>It's, the impact like on children, like on friends, how are they going to look at you or, if people are not educated about it they have a negative feeling towards it yeah but some are more educated about it, I think they are ok yeah.... think it's the education behind it, they don't know, they think you're a different person yeah.</p> <p>People say be open to them but they didn't understand it yeah. Some people might take it in and others might not yeah.</p>
		<b>Esther</b>	<p>Sighs, it is, it is very stressful, you know you can't do anything, yeah and I'm not getting any younger [laughs/sighs], you just keep it quiet and keep going, just try not to tell anyone.</p>
		<b>Mercy</b>	<p>Um I don't know because some people say that when they told their family, they were very supportive. There are many stories. Some told their families, they were very supportive to them, others, like I know a lady who I go together to the group with X but um her children don't want her to pick up her granddaughter. She's not allowed even to touch her grandchildren so I don't know</p> <p>I'd rather keep quiet.... because I'm asthmatic, I was, I grew up with asthma and then I was anaemic all my life and that's when I think I had this so I think I would tell her (sister) it's related to my anaemia or my asthma.</p> <p>I get cross very quickly, I get low yes... I think it is the condition because um at times I'm thinking that if people, there will be a stage when they will know my condition, how are they going to take it and that really affects me.</p> <p>Yes, yes, because I'm, again I don't know because some people say it's better for you to disclose, it maybe,</p>

			maybe they will be supportive but I'm afraid if they're not supportive, what next? It will affect me a lot.
	<b>Loneliness and longing</b>	<b>Juliana</b>	<p>...this lady was telling me some time, umm two months ago that she was not well and she is 58 and she is on her own, I mean 60 something. If you are on your own, who does the shopping for you, who does the cooking for you yeah, it's hard yeah.</p> <p>The good thing because I have a big family it's not, yeah it's not er, it's not happening to me but you can imagine someone who did, was alone, waking up alone yeah.... How hard it would be and, cos when you have people around you I think you're not thinking about what you have yeah, the other person might wake up and she's just alone yeah.</p> <p>Men try to refrain from women who are sick and that's why they are lonely. Yeah, unless those who understand it, they don't mind whether you have HIV as long as your health, you are on your medication, there are a lot of men who are negative but they do go for positive women, yeah so.</p>
		<b>Brenda</b>	<p>There's a change as I'm growing older, than before, almost every time, because most of the time I'm alone. No, it has changed in a bad way because I'm not supposed to be here, I'm here because I'm having some better medication and if I was home I would've been dead by now, but it has separated me from part of my family.</p> <p>My family] yes but er, you know when you have HIV you start becoming thin, now people started noticing, so this is what happens and then they start deserting you, that you are sick.</p> <p>Yes, back in Zambia there is more looking after, but here it's worse here because you are always alone, if you don't go to socialise you are always alone. Yeh, it's too] much and you are old, you can't have a boyfriend and if they know you are sick they can't come for you.</p> <p>Yes, and sometimes it's worse with the old ones because ... you are already old. They won't, they won't need children from you and most of the old ones, many die much, much, much quicker with HIV than women like me, I'm still living but my husband died twenty-one years ago.</p>
	<b>Maureen</b>	<p>Um in Africa it's not all difficult, you can get someone to look after you, so many relatives around, it's not like here but you know kids, my kids are here, they've come to western lives, they don't mind, they don't mind about me, they're on their own, they're paying off their bills, their work.</p> <p>Back home, when you say you try to help out and we will come, can I do this for you, can I come, you need, you help them, but here children they don't mind about you... It's not their business. You're old, But you know when you are older and you've got HIV, ohhh, it's terrible. You can't get a relationship, umm, I would like to have a you know a person just to care for each other, you know someone who can come and give you a cup of tea, drink for you, go out with you, that is enough.</p>	
	<b>Andella</b>	<p>I'm very lonely, er I'm very, very lonely because they're other elderly lady who is Zambian, she has decided to go back home...</p>	

			<p>Yes! That's what I'm saying, who will pick me if I fall down?... there has been some time I was looking for a single room to stay in to live, this house third floor, fourth floor and just to go and to live with families who just give me a room, but they want to know. I receive boxes of a lot of medication so privacy... you know it is hard, hard, so hard.</p> <p>Yeah the family's not here, even in elderly accommodation you must have people visiting you but for me, I have friends from church who visit me, they don't know my health condition. I have other people from charities we go for HIV, they also have their own conditions so they are not coming to lift you up, maybe they will even bring an issue which even puts you down. They are expecting you to help them so yeah...</p> <p>It's loneliness, how do I stay in a cold house like this and just look at the sun shining outside and it's cold inside and I have to run the heater, it's electrical, I don't have heating system which means I'm running more costs on me so the best is...</p> <p>First of all the people who might want to associate their age and time with you, they're not positive. Also people, those who are positive they have their own issues as well.</p>
		<b>Esther</b>	<p>You start thinking a lot! You start thinking you are alone and you just start thinking you know, so I tend not to stay in the house. Yeh, I go out, I go to support groups.</p> <p>I don't know...maybe. You know now that I have HIV and all these other illnesses [pause] umm, if I didn't have HIV maybe people would be closer to me but now it's like they're driven away, you know? you get lonely, you know it's not easy, you get lonely you know, if you are sick there is no one to help you, you need somebody to be there for you, you know but when you don't it's not easy.</p> <p>you know even if you didn't have this condition, I'm sure people do you know get lonely, you know when you are alone because one day when you are sick there is no one to help you, yeah and people die alone in their house, you know and it's sad, yeah.</p>
		<b>Mercy</b>	<p>It's really worrying, you know because when you live alone [pause] like when I got this stroke I, I live alone, the first thing that came to my mind was call the GP, so I called the GP and the woman told me, the receptionist said 'oh there's nothing we can do for you it's fully booked'</p>
	<b>Lost Dreams</b>	<b>Brenda</b>	<p>So it has really bought me to the UK, but I have problems in securing my remain here, every time you go to the home office to report, so all this affects me.</p> <p>I've lost] my family, I've lost whatever I was doing before.</p> <p>I wanted to be comfortable, hmm. I don't become a beggar</p> <p>...I don't...have umm, poor, I didn't want to be poor and I was working always, very hard for the future so that I could retire and rest comfortably.</p>
		<b>Maureen</b>	<p>I know it's very difficult to get a job when you're old... They think you're too slow, you can't be quick.</p>
		<b>Andella</b>	<p>So this is why I'm saying it's embarrassing to tell them. I thought I was going to find some Mr Right here and</p>



			<p>settlement and then I ended up in this road block In health you can't do any work if you are talking of legs and hip, how do you lift up and roll the patient? You need to have your physical body and the lower body supports all the weight that you do.</p>
		<b>Mercy</b>	<p>Before I when was there (Zimbabwe) I wanted to start nursing but when I was diagnosed I didn't know that um if I go through nursing and they screen everything they would take me for those courses I don't know so all my ambitions, they were gone so Because what I was thinking that I would be someone or something because I was diagnosed in 2010, five years now so 2010 November, so um I would have finished my nursing by now and I wanted to go to America when I've got my degree in nursing and travel and do things but now I don't think ??</p>
	<b>Facing a life of imprisonment</b>	<b>Brenda</b>	<p>Here it is quite different, you have to prepare yourself to go in a home, but 'how do I go in a home? I don't even have an account here! No my children are discriminate me, they don't want to look after me. They are supposed to look after me in my old age, that's why you have children in Africa, whereas it is different for me here, to grow old your children will put you in a home! And they will visit you maybe once a week or once a month but in Africa it is their duty to be on my bedside when I am dying, to be there when I need food, to be there whenever I am in need of anything.</p>
		<b>Maureen</b>	<p>...I think how will I go to the home I don't know. One time when I went to hospital I met one man from my country. I was asking him 'do you think you are going to be old in this place'? He say 'yes I have to'. 'What in a home?' 'He says yes what can we do?' I say 'oh that's my worry, I don't want to go to a home, I want to go back in Africa'. And this would be a home for those with HIV only but if you mix the homes people will neglect you.... With HIV. HIV's a problem.</p>
		<b>Andella</b>	<p>When you come back in your house you are lonely, you are sad, it is very sad, and if you are in a nursing home, a general nursing home, it is even worse! Oh! I don't know! I don't know how they will treat me.</p>
		<b>Mercy</b>	<p>Quote used in write up.</p>
<b>Escaping the labyrinth of distress and uncertainty</b>	<b>The oasis of normality</b>	<b>Yvonne</b>	<p>I am so active that if I tell people that I am this way they don't understand it because of the way I help others and the way I am active, you know? I told myself 'I won't be let down by being ill', you know so that makes people wonder how am I managing when I give some complaints about my health. ...just say it is an illness, it's just an illness In Africa there is no house where it didn't touch, every family there is one or two! So it can happen to anyone you know?. ...the kids say 'no mummy you are ill' and I say 'I am not ill, I have got a condition which is monitored by the doctors, I will do what I can to survive'.</p>
		<b>Juliana</b>	<p>I think it's like any other illness now, you just worried. I was reading it's, it's actually people living more</p>

			<p>longer with HIV than cancer so it's the same thing. You're thinking oh even the person with cancer is thinking about their family, if you want to achieve more, you want to, will I achieve other things, things like that</p> <p>That is just to be happy, be happy with friends, helping friends, things like that yeah, looking after my family because family's the worst nightmare when you're thinking about that, would I still be there but I think everybody does that whether you're ill or whether you're not yeah.</p> <p>This things is like just Just part time, Part time yeah. Yeah and the future is, you look forward to the future is the main thing.</p> <p>I think one, one thing is eating well, exercise, and looking out, what am I going to do tomorrow, not oh can, be positive on what's happening even if there are downfalls, you shouldn't unless you're really ill, really downhill but you shouldn't put yourself down and say I can't do this because I, try and be positive, things like that.</p>
		<b>Brenda</b>	<p>It's a long illness. Because it will remain with me for the rest of my life.</p> <p>I don't think so, I would have been the same because if I didn't have this medication, this good medication it's the same as if I am just healthy without my long illness because I don't have diarrhoea, I don't vomit, I just live with it like that.</p>
		<b>Andella</b>	<p>I don't know because at the moment this questionnaire whatever job you want, they want to know your health condition, I just leave it, I just write my high blood pressure at the moment is not well and this is the remedy I take</p> <p>No, I, I'm a human being, I'm human. go to the GP and you tell them you're not well, they relate everything to HIV, you're not a human being anymore, everything is HIV related. I told my GP, I said excuse me I'm a human being you know just forget that I have that HIV, why do you have to relate everything to HIV?</p>
		<b>Esther</b>	<p>...I said no I don't have aids, I have HIV and I am sure you have seen how I look, you know there is nothing wrong with me.</p>
		<b>Mercy</b>	<p>...take your pills and if the pills clicks then there's nothing wrong with you but with diabetics someone can be taken to hospital because it goes up and down.</p> <p>They think that you're different than those who have got diabetes. I don't understand that.</p>
	<b>The gift of dreaming</b>	<b>Yvonne</b>	<p>I thought about getting money from a bank, but I thought if something happens to me then I am leaving problems for my children, unless my children are well settled then they can help me sometimes. My wish is to do something for myself and be self-reliant really hmm, that's my wish.</p> <p>...In this country I can live forever as long as I look after myself, don't ever think I will die, don't even worry'.</p>
		<b>Juliana</b>	<p>...with medication, exercise and eating well, you can live happy.</p>

			Yeah I think the future is very important yeah but not think about the illness and you go on yeah, you'll be there tomorrow.
		<b>Brenda</b>	So...at home they will go and dig somewhere, bury me where they bury everybody, even if I have to pay, I won't pay as much as they pay here and which my poor relatives can afford. I, I know] I will be looked after by my family, but my family is poor, that's the problem, if I had money, my family could be happy to look after me because they will be comfortable to feed me from my money.
		<b>Maureen</b>	I don't know, I haven't made up my mind. I might go back to Uganda. If I come they will ask why do you do this cos I say I'm going to be buried here. Why won't you be buried in I say if I get weak I go on a flight and go back to Uganda and I'm going to die. I don't want to be buried here....
		<b>Andella</b>	Oh very hard, that's why I was trying to be friendly to my friend who has a xxx man, I said she's in a different community, maybe if I relate more with her I'll find a saviour but he hasn't come my way easily (laughs).
		<b>Esther</b>	you know, you can't do anything. I'm not allowed to work! I can't do anything, you know so I really don't know, I don't know what to do.
		<b>Mercy</b>	I'm trying to work and establish business back home and then whatever happens to me I'll go and stay with my grandchildren and whatever happens I'll be at home. ...my daughter, the one who's here, she's married to a white man so the tendency is that when you are old they put you in a home. The husband will say put your mum in a home. if I work hard, I've got something, money, so that they can look after me because in my place it's not good enough. So in five years from now until I turn 60, I am praying that God will give me that ability and then, and the chance to work and save and do whatever I want to do If I'm a citizen then I'll be allowed to go in and come or come for my medication. Live in the sun that will make me live long I think.
	<b>The search for acceptance and belonging</b>	<b>Yvonne</b>	...the doctor was so good he told me about the organisations which can help me, the groups where I can go and meet others' and I was just there asking others 'how long have you been diagnosed? What are you doing? How are you moving on? The doctor comes and he is smiling, there is no doctor who could come and showing a face of fear or something, there is always happiness and you know accepting us. So that me feel like I have found another home, where I can be liked. I have got friends who are in the homes and the way they are being handled, it pains me, I feel if we had our own home, people with the same element, then those who are able bodied, who can help others could be working, knowing the situation and see them through it.

			because you have gone through the journey, you know how it is, you know. Like now you can, you know I have this friend and she knows I have got it, and she met me at one of the groups and so she knows I know how it is, how to treat people like this, you know she feels free when I am in her house doing anything, she can even say can you give me my tablet, but if you have a carer, who is not like you, some of them,
		<b>Brenda</b>	....It gives you that hope, it gives you that excitement, know there is that, if that one can do it then you can do it yeah Yeah. I keep doing, even with other people who are HIV, I keep asking them what they're doing, sort of work, things like that so that I get ideas and some yeah. I think communication is very important yeah and support groups are very important yeah to make sure that there is something there for you tomorrow.
		<b>Maureen</b>	Human beings important for my life... Exchange ideas.
		<b>Andella</b>	Yes, you are in the same trade. That's why I was trying to make it a habit whenever there's a programme I say come to my house, I'm trying to open up.
		<b>Esther</b>	Meeting other people who are in the same umm, condition as I am, yeh and I go to X (name of charity) every Tuesday and there is another group in X (London) that is every week and another one on a different day. Every time there is something going on so I make sure I go there. At least if I tell a friend, somebody who's like me they know what I am talking about, you know so.
		<b>Mercy</b>	they can open homes or residential homes for us, for people who are like me and then people work there, people like us because they, if I'm able now and they're discreet, is she like that, I wouldn't live in stigma because they know what we are going through but if someone's not like that then it will be difficult really.
	<b>Defending against distress</b>	<b>Yvonne</b>	I am an outdoor person, yeah and I like helping people like now there is a lady who is from the same country as me but she had to go to the hospital and I said 'you just bring your children here and I will look after'. So I love just keeping myself occupied
		<b>Juliana</b>	I think it's the mind that makes you, if you think positive then whether you're 90 or whether you're 20, still the same, you could be 20 and you're not thinking positive and you could be, the more positive I think the better
		<b>Maureen</b>	My life is, I just move up and down, groups??(32.19) see friends, that's it. I don't want to sit in the house. I don't want to be in the house... I don't know. I feel down if I'm in the house, I feel down
		<b>Andella</b>	Like now I'm doing IT classes and English so I am busy Tuesday, Wednesday, Thursday with classes but Monday I go somewhere to learn with the asylum seekers how to draw from two o'clock to five. Day like today. Friday I go, it's supposed to be Zumba but over sixty exercise but it is called Zumba but

			<p>it's a bit hard for me.  so that's what I do then Saturday normally there are either one or two support groups. It's big London, so the other church may have something for Saturday. You go there and socialise and eat whatever is there. If I go in the morning I don't come back until evening.  ...Go out and take time to come back slowly either on the bus or sightseeing, I do that if I don't have anything. I'll leave this place around midday after breakfast and go to St Paul's sightseeing, in the evening I sit at St Paul's for evening prayers, just like that.</p>
		<b>Esther</b>	<p>Oh...you know this immigration is umm, torture! You know? But I have taught myself not to...think, dwell on it. You know, if you have a long, long ongoing problem I say to myself 'I'm not going to let myself worry about something that I can't solve'. Yeah although at times it does get to me, you know? But I tend not to worry, yeah but it's there somewhere. [laughs].  Umm...I don't stay in the house, I go out, I go to support groups yeah and er, it really keeps me going umm, times I just got out, go window shopping, I don't stay in the house, yeah.  Yeah, I told myself that if I can't do anything about a situation what's the use of me worrying about something that I can't, I can't do anything about? It does get to me, once in a while, but I tend not to dwell on the problems that I have.  You know you can't do anything when it's there, when it gets to you, it wears out gradually, yeah [pause] it's just there, can't do anything about it, I have tried shopping, when I have a problem, if I have money, I go shopping and if I buy something I feel better, it keeps me going, you know, I try not to stay in the house [laughs].</p>
		<b>Mercy</b>	<p>Yes I put my bible there, when I'm alone I read my bible then I pray, I sing and I try to shut down those bad memories. It gives me the strength and the hope that God is in control of my life.</p>

**Appendix 17: Table A5, Initial themes produced from triangulation involving two cross checkers**

Researcher	Cross-checker 1	Cross-checker 2
Ageing with uncertainty The loss of expectations The dependent self An uncertain future Preparing for a home Facing financial uncertainty Loss of goals/aspirations The questioning self Living with uncertainty The physical impact of ageing HIV as a 'long illness' The rejected self Being feared HIV as a visible condition Receiving 'silent' support Talking about the unspoken Resisting shame as a woman Men as decision makers The multiply stigmatised self Resisting ageing The shame of growing older without family support The psychological impact of loneliness The abandoned self The lonely self Shame The gendered nature of HIV The importance of staying connected Resisting rejection Wanting belonging and acceptance An invisible illness The 'normal' self Medication as a life line The accepting self Living with loss Diagnosis and a lost life Worry/rumination Avoiding a home	Pain Feeling Lonely Living with HIV Having social support Being sociable Accepting illness/diagnosis Diagnosis as life changing Pain Feeling Lonely Living with HIV Having social support Being sociable Accepting illness/diagnosis Diagnosis as life changing The questioning self Denial of ageing, wanting to hold onto something HIV as life changing Loss Diagnosis bringing uncertainty Being positive The hopeful self Feeling rejected Feeling comfortable Feeling isolated Uncertainty related to diagnosis Feeling lonely Fears of rejection Worrying about the future Preparing for the future The worrying self Identifying with other HIV sufferers The stigma of HIV The invisibility of HIV Being positive about HIV Accepting HIV Having social support Being understood Having conflicting desires/wishes	Age, importance of being 70? Good emotional regulation Low mood Mood related to age – is she alone or lonely Living with diagnosis or a long time Diagnosis associated with Africa Just focusing on life Importance of friends and family Contrast with hope for her life Reliance on medication Self-doubt Age, importance of being 70? Good emotional regulation Low mood Mood related to age – is she alone or lonely Living with diagnosis or a long time Diagnosis associated with Africa Just focusing on life Importance of friends and family Contrast with hope for her life Reliance on medication Self-doubt Constantly looking towards end of life Feeling youthful Pros and cons of UK – separated from family Looking at positives Idea that HIV cannot be hidden Blaming husband? Stigma around HIV Not having knowledge of how HIV can be contracted – sense of fear Still facing discrimination Idea of older people taking it more seriously Searching for cur for all people with HIV (we) Importance of extended family Practical aspects of home

**Appendix 18: Table A6, The representation of master themes and subthemes across all seven participants**

Master Theme	Subtheme	Yvonne	Juliana	Brenda	Maureen	Andella	Esther	Mercy
Spoilt identities	<i>The contaminated self</i>	✓	✓	✓	✓	✓	✓	✓
	<i>The shamed woman</i>	✓	✓	✓	✗	✓	✓	✗
	<i>The self on trial</i>	✓	✗	✗	✓	✓	✓	✓
	<i>The threatened body</i>	✓	✓	✓	✓	✓	✓	✓
A present without light and a future without hope	<i>Suffering in silence</i>	✓	✓	✗	✗	✗	✓	✓
	<i>Loneliness and longing</i>	✗	✓	✓	✓	✓	✓	✓
	<i>Lost dreams</i>	✗	✗	✓	✓	✓	✗	✓
	<i>Facing a life of imprisonment</i>	✗	✗	✓	✓	✓	✗	✓
Escaping the labyrinth of distress and uncertainty	<i>The oasis of normality</i>	✓	✓	✓	✗	✓	✓	✓
	<i>The gift of dreaming</i>	✓	✓	✓	✓	✓	✓	✓
	<i>The search for acceptance and belonging</i>	✓	✗	✓	✓	✓	✓	✓
	<i>Defending against distress</i>	✓	✓	✗	✓	✓	✓	✓









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