The Lived Experience of HIV Positive Immigrant African Mothers in the UK: An Interpretative Phenomenological Analysis

Debbie (Deborah) Levitt

A thesis submitted for the Professional Doctorate in Counselling Psychology in partial fulfilment of the requirements of London Metropolitan University.

February 2020

Declaration

I hereby declare that the work submitted in this dissertation is fully the result of my own investigation, except where otherwise stated.

Name: Debbie (Deborah) Levitt

Date: February 2020

‘It always seems impossible until it’s done’
Nelson Mandela

Acknowledgments

This thesis is dedicated to **R&R,** two people who have always believed in the power of a good education, remain soul mates and do not complain about whatever life presents to them, which remains inspirational.

This thesis would not have been completed without the belief that **CK** had in me and that the impossible could be done. No thanks will be enough, and I remain in awe of the patience and generosity shown to me.

Without a patient supervisor no thesis will ever reach its end point and for this I will always be appreciative of the time given to me by **Catherine Athanasiadou-Lewis.** Thank you is most definitely not enough.

To friends and family who have supported me along the way, I know many of you did not believe this would reach an end point and, on many occasions neither did I, so thanks for the endless support, encouragement and belief that this could be done by an ‘oldy’ like me, I am forever grateful.

Finally, this would not have been possible without the generosity of the six participants (and those who wanted to come forward but for their own reasons could not). I am humbled by your experiences and sharing such personal stories for the benefit of this research project. I am in awe of your courage and the challenges you have faced. Thank you is definitely, not enough.

Bridging statement: explain why the thesis changed

This bridging statement is an attempt to explain why the research question and research focus changed between the first and second viva. The research question presented in the initial viva was “Understanding parents’ decision-making whether to test their child/ren for HIV: An Interpretative Phenomenological Analysis”. The focus for the thesis at this point was to understand the lived experience of HIV positive parent/s in relation to their decision making around testing their older child/ren (or not) for HIV.

This was an area of interest for the researcher because they work in the field of HIV. A workshop titled “Don’t Forget the Children” highlighted the issue of older children who were not being tested for HIV, did not receive treatment, and were dying prematurely as a consequence. In the UK, although HIV testing and treatment is provided free on the NHS there are still a proportion of people who remain undiagnosed. This raised the question of why people chose not to test themselves or family members, in particular child/ren, and how do people reach and experience this decision. Current literature still does not offer insight into the reasons why people do not test themselves or their family, or how to help facilitate overcoming challenges and barriers to testing.

The aim of this exploratory study was to generate in-depth knowledge and understanding of how and what people experience when deciding to test or not their child/ren for HIV. It was hoped that the research findings would contribute to closing the gap in the literature and offer counselling psychologists’ new insights and approaches to working with clients who are being asked by healthcare professionals to test their child/ren for HIV.

During the first viva, a problem was raised by the examiners who felt that there was a discrepancy between the interview schedule and the research question. The questions in the interview schedule were made up of a number of areas, other than testing. This led to the topic of testing becoming one part of the study rather than the entire focus of the thesis. On reflection and re-listening to the interviews, it became clear that the interview schedule generated data on the “Lived Experience of HIV positive Immigrant African

Mothers in the UK", of which testing and decision-making of their child/ren was one aspect of their experience. In response to this, the research question and focus changed to reflect the interview schedule and data generated. The research question was changed to reflect the interview schedule which became "The Lived Experience of HIV Positive Immigrant African Mothers in the UK". This change warranted a new literature review and a substantial revision of the remaining chapters. This is reflected in the thesis that follows.

Abstract

Background: HIV positive immigrant African mothers living in the UK are likely to experience a decline in their mental and physical health. The women often encounter multiple challenges which need to be explored and understood to improve the health outcomes for themselves and their families.

Aims: The study aims to bridge the gap in the literature by exploring how Immigrant African mothers experience living with HIV in the UK.

Methodology: A qualitative approach was used to generate in-depth data. Interpretative phenomenological analysis (IPA) was chosen to explore the lived experience, focusing on a small, homogeneous cohort. Using semi-structured interviews, six accounts were recorded, transcribed and analysed for meaning and sense-making.

Results: The analysis generated three main superordinate themes. These included *'Quest for Survival', 'Impact of diagnosis on identity', and "It's there, but HIV is not me...".*

Superordinate themes encompass themes and sub-themes which are reflected in psychological theories and literature.

Implications of study findings: The findings could help to develop specialist training for healthcare professionals around engaging these women and their families in early testing for HIV, adherence to treatment, and challenge stigma. This study might inform counselling psychologists about the background beliefs and cultural norms that influence these women when attending therapy and offers an insight into the areas of work that may need to be addressed therapeutically.

A further implication of this study was the importance of approaching African community leaders/elders around education for women who are living with HIV in the UK and addressing barriers to accessing healthcare.

Table of Contents

Glossary

AIDS-Acquired Immune Deficiency Syndrome

ART-Antiretroviral therapy/treatment

BASHH-British Association for Sexual Health and HIV

BHIVA-British HIV Association

BPS-British Psychological Society

CD4-type of white cell to fight infection, HIV causes these to reduce

CHIPS (and now CHIPS+)-Collaborative HIV Paediatric Study (UK/Ireland)

CHIVA-Children's HIV Association

HAART-Highly Active Antiretroviral Treatment

HCPC-Health Care Professions Council

HIV-Human Immune/Immuno-Deficiency Virus

Immigrant-a person who comes to live permanently in a foreign country

IPA-Interpretative Phenomenological Analysis

Migrant-a person who moves from one place to another, especially in order to find work or better living conditions.

MTCT-Mother-to-child transmission of HIV

NGO's/Charities-Non-Governmental Organisations/Charity Sector

NHS-National Health Service

NSHPC-National Study of HIV in Pregnancy & Childhood (UK/Ireland)

PLWH-People Living with HIV

UNAIDS-The Joint United Nations Programme on HIV/AIDS

VL-Viral Load, indicates amount of HIV in the blood

WHO-World Health Organisation

1. INTRODUCTION

This study will investigate the lived experience of HIV positive Immigrant African mothers in the UK. It will focus on at least one parent/caregiver being HIV positive, primarily the mother, as HIV transmission to a new-born is from mother to child. Although the research did not specify, this was reflected in this self-selected homogeneous sample of mothers who experienced the phenomena of either learning their HIV diagnosis in pregnancy or prior to falling pregnant. They had all left their countries of origin and the reason for focusing on a homogeneous sample is because non-positive immigrant mothers may hold a different experience, knowledge and understanding of being diagnosed HIV positive and their decision-making will be influenced by their negative status.

There appears to be a dearth of literature concerning mothers (or parents) experiences and decision-making in relation to testing their child/ren for a chronic health condition such as HIV, and the subsequent process of disclosing their status to child/ren and partners. In addition, there is limited research in relation to the lived experiences of immigrant African mothers in the UK. In the area of HIV, this knowledge gap exists in both qualitative and quantitative research. This qualitative study will attempt to contribute towards closing this gap.

The relevance of this study to the field of Counselling Psychology highlights a number of important areas that counselling psychologists can contribute towards the field of HIV. It is relevant to note that African populations are disproportionately represented in the HIV cohorts in the UK. (Falola & Heaton, 2007). These populations often experience poorer mental health and physical outcomes which impact on their quality of life. (Glantz, 1997) Counselling Psychologists can help therapeutically to address specific areas such as adjustment, coping, adherence, living well with a chronic health condition, amongst other areas, but first and foremost is the need to understand the experience of these individuals and the way in which an HIV diagnosis impacts on their daily life, sense of self, and interpersonal relationships as mothers and wives. (Milton, 2010) Counselling Psychology, as a unique

discipline, has an integral role to play in the field of HIV.
It is important to gain an in-depth understanding how HIV positive Immigrant African mothers living in the UK make sense of their diagnosis and how they translate this to dealing with the challenges of being a mother and in most cases, a partner. (Ndirangu & Evans, 2009) Their experience of being an immigrant to the UK created a major challenge in the first instance, and the role of UK healthcare professionals became increasingly evident which will be highlighted throughout this study. The knowledge generated may enable healthcare professionals and mothers to develop a collaborative approach to making decisions in the best interests of their child/rens and partner's health.

In the UK, some information is lost when HIV positive children transition from paediatric to adult services. In the past, information stored on the national paediatric database (CHIPS-Collaborative HIV Paediatric Study) was not followed up once they transferred into adult care. This is currently being addressed and children who transition into adult HIV services in the UK are now being monitored by a national database called 'CHIPS +'. Because of the complex journey that many HIV positive immigrant mothers living in the UK go through prior to obtaining their settled status, there was concern by healthcare professionals that HIV positive children may not have been diagnosed. In 2008 a day was held for 160 participants in London from adult and paediatric teams, voluntary sector organisations, social services, the police and legal experts, called 'Don't Forget the Children' to address omissions resulting from undiagnosed HIV infection, which aimed to offer some understanding as to why some children who were born HIV positive present later to the healthcare system. The experience for families and the dynamics that underlie how they make sense and attach meaning to an HIV diagnosis needs further exploration. In this study, the focus became how HIV positive immigrant African mothers living in the UK experience their diagnosis.

On the one hand, antenatal care has been successful in reducing HIV infection in the UK, due to the opt-out system for pregnant women. It is older children over the age of 2 years and under 16 years that were apparently being missed. It is still undiagnosed HIV, especially in children that has increased the risk of morbidity and mortality. At the 'Don't Forget the

Children' Conference, an attempt was made to understand the experiences that led to HIV positive parents not testing their 10-year-old child, resulting in death. Over a decade later and unnecessary deaths for adults and children continue, who are found to be HIV positive. In the case of children and adults without antiretroviral treatment (ARV's) most HIV positive children die before they are 5 years old. Late diagnoses in HIV positive men are common in the UK. The perceived responsibility held by HIV positive mothers, is part of their lived experience. Shame and stigma remain prevalent amongst these women today. (Oldson, 2013) The experience of HIV positive immigrant women, and, in particular, those that are mothers, has largely been neglected in research studies in the UK to date. All too often this invisibility remains, and in this qualitative study, the aim was to give a small cohort of (self-selected) women a space to highlight their lived experience of both being an HIV positive mother and an immigrant living in the UK. (UNAIDS report, 2016; &Timothy, 2019) The impact of their cultural and religious backgrounds on their present-day realities became apparent, whilst they made sense and attached meaning to their everyday experiences of living in the UK.

Early HIV diagnosis is critical for adults and children alike. It is estimated that taking ARV's under the age of 2 years, can reduce children's death rate by fifty percent. (WHO report, 2018 & UNAIDS, 2017) This thesis will explore the meanings and sense-making that HIV positive immigrant African mothers attribute to their diagnosis and how they manage the challenges they face in relation to their partner's and children. This qualitative project will aim to produce a deeper understanding of this topic and may reveal further areas that need to be investigated. In particular, this will focus on UK (United Kingdom) residents who access their healthcare through the National Health Service (NHS), as this is an under-researched area. The surveillance methods used in paediatric and adult health services are not joined together, meaning that at times vital information may be lost, and numbers of undiagnosed HIV patients remain unknown.

While most studies use quantitative methodology and randomised control trials (RCT's), which are seen as offering scientific efficacy, qualitative information is not always systematically gathered. Because of the small

sample size, validity and specificity cannot be generalised. (Yardley, 2008) These small-scale studies can be dismissed within elements of the scientific community, in the UK and abroad, but the information provided by IPA and other qualitative methodologies, are providing deeper insights in their own right. Alongside quantitative data, qualitative studies are offering an in-depth look into important phenomena that can deepen and enrich our understanding. This study provides a small window into the world of an HIV positive parent and the experiences they face when living as an immigrant African mother in the UK.

2. LITERATURE REVIEW

This chapter will introduce the phenomenon of the lived experience of HIV positive Immigrant African mothers in the UK. The literature will include a general definition of HIV/AIDS, outline its global prevalence and focus on the differences in healthcare systems between Africa and the UK. Other areas to be covered include a specific focus on immigrant women's experiences of living in the UK in the context of an HIV diagnosis. The experience of receiving a diagnosis, stigma, and the impact this on family dynamics will be addressed. The challenges and barriers to accessing and engaging with service provision in the UK will be highlighted. This chapter further aims to review the literature on the role of culture and media, in relation to the sense-making process and coping with being HIV positive. As this study hopes to explore African Immigrant mothers' experiences, the literature will extend to the area of how religion/spirituality might affect their engagement with health care services for both themselves and their child/ren. There will be a specific focus on any literature about mothers' decision-making around testing their child/ren for HIV. The relevance and importance of Counselling Psychology to the areas of adjustment and coping will be outlined. Gaps in the literature will be highlighted and the aims and rationale for this study will be summarised.

2.1 Rationale for the study

The research question for this thesis is: the lived experience of HIV positive Immigrant African mothers in the UK. The rationale for undertaking this study was that despite the NHS offering free HIV testing and treatment in the UK, recent studies have found that immigrants are at higher risk of contracting HIV when moving to Europe (Ross, Cunningham and, Hanna, 2018). This contradicts previous studies which thought that immigrant/ refugees contracted HIV prior to leaving their home country (Rice, Elmore, Yin and Delpech, 2012). The Marmot Review *Fair Society, Healthy Lives* (2010) highlights the correlation between poor health outcomes and socioeconomic status. Often immigrants are from resource poor countries and due to their immigration status, remain in lower socioeconomic circumstances when they migrate. HIV positive immigrant African mothers encounter multiple challenges which are specific to women, however little is known about how these

challenges are experienced. Some migrant women are more likely to experience a decline in both physical and mental health (Delara, 2016) during their period of acculturation to their new country. HIV positive African pregnant immigrants often present late in pregnancy to maternity services where they are diagnosed HIV positive (Favarato, Bailey, Burns, Prieto, Soriano-Arandes and Thorne, 2017). The consequences of this are that these women and their unborn children are diagnosed and treated later than UK born mothers. This is important in the prevention of mother to child transmission of HIV (MTCT). A further rationale for this study raises the question of what it might be like for HIV positive African immigrant mothers who have older children born outside the UK and who have not been tested for HIV. Through this research, an increased understanding of why mothers do not test their children earlier might be helpful to encourage their engagement with the testing process.

To date, literature on HIV African migrant mothers focus on epidemiological or quantitative data. Whilst there are limited qualitative studies exploring the experience of HIV positive African women in the UK, there are no specific IPA studies focusing on what it is like to 'live' as an HIV positive immigrant African woman and mother in the UK. For the past twenty years the primary research conducted in the UK relating to HIV positive women have focused on either trying to understand women's experiences to help them engage better in care (Anderson and Doyle, 2004). While in 2011, Treisman's thesis focused on the experience of being diagnosed HIV positive in pregnancy, Dibb and Kamalesh (2012) conducted a small-scale study to see how women cognitively adjust to a positive diagnosis. Later Tariq (2013) focused on women's engagement in care during and after pregnancy; and Tait in the same year, 2013, studied the role of identity amongst Black and ethnic minority women living in the UK; then a number of years later Proudfoot, 2017 looked at women's experiences of antenatal care specifically focusing on experiences during pregnancy. None of the research to date in the UK has looked at the lived experience of being an HIV positive African immigrant mother. Through this study it is hoped that new insights and understandings will give a voice to these women's accounts as mothers, and challenge perceived stigma and marginalisation,

through generating in-depth and rich data. The study findings should highlight the important role of counselling psychology in helping this cohort to 'live well' emotionally and psychologically.

2.2 HIV/AIDS

The Human Immunodeficiency Virus (HIV) affects the immune system and weakens people's ability to fight infections. Undiagnosed HIV usually destroys and limits the function of our immune cells which makes people more prone to numerous infections and other diseases that individuals with healthy immune systems can usually fight. Acquired Immunodeficiency Syndrome (AIDS) is considered to be an advanced form of HIV. Generally, individuals considered to have an AIDS defining illness will experience more than one opportunistic infection that negatively impacts on their health system and makes fighting infections more difficult.

There is currently no cure for HIV, however effective antiretroviral treatment (ARV's) can control the virus, help prevent transmission, so that those diagnosed HIV positive can live long and healthy lives. HIV continues to be a major global health problem, with over 35 million lives lost so far, and over one million individuals losing their life each year. New infections continue worldwide and by the end of 2016, there were at least 1.8 million new diagnoses. Current figures place the numbers of HIV positive people around 36.7 million across the world. Africa still has the highest number of HIV infected individuals, figures around 25.6 million and according to WHO figures also accounts for around two-thirds of new infections.

The World Health Organisation (WHO) estimates that currently only 70% of people with HIV know their status. More needs to be done to promote testing according to the WHO. There are different tests used to diagnose HIV, most of these have become rapid and are helpful for early treatment and care, resulting in adults and children living longer, especially since the access to ARV's has improved in many parts of the world. The WHO has clear guidance on testing, which they feel should be voluntary with the person having the right to decline, as they feel this is best public health practice and can infringe a person's human rights. (WHO, 2017; UNAIDS, 2016; UK

Government, 2017; BHIVA and CHIVA, 2017).

Global estimates of HIV from UNAIDS 2017 shared that 54% of adults aged 15 years and older living with HIV were accessing medication (ARV's) but only 43% of children under 15 years old had access to any treatment. AIDS related deaths have fallen by 48% since 2005, but this means that people living with HIV who are living longer can transmit the infection if they are not on medication, or unaware of their own HIV diagnosis. (WHO, 2017; UNAIDS, 2016; UK Government, 2017; BHIVA and CHIVA, 2017).

The numbers of children living with HIV exceed 3.2 million and are primarily located in sub-Saharan Africa. Most acquire their HIV from their infected mothers during pregnancy, during the birth process, or from breastfeeding. The risk of this transmission can be reduced with effective treatment, although in resource limited countries this can be difficult to achieve. (WHO, 2017; UNAIDS, 2016; UK Government, 2017; BHIVA and CHIVA, 2017). Wiener et al (2007), highlights that the prevalence of paediatric HIV is higher amongst economically deprived and ethnic minority communities who often have been subjected to racism and prejudice.

In developed countries the antenatal screening process has reduced transmission, but it is children that have either 'slipped through the net' or come to the UK at an older age that usually needs to be tested. Currently, in the UK and Ireland the number of known HIV positive children under 16 years' old who are receiving medical treatment, number 927 with the median age being 14 years old. (WHO, 2017; UNAIDS, 2016; UK Government, 2017; BHIVA and CHIVA, 2017). Favarato, Bailey, Burns, Prieto, Soriano-Arandes and Thorne (2017) found that migrant communities living in Europe have high rates of HIV infection and this particularly impacted on pregnancy and accessing healthcare. This often resulted in these women being diagnosed later in pregnancy, placing their unborn baby at higher risk of contracting HIV. The decade that these statistics were drawn from corroborated previous studies undertaken in France and Italy. Although they found that many of the women knew their HIV status before conceiving, the focus needed is on

keeping these women engaged in care which has proven challenging. This was the focus of another study by Spiers, Smith, Poliquin, Anderson and Horne (2016) who looked at the experience of Antiretroviral medication for a group of West African women and when non-adherent the impact on morbidity and mortality. They found that in many instances adherence is often higher in Africa than in the UK/Europe.

In 2017 it is estimated that 101,600 people were living with HIV in the UK. This figure includes both the diagnosed (93, 800) and undiagnosed (7,800) cohort. Of those that have been tested, and are receiving HIV care in the UK, 64,472 were men and 28, 877 were women. It is predicted that over half of heterosexuals diagnosed in the UK in 2017 acquired their HIV infection in the UK or soon after arrival. The largest number of HIV positive heterosexual men and women were from Black African communities, 8,200 men and 17,400 women. The largest proportions of people who have a HIV diagnosis in the UK live in London (36%). This is followed by the Midlands and East of England region (22%). (Public Health England 2018 report: Progress towards ending the HIV epidemic in the United Kingdom).

2.3 Defining 'Black African' within the UK

The 2014 policy report published by the National Aids Trust (NAT) identified that HIV in the UK is significantly represented by the Black African population. They clarified that Black African is not one single ethnic group, but according to the 2011 UK census, a term that reflects ethnicity which is socially and culturally generated. They emphasise that this term 'Black African' does not only mean someone who is born in Africa. According to NAT, Black Africans make up 1.8% of the UK population and in 2012 comprised 34% of HIV positive individuals in the UK. They cannot be considered a homogeneous group and come from diverse backgrounds spread across South, East, West, North and Central African countries. This is the not the only factor that needs to be understood, but armed conflict, unemployment and domestic or gender-based violence should be considered within the HIV population. This was illustrated by Wehmbolua, Conserve, Thomas & Handler, (2017); and,

McLeish & Redshaw (2016) who spoke about the devastation caused by HIV and clarified that men and women migrate to European countries seeking a better life.

2.4 The impact of receiving an HIV diagnosis

The NAT Report (2014) quoted an earlier qualitative study, conducted in London (2001), which specifically focused on HIV positive African Women's Experiences of being a migrant. Many of these women experienced depression and anxiety related to their HIV status and had a close family member or relative die from HIV which affected their own approach to managing their HIV diagnosis. These women spoke about concerns relating to conception, whether a child would be born positive, and had a fear of transmitting HIV to their partner. Some of these women experienced poor socio-economic circumstances while trying to raise children as single parents. Whilst others were traumatised about children left behind in Africa.

Many of these women were afraid of attending support groups or accessing peer mentors for fear of people finding out their HIV status. NAT found in a more recent report (2011), subsequent to the 2001 study, that these concerns and worries remained today. In 2020 many of these same concerns affect African immigrant populations.

African migrant women who receive an HIV diagnosis in the UK may face various challenges including how to inform their partner, and how their partner might react (Whembolua-Donaldson, Thomas, & Handler, 2017). When diagnosed in pregnancy, this can be particularly traumatic, as highlighted by NAT (2011). They went on to say some of the women feared disclosing to their partners and in certain situations they experienced physical and verbal abuse. In some instances, they were rejected, raising the fear of abandonment by a negative partner. An additional impact for some of these women included a change in their relationship dynamic resulting in a loss of power and concomitant unhappiness. This had a consequence on their sexual lives. For a number of positive women, they experienced domestic violence which could be physical, verbal threats to disclose status and

needing to accept partner's demands if they did not cooperate. Lingen-Stallard, et al (2016) found that the women they interviewed were alone when receiving their HIV result despite being asked to come with a support person. Some of these women reported suicidal ideation on receiving their diagnosis. It could be argued that a limitation of this study was that the IPA analysis was conducted by several research midwives. The themes identified would have been subject to multiple interpretations and their individual biases. The study participants were recruited from two healthcare clinics. Their findings were limited to women who were already engaged in healthcare services and may not capture the experiences of those who do not engage in care. Similar IPA studies using one rather than a number of researchers to identify meanings attributed to experiences, might generate different data. This gives further weight to why this study should be undertaken.

What this study highlights is the impact of having a HIV diagnosis, rather than how these women made sense of it. The role of culture and religion is not explored, as well as the decision-making process of testing children for HIV, which this current research aims to address.

2.5 Resources

Access to resources has been shown to have a direct impact on how people with an HIV diagnosis manage and cope with their condition and that of their family. Most studies and articles stress the phenomenon of poverty as a factor that needs to be taken in to account when understanding the experiences of people living with HIV. The primary difference between living with HIV in Africa rather than the UK is the 'free' provision of HIV testing, medication and treatment offered to people in the UK through the NHS, whereas in the developing world, free access to testing and treatment is primarily through the NGO sector. NGO's often conduct outreach work targeting hard to reach groups and capitalising on opportunities for testing, advice-giving and treatment. In the UK there are Charities such as Positive East and Positive UK which offer free counselling, advice on how to obtain government assistance and how to talk to others about their HIV status. Murane et al (2017) illustrated those guidelines that have been established on how to facilitate HIV

disclosure and the need for systematic support. In Africa resource provision is variable amongst countries and dependent on a number of factors such as war (internal stability), if NGO's are present, and whether local elder's/church leaders recognise HIV prevalence in their communities and support any form of intervention by healthcare professionals.

Limited access to financial resources has also been shown to influence mothers decision-making whether to test their child/ren for HIV. On the other hand, for immigrant mothers, decisions about testing their child\ren and families for HIV are often based on their experiences from their home countries and influence how they are likely to respond to healthcare professionals in the UK. Their sense and meaning-making from these experiences will be influencing factors in whether they agree to test their child\ren for HIV.

According to the World Health Organisation (2016) children from rural and poorer socio-economic backgrounds are less likely to be able to access HIV testing and pharmacological treatment. Wagner, Wachira, Njuguna, Maleche-Obimbo, Sherr, Inwani, Hughes, Wamalwa, John-Stewart and Slyker (2016) found that there was a 14% increase in children being tested for HIV when offered free testing and a choice of venue. Lorenz et al (2016) found that affordability of transportation to healthcare facilities was a barrier to parents testing.

Studies have shown that even as immigrants to the UK/ Europe, an individuals' access to financial resources plays a role in how they obtain their health care. Fakoya et al (2018) found that for many migrants the lack of affordability such as travel expenses and prescription charges impacted on HIV testing and adherence to treatment. This study involved 2093 participants completing self-reported electronic questionnaires across nine European countries and multiple languages. This methodology limits the findings to pre-determined answers to questions and does not afford participants the opportunity to offer alternative responses. The questionnaire was translated into different languages that may have caused some meanings to be lost or misunderstood. What is unknown is how these individuals experience financial

restraints in the context of accessing healthcare services. For example, what the experience is like for them not to be able to afford to travel to a clinic. This research might offer some insight into this, as part of the overall IPA investigation into what it is like to be an HIV positive immigrant African mother living in the UK.

Ross, Cunningham and Hanna (2018) found that HIV positive immigrants from low-income countries living in high-income countries have poorer health outcomes related to their HIV diagnosis. Kramer, Mackenbach, Harding et al (2016) found that immigrants are more likely to die from HIV than non-immigrants and present later to healthcare services (Hernandez, Alvarez-del and Alejos et al, 2012). Late presentation to care has been associated with immigrants not knowing their HIV status, which in turn is linked to a lack of HIV testing, because of cultural barriers and limited opportunities to test (lack of health insurance, stigma associated with a potentially positive outcome and cost of medical care).

Although financial considerations are shown to influence patient access and engagement to healthcare services, what still remains unknown is how HIV positive African immigrant mothers in the UK experience these services. The question of what it is like as an immigrant within these services, and the role the NHS might play on people's sense and meaning-making of their own and their child/rens HIV diagnosis, has not been investigated to date. Even less is known about how the experiences of navigating the NHS, compares with resource provision and access to healthcare in their country of origin. It is important to conduct this study in order to gain an in-depth understanding of any barriers and challenges that are not documented in the current literature. (Watson, Harrop, Walton, Young & Soltani, 2019).

2.6 Role of culture

The role of culture and social structure has been shown to not only influence who in society is at a greater risk of contracting HIV, but whether they seek services for testing themselves and their child/ren for HIV, and subsequently engaging in treatment. Although there are differences between people who reside in Africa and those who migrate to the UK, immigrants often hold onto

their cultural beliefs and norms. These norms, and their influence on people's experiences of living with HIV, will be explored.

Hallfors, Iritani, Zhang, Hartman, Luseno, Mpofu, & Rusakaniko, (2016) highlight how the culture of polygamy, being a child orphan, and child marriage in sections of Zimbabwean society places females at higher risk of contracting HIV. Blair, Paxton and Kamb (2013), report that in some cultures in Africa it is acceptable for men to have multiple sexual partners before and during marriage, whereas females are expected to remain virgins and sometimes marry older men. Birdthistle, Floyd, Nyagadza, Mudziwapasi, Gregson & Glynn (2008) found that married females had a higher risk of being infected with HIV as opposed to unmarried young woman. Within these societies, it could be argued that these trends might be explained by men and religious leaders often deciding for women whether and how they should engage with healthcare services, as well as their sexual practices (their expectation to have unprotected sex) (Hallfors et al, 2016). This may extend to women's autonomy about decision-making in relation to their child/rens health.

Blair, Paxton & Kamb (2013) considered that in a number of cultures, sexuality is not discussed or addressed. This was corroborated by Agbemenu, Hannan, Kitutu, Terry, & Doswell (2018) who spoke about mothers being from communities that did not condone premarital sex and commented on their cultural attitudes towards reproductive health, and threatening their daughters to disown them if they became pregnant before marriage. When these mothers came to countries like the UK/US/Europe they were challenged to have different conversations with their children, in particular their daughters, which they did not feel prepared for, and were contrary to what was expected in their home countries.

Cultural understandings of how HIV is contracted and the physical appearance of someone with HIV has been shown to play a role in people's sense-making of the condition. There is a common belief amongst some African communities that if you are not showing symptoms of illness then you were unlikely to be HIV positive (Wagner et al, 2016). This may account for why some women either delay testing or are unaware that they, or their

children are HIV positive. Rwemisisi, Wolff, Coutinho, Grosskurth & Whitworth (2008) found that children in Uganda were only tested for HIV once displaying physical symptoms of ill health. This was found amongst several studies conducted in various countries in the developing world, including Lorenz et al (2016) & Wagner et al 2016). It was further proposed by Lorenz et al (2016) that parents only tested their child/ren for HIV when physically unwell, because in the first instance visiting a doctor was expensive and often a logistical challenge.

The intersection between long-held belief systems that were formed in their countries of origin and the challenges they faced moving to the UK, or another European destination, often impacted on the physical and mental health of HIV positive migrants (especially women) and their ability or willingness to access care. These deeply held beliefs are still prevalent today. Proudfoot (2017) found that many immigrant women did not test for HIV if they held a belief that they did not fit the stereotypical profile for someone with HIV, or if they believed they were in a 'low risk' category (belief that only drug-users, homosexuals or promiscuous people contracted HIV).

The role of culture in some studies has been reported to be a barrier for immigrant women to access healthcare because they follow traditional practices and remain closely within their own communities and not exposed to outside influences (Delara, 2016). This is illustrated by Kalara, Christodoulou, Jenkins, 2012) who highlight that for some of these women they will not accept male healthcare professional's involvement in their treatment. They go on to say that immigrant's heterogeneity needs to be understood as this can impact on the way they accept care. Not all immigrant women are the same, and not all healthcare providers understand cultural differences when providing care. This study was not specifically focusing on African HIV positive women.

In developed countries such as the United Kingdom (UK), other European Countries and North America, people's health and their decisions regarding their healthcare, is influenced by cultural norms that are embedded within

state sponsored public health campaigns. These have focused on raising HIV awareness, educating the public on transmission, testing and prevention. For example, the UK national AIDS awareness day is on the 1st December. During these campaign periods there is usually an increase in uptake of HIV testing. In the New England Journal of Medicine (Frieden, Foti & Mermin, 2015) they illustrated the point, that current knowledge informs us that early HIV treatment of infection is most effective when started early and adherence is maintained for life. It was also found that stigma complicated this and encouraged the collaboration between healthcare professionals and communities. They propose that the outcomes and impact on HIV management of harnessing patient involvement, engaging with communities, current scientific knowledge and public health awareness, could serve as a model for combating other chronic diseases. These public health campaigns serve to dispel stigma and prejudice while promoting good sexual practices. The literature on culture and the role it plays is limited to exploring HIV positive immigrants understanding of how HIV is transmitted, and subsequently whether they consider themselves at risk of contracting this.

Other literature cited has highlighted cultural norms and practices around accessing health care in relation to HIV and mention the impact of stigma on the management of their diagnosis. What is not addressed is the role of culture on how African HIV positive immigrant mothers experience living in the UK. This research aims to narrow this gap and provide additional understanding about how this group of women's experiences are shaped and influenced by their culture.

2.7 Stigma and HIV

Bolsewicz, Vallely, Debattista, Whittaker & Fitzgerald (2015) looked at a review of published peer-reviewed literature from Australia, Canada and the UK and found that between 20-25% of HIV positive people remain undiagnosed. In some cultures, HIV is still a highly stigmatised condition and considered a main factor for people not testing themselves or their family members. Lingen-Stallard, Furber, & Lavender (2016) corroborated this notion of stigma when they discussed how HIV is seen as a self-inflicted health

condition and therefore not ‘worthy’ of sympathy or empathy and these were views held in home countries as well as the UK. Vitale and Ryde (2018) identified in their study that immigrant women living with HIV are a vulnerable group due to many factors including facing social and gender-based inequalities; HIV stigmatisation; and are often faced with racial discrimination as immigrants. They have also reported experiencing legal challenges, social isolation, poor health literacy, linguistic barriers and lack of disclosing an HIV diagnosis due to fear of stigmatisation. (Shangase and Egbe, 2015). This is supported by De Jesus, Carrete, Maine and Nalls (2015) who found that immigrant African women living in the United States of America reported feeling that testing for HIV indicated that they had ‘engaged in bad behaviour’ and that they would be judged negatively by their communities. Furthermore, that testing for HIV represented infidelity and that there was a concern that their diagnosis was not confidential.

Nevin, Frey, Libra, Endeshaw Niemann, Kerani and Rao (2017) conducted semi-structured interviews with HIV positive African immigrants living in the USA about their experience of stigma. HIV-related stigma was described as having an impact on how this cohort managed their health condition, leading to poor mental health outcomes. The themes identified included emotional vulnerability, depression and negative coping skills. The analysis was initially conducted by a student coding the data and using a software package to help identify and code themes. This was followed by the primary researcher who continued the analysis process. It could be argued that the findings of this study were prone to two individual’s ability to identify and concur on themes, rather than in the current study which will use one researcher. As this study was conducted in USA and not in the UK with both men and women, it is unknown whether similar findings would emerge when focusing specifically on the lived experiences of HIV positive immigrant African mothers in the UK.

Parents fear or experience of HIV stigmatisation within their community appears to play a role in their decision-making to test or not their child/ren for HIV, and whether to disclose an HIV status or not (Arun, S; Singh, A; Lodha, R; & Kabra, S.K.: 2009). Parents’ experiences of their own diagnosis and treatment shaped their attitudes and beliefs towards seeking healthcare

services. Parents who experienced stigma when disclosing their own HIV positive status was less likely to promote HIV testing of their child to other parents in their community. Fear of infant diagnosis and stigma are barriers for these rural communities to test their child/ren. Adeniyi, Thomson, Goon, & Ajayi (2015) found that parents experienced guilt, shame and embarrassment when raising an HIV infected child.

Lorenz et al (2016) documented that HIV is a stigmatised condition that leads to alienation and isolation, which is a concern for parents when considering their child/ren HIV status. This experience was shared with members of Ghanaian society, as found in Gyamfi, Okyere, Enoch, & Appiah-Brempong's (2017) study. These authors further highlighted that as people with HIV are perceived to possess negative qualities and considered to be of 'less value', parents will commonly conceal their own and their child's HIV status as a means to protect them from stigmatisation. Gyamfi et al (2017) highlighted that within the traditional and cultural Ghanaian society, it is of upmost importance for family members to protect the immediate and extended family's reputation. People are afraid to find out their HIV status because of this possible stigmatisation and social isolation. Arun, Singh, Lodha & Kabra (2009) suggested that sharing an illness diagnosis was influenced by cultural norms.

In a multitude of articles that mention HIV, there is concern about the role of stigma and the impact on individual and family life. In addition, the impact on parent's decision-making processes, and how they make sense of and attribute meanings to finding out their own HIV status (or that of their child/ren), is periodically mentioned. More often than not, stigmatisation is the reason given for not wanting to know their own or family's HIV diagnosis.

There is a strong correlation between the perception in immigrants' countries of birth and when they migrate to developed countries like the UK, of stigmatisation and marginalisation. What has not been explored in any depth, is how immigrant populations, and in this particular study, HIV positive mothers, experience and make sense of living with their HIV diagnosis when they move to the UK. Whether these experiences corroborate those around

stigmatisation within their countries of origin or change when they migrate is unknown. It is important to conduct the current study in order to narrow the gap in the literature whilst generating data that might offer new understandings and de-stigmatise a heavily stigmatised medical condition.

2.8 Fear of testing children

African immigrant mothers with a positive HIV diagnosis in the UK are offered free opportunities to test their child/ren for HIV. The UK adopts an opt-out policy around HIV testing as part of their antenatal screening. Despite free HIV testing, Elmahdi, Ward, Cooke and Fiddler (2014) found that outside of antenatal and sexual health clinics the uptake of testing was only 27.2% in eligible populations. Authors have identified several factors as to why immigrant African mothers may be reluctant to test their child/ren for HIV. Baugh, Pammi, Butler Cliffs, Ahmed and Smyth (2014) highlighted, in support of the 'Don't Forget the Children' (2009) document, that audits indicated that some parents were reluctant to test their child/ren for HIV. This was because they appeared physically well and had a concern around disclosing the child's HIV status and that they would be stigmatised. These authors further outlined that there was an increase in the uptake of testing when parents were offered access via their GP surgery or through paediatric teams in a hospital environment. There were also financial considerations for some families.

Adeniyi, Thomson, Ter Goon, and Ajayi (2015) found that personal experiences of being stigmatised by their own community for having an HIV diagnosis influenced caregiver's decision-making about whether to test their child/ren. In the first instance there was a fear to approach clinics due to the derogatory attitudes, beliefs and behaviours directed towards those people that tested HIV positive. These feelings were shown to influence not only testing, but access to healthcare (Simbayi et al 2007, and Parker et al, 2003). Wiener, Mellins, Markefka, and Battles (2007) found that parents avoided testing their child\ren because of a belief their child/ren would experience psychological distress if they had a confirmed HIV diagnosis. Lorenz (2016) found that caregivers are often reluctant to test their children/ren for HIV

because parents wanted to protect them from emotional harm and societal prejudices. An important point that Wiener et al (2007), Arun et al (2009) and Atwiine (2014) highlighted, was that still to date there are limited global guidelines for parents/caregivers and health care professionals in how best to disclose a child's HIV status to them. In contrast, the Children's HIV Association (CHIVA) and Paediatric HIV Psychology group (PHP) (UK) wrote guidelines in 2014 focusing on the psychological management of children and young people living with HIV and developed the Standards of Paediatric Care which echoes that of adult standards of care (2011). This guideline acknowledges the impact of a child living with HIV, on other family members, such as facing the increased likelihood of a HIV positive child or sibling developing neurocognitive problems and a higher incidence of emotional and behavioural difficulties.

Wiener et al (2007) proposes that as children with HIV live longer, parents/ caregivers are faced with the emotional challenge to disclose their child/rens HIV status to them. Simoni, Yang, Shiu, Chen, Udell Bao, Zhang and Lu (2015) corroborated this and place focus on the stress that parents experience when deciding to disclose their child's HIV diagnosis and the need of culturally sensitive approaches and peer support. Murnane, Sigamoney, Pinillos, Shimu, Strehlau, Patel, Liberty, Abrams, Arcadia, Coovadia, Biolari and Kuhn (2017) found that disclosing a child's HIV status to them is frequently delayed. They argue that disclosure is a complicated and protracted process for both parents and healthcare providers, requiring systematic support. Proudfoot (2017) found that the HIV positive immigrant women experienced anxiety concerning learning about their child/rens HIV.

These women reported that on hearing about their own HIV status their immediate concern was whether they had infected their child/ren. Proudfoot (2017) found that mothers of HIV positive children placed their own needs secondary to that of their children. They felt that during the time they were waiting to find out their child/rens diagnosis, this was like a 'moment of being frozen in time'.

Rwemisisi, Wolff, Coutinho, Grosskurth and Whitworth (2008) found that even when parents have access to healthcare resources, the wide range of advice offered to parents might influence parents' decisions to test their child/ren. Rwemisisi et al found (2008) that in Uganda, counsellors were divided in their advice about testing, with some encouraging early testing whilst others recommended waiting to see whether physical symptoms were evident. Halfords, Iritani, Zhang, Hartman, Luseno, Mpofu and Rusakaniko (2016) found that parents' decision making around testing their child/ren for HIV was influenced by their belief in modern medicine. Those who were sceptical about testing and the efficiency of treatment were less likely to test their child/ren.

It is relevant to note that there is limited literature focusing on the testing of child/ren for HIV. There is also an absence of studies focusing on HIV positive migrant mothers' experiences of living in the UK, and how they make sense of their condition, in the context of parenthood. The current literature does not provide an understanding of how these women experience the possibility of having a positive child and the decision-making process on managing any health challenges. This research project will aim to address this deficit and further elaborate on this highly emotive area and narrow the current gap in the literature.

2.9 Role of religion/spirituality

How African immigrant women make sense of and experience their positive HIV status in UK is suggested to be shaped through their cultural backgrounds as well as their religious/spiritual beliefs and practices from their countries of origin (Arrey, Bilsen, Lacor and Deschepper, 2016).

Agadjanian (2005) and Arrey et al (2016) suggest that religion and spirituality have a "powerful influence" over African women's health beliefs and health behaviours. The latter authors posit that religion/spirituality is multifaceted in both a positive and negative way having an impact on the course of their HIV condition. Van (2013) commented that whilst immigrant African HIV positive people are aware that modern medicine has a key role to play in their physical health, the importance of their cultural and religious background cannot be overemphasised.

In some cases, HIV positive African women make sense of their diagnosis as a punishment from, or of being abandoned by God. This is supported by Gyamfi et al (2017) who proposed that HIV is considered a punishment and a 'spiritual sickness' from the 'supernatural/God' for breaking 'rules and taboos' and is an illness that is shameful. The outcome of this is that these women choose not to take conventional medicine as they believe that prayer will cure their condition (Arrey et al, 2016). They continue to suggest that religious beliefs held by some immigrant HIV positive women negatively influence their attitudes towards taking antiretroviral therapy (ARV's) and "call on God" for "protection" and asking God to "take control of their health". Ha, Salama, Gwavuya and Kanjala (2012) found that Apostolic churches are more likely to discourage their followers from adhering to modern medicine and engaging in HIV care with preference to faith healing. This is corroborated by the earlier work of Nenge, (2013) who found that Churches in rural African communities had a conservative and restrictive approach to women's decision-making and accessing healthcare services.

Ccore (2011) found that pregnant women from Apostolic Churches in African communities were less likely to attend these healthcare facilities for their antenatal care, delivery and HIV testing. The influence of UK Pentecostal and Apostolic church doctrine over their congregations has been found to echo practices from immigrant community's home countries with regards to adhering to ART medication (McLeish and Redshaw, 2016). In some instances, ART medication is perceived as a 'divine' intervention, whilst on the other hand discouraging adherence. To reiterate, Donnelly, Huang, Ewashen, Adair and Clinton (2011), identified that religious beliefs were a factor in female immigrants' decision-making about whether to access modern or traditional medicine. These findings were not specific to HIV but addressed broader health conditions.

From a positive perspective, Arrey et al (2016), found that immigrant African women drew upon their religion/faith which offered them emotional strength, resilience and wellbeing. Prayer and religious activity are used as a form of

coping and adjusting to their HIV diagnosis including adherence to medication. These immigrant women make sense of their ability to access HIV treatment as given by God as a means for them to continue living. Their sense-making of their HIV diagnosis and reason for taking anti-retroviral medication was that God has “forgiven them” and they now had been offered a second chance which they could not ignore and reduced their stress/worry about illness and death. These women reported experiencing a new sense of purpose, hope and control over their condition. They continue to propose that healthcare professionals need to understand the relevance and importance of religion and culture on patients’ engagement and incorporate this as part of their treatment plan.

Like stigma, the significance of religion and/or spirituality for immigrant communities can be comforting but also prove challenging at times. Literature pertaining to migrant populations, in particular those that migrate to developed countries from resource-poor environments identify the numerous challenges faced. There is a gap in the current literature that does not address directly the research question which focuses on the lived experience of HIV positive immigrant African mothers in the UK. There is information on the role of religion and spiritual practices in migrant populations’ home countries and how this may affect their journey and adjustment post migration.

These studies do not offer an insight as to how this may impact on them as mothers, who either arrive having already being diagnosed HIV positive, or receive this diagnosis in their new home country. Whether this gap in the literature will assist in encouraging testing, learning to accept and adjusting to being HIV positive may result in new understandings and management of illness. The power of religion and spirituality for migrant communities cannot be underestimated and requires further investigation which will be explored in this research.

2.9.1 Role of media

The European Centre for Disease prevention and Control (ECDC) (2009) published a report which proposes that media has played an influential role in

shaping attitudes and creating a forum for debate around migration and HIV. The ECDC highlighted that media reports on immigrants living with HIV has not always been portrayed positively. This is supported by Del Amo et al (2006) who study specifically focused on daily newspaper views on HIV and immigrant communities. Media articles often reflect societal attitudes towards migration and HIV and have been shown to vary from country to country. Persson and Newman (2008) examined Western media attitudes towards people living with HIV and the changes in these attitudes over time. They propose that the media initially portrayed HIV as a condition that only affected those from outside the 'mainstream heterosexual' population but since has moved towards conveying HIV as a global heterosexual issue.

Persson and Newman (2008) found that in the 1990's media articles contained 'blame' and 'hysteria' themes which shifted towards contextualising HIV as a 'health story' and 'social justice' problem. The study further proposed that people living with HIV have been reframed as 'innocent' or 'guilty' in connection to HIV-related offences that lead to criminal prosecution. Those with Black and/or African origins are proposed to be equated with negative connotations which are argued to contribute towards racial tensions. This is supported by Bickerstaff (2007) who found that in the UK, there are more negative stories written about HIV positive African men who have been involved in criminal HIV-related cases. This was also corroborated by Bernard (2007) who suggested that this ethnic group attracted disproportionate media attention.

In more recent times, media has also played an instrumental role in promoting positive attitudes towards HIV and raised public health awareness, as outlined in an editorial in The Lancet magazine (2015). Celebrity endorsements have been utilised to raise health awareness. They went on to indicate both the salubrious and unfavourable aspects that have taken place with public exposure of prominent individuals in the press. The need for open dialogue about HIV awareness, testing, prevention, disclosure and treatment remains today. As this editorial so eloquently said, "the tone of much of the coverage has been salacious and shaming; it would have been inexcusable in

the 1980's and today 'beggars' belief". The uneasy relationship between the media, celebrity and HIV continues in 2019. In 1998, Kalichman spoke about the impact of Earvin 'Magic' Johnson's announcement in 1991 that he was HIV positive. He reflected on how a celebrity sharing their diagnosis like 'Magic' Johnson should affect an increased awareness in individuals and a desire to protect themselves and others, from contracting a chronic illness based on this new knowledge. His announcement seemed to generate a plethora of research in the area of celebrity influence. The pros and cons of this continue to be contentious to date.

The influence on de-stigmatising HIV as a condition and increasing testing remains an on-going challenge. It is unknown whether the media influences the lived experiences of HIV positive immigrant African mothers in the UK. Even less is known about the impact of modern social media platforms such as Facebook, Instagram, You Tube, Twitter and various websites. This knowledge gap may be addressed from the current study findings.

2.9.2 Coping with an HIV diagnosis

There are many challenges facing immigrant women. Delara (2016) has highlighted there are a number of social determinants that affect this particular group of women's mental health. They have to face many obstacles and meet the basic requirements of housing, food, and employment while also going through the immigration process that can be difficult to navigate and impact on their health and wellbeing. Delara (2016) proposes that they may face social, psychological, spiritual, cultural, and economic challenges which can have a long-term impact on psychological wellbeing. It could be argued that mental health mediates people's ability to cope with being HIV positive. An immigrant's culture in not recognising symptoms of depression and the impact of internalised stigmatisation related to mental health (Latin, 2014) have been found to be a barrier in accessing psychological services.

Lingen-Stallard (2016) quotes Elizabeth Kubler-Ross comparing receiving and accepting an HIV positive diagnosis to someone going through a bereavement process (denial, anger, bargaining, depression and finally acceptance). These

authors described the process of acceptance for the HIV positive women as being able to live “the best possible life”. In time they are then able to recognise their personal resilience and coping skills. This gives them the ability to deal with adversity and be strong. Cal, de Sa, Glustak, and Santiago (2015) describe resilience as the ability to have adaptive responses to adversity such as chronic ill-health experienced by an individual.

In Ghana, Acheampong, Naab, and Kwashie (2017) found that hope, prayer, and belief in HIV medications helped breastfeeding mothers to find meaning in life. Ironically denial was another coping mechanism identified as being the brain’s way of dealing with stress which avoids confronting the ‘truth’. The concept of denial had both helpful and unhelpful aspects for these women but was considered as one of the myriad of coping strategies they employed to help them move forward with accepting their HIV diagnosis. Dibb and Kamalesh (2012) articulate this by explaining that stressful events can challenge core beliefs which in turn mean that individuals try to restore meaning, mastery and self-esteem.

With adversity comes hope, African women, who have children, felt they were the reason to keep ‘strong’ and ‘carry on living’. McLeish and Redshaw (2016) identified that in the UK, Black African women were the highest percentage of people who were HIV positive in terms of pregnancy. This was further highlighted in Lingen-Stallard’s article, who commented on the importance for this group of women, on their development of a ‘new’ identity once they had adjusted and accepted their HIV diagnosis. Part of remaining alive and well, was considered being a ‘good mother’ for their child/ren.

Another aspect of coping was faith. While this has been discussed already, it is important to reiterate that as McLeish and Redshaw (2016) explained, for many African mothers religion gave meaning to their experience of illness. A further important area to mention in this section is the role of non-governmental organisations (NGO’s), or the Charity Sector, which provide a significant contribution to helping HIV positive individuals cope and manage their health in the long-term. In the UK (and London specifically) this is

provided by organisations like Positive East, Positive UK, Body and Soul Charity, and the Terence Higgins Trust. In the developing world the NGO's are often funded from abroad. Some common funders include the United Nations Development Fund and World Health Organisation.

These organisations provide a place where many HIV positive individuals can meet and receive support. The provide a place where the individual can find a community and challenge isolation and loneliness, while developing their resilience to manage their health condition, have the strength to test their children, and begin to think about talking to their child/ren about HIV.

Fearnley and Bolan (2017) found, that parents looked to healthcare professionals for guidance in communicating with children about life-limiting conditions. This was mirrored by children who also looked to the healthcare providers to understand chronic ill-health. While for a number of healthcare workers they found that time constraints and feelings that they lacked the necessary skills and expertise to take on this role, was cited as a reason that critical conversations did not take place about serious health conditions. This appeared to be more relevant in resource poor settings. This particular study was based on the United Kingdom (UK) population, where the impact and disruption to family life caused by chronic ill health, continues to negatively affect the family system and is relevant in relation to the effect it can have on migrant communities. Both UK healthcare staff and the Charity sector, often work together, to address these areas and facilitate coping.

While there are a number of different ways that HIV positive individuals learn to cope with their diagnosis and manage the long-term health implications, there is little research on how HIV positive immigrant African mothers in the UK harness coping strategies. The role of Counselling Psychology in helping HIV positive African migrant populations to cope with their diagnosis and any mental health difficulties related to living with this condition will be addressed in the following section. This study will attempt to address any gaps in the literature and offer any useful ideas that may help HIV positive immigrant African mothers in the UK cope better in future.

2.9.3 The role of Counselling Psychology in HIV

The prevalence of mental health problems amongst the HIV population is considered to be 2-3 times higher than that of the general population (POPPY study, 2013/2014). Evidence has shown that there is a correlation between poor mental and physical health outcomes and a decline in quality of life (BHIVA, 2011). Lampe (2018) highlighted that the mental health of HIV positive people are higher than any other chronic condition. The need for psychological care for adults living with HIV in the UK was identified by the British HIV Association (BHIVA) in 2011, which published the first standards for psychological care. BHIVA has been accredited by NICE for all HIV guidance since 2012.

The aim of the BHIVA recommendations was to recognise the importance of psychological intervention and propose that this could be provided through a 4 stepped-care model. Level 3 and 4 recommends HIV specialist psychological support for PLWH (people living with HIV). According to Orza, Bewley, Logie, Coe, Moroz, Strachan, Vazquez and Welbourn (2015) 70% of HIV positive women experience shame, feelings of rejection, self-blame and depression and of these 50% have co-morbidities. They argue that there is a lack of global policy guidelines addressing mental health amongst HIV positive women. Whilst the UK provides free mental health treatment through the NHS, psychological provision for HIV positive women is primarily accessed through their specialist HIV Centre (Hospital) (Positive UK, 2013). Therapeutic services are offered by HIV charities. Access to psychological therapy varies throughout the country.

Counselling Psychologists are generally trained as evidence-based practitioners to work with patients who are experiencing mental health problems such as anxiety, depression, personality/ mood disorders, phobias, obsessive-compulsive disorders, addiction and self-harm. The HIV patient cohort often presents with complex mental health and therapeutic needs which are well suited for the practice of Counselling Psychology.
Working in the field of HIV, Counselling Psychologists are required to have specialist knowledge and expertise in several areas including, chronic health conditions, pre-and post-test counselling, acceptance and adjustment of

diagnosis, adherence to treatment, sexual health behaviour, disclosure, substance misuse, working with children and families, aging, stigma and discrimination (BHIVA, 2011), (Orza et al, 2015). African populations are disproportionally represented in the HIV cohorts living in the UK. The importance of this study is the aim to understand the lived experience of HIV positive African immigrants living in the UK and by focusing on qualitative data, gain an in-depth and better understanding of the needs of these communities, with the purpose of further closing any gaps that may be present in the literature.

2.9.4 Psychological theories: Understanding the lived experience

Counselling psychologist's employ different psychological approaches to understand and work with their clients. The psychological methodology adopted will depend on the particular presenting problem. This section will explore some of the ways in which counselling psychologists address the difficulties that HIV positive immigrant African women may experience in the UK.

A simplistic explanation of cognitive behavioural therapy (CBT) is the aim to work collaboratively with clients, and focus on the link between their thoughts, feelings and behaviour while helping them identify and modify unhelpful thoughts, assumptions and cognitive patterns about the self, others and the world. (Beck, 1979) In recent decades, the idea of third wave CBT approaches have arisen which target the way the person relates to their thoughts and emotions using a range of interventions such as mindfulness-based training to help facilitate change.

Using CBT (Hawton, Salkovskis, Kirk & Clark; 2001), we can learn and understand what drives some behaviours. Patients, who demonstrate avoidance such as non-engagement with healthcare services or non-adherence to their medication, might be explained by unhelpful thinking patterns and negative feelings about contracting HIV. People who fear contracting HIV might react with a 'fight or flight' response to which a CBT practitioner will help challenge their underlying thought processes that

maintain their behaviour. Evidence of the effectiveness of CBT within the field of HIV was demonstrated in the work of Newcomb, Bedoya and Safren (2015), who found that CBT reduced depression and improved adherence to HIV medication.

In person-centred or humanistic therapy, Carl Rogers (1959) suggests that if we do not have a nurturing parent and they place conditions of worth on their child/ren, people separate from their organismic valuing self and seek approval outside of themselves. Therapy aims to facilitate self-autonomy, self-worth and reconnect the person to their true self (organismic valuing).

Rogers (1959) proposes that 'core conditions' of empathy, genuineness and unconditional positive regard are essential elements to facilitate insight and change. There are numerous studies which show how HIV is heavily stigmatised such as Adeniyi, Thomson, Ter Goon, & Ajayi (2015) and leads to social isolation and rejection. Avoiding testing as well as non-disclosure of an HIV status and non-adherence to medication might be explained by a fear of rejection. Those who have relationships that offer unconditional worth may be more likely to test for HIV, adhere to treatment and disclose their HIV status if they feel that they will not be rejected or stigmatised. Pantelic, Segling and Restoy (2018), identified that person-centred therapy can be used to shift the therapeutic paradigm from standardised intervention and risk focus approaches to that which is responsive and tailored to individual needs. Olsson Jakobsson, Swedberg and Ekman (2013) conducted a systematic review which found that Person-Centred therapy was effective in improving health outcomes for patients with a positive HIV status.

One of the original psychoanalytic theorists, Sigmund Freud (1949), focused on unconscious thoughts that stem from childhood experiences that affect behaviour and thoughts in the here and now. The idea, that the conscious and unconscious parts of the mind can come into conflict and cause distress (state of repression), requires the individual to resolve early developmental stressors, for later mental wellbeing. Within HIV, especially in the early years

of the disease, attachment was often interrupted by loss/death of a parent, and in many instances, this was the mother. The impact on ego development would be affected by this early trauma and affect interpersonal relationships.

The ego which is the mediator between the id and the superego, tries to meet the needs of both and employs defence mechanisms which aim to protect the individual from anxiety by reducing psychological distress and helping maintain balance. (Nelson-Jones, 1990). For example, immigrant women might repress thoughts/experiences about being HIV positive, which may in turn reduce or increase their anxiety and/or depression. The efficacy of psychodynamic therapy is supported by studies such as Shedler (2010). Family therapy, which includes Systemic therapy, enables family members to better understand and communicate with each other to resolve conflict, which might be causing psychological distress (Vetere & Dallos, 2003).

It is a therapeutic approach which has at its core people's relationships as a key to understanding their experiences. Systemic therapists encourage individual family member's participation in sessions, working collaboratively to explore their relationships remaining sensitive to their beliefs and culture. Immigrant women who are HIV positive might have lost their support systems in their country of origin and struggle to re-establish themselves in their new environment. They may have feelings of isolation, be unfamiliar with health, education and social systems as well as dealing with their own immigration, social and economic difficulties (Haour-Knipe, 2009). Immigrant women with a positive HIV status might also experience family rejection or a change in the dynamics within family relationships. The work of Li, Wu, Wu, Sun, Cui and Jia (2006) found that family support is important in the long-term management of people living with HIV/AIDS and systemic therapy can assist with addressing individual's sense of shame and stigma.

Counselling psychologists working in the health sector may employ health psychology theory to understand their patient health beliefs and behaviours to enhance their practice. For example, the Health Beliefs Model (Rosenstock, 1966) focuses on individuals' real or perceived costs and barriers to behaviour

change, cues to action, and perceived severity and susceptibility of their health condition. Despite knowing the positive benefits of treatment, non-engagement to health services might be explained by barriers such as culture, language, financial or logistical challenges. Health behaviours are influenced by other factors including cues to taking action (becoming unwell) and how susceptible or severe they consider their condition to be. An individual, who holds the belief that they will not contract HIV and feels physically well, is unlikely to practice safe sex or seek testing. Individuals, who are HIV positive but do not believe that they will die from this, are less likely to engage in treatment and healthcare services.

The COM-B model (Mitchie et al, 2011) proposes that health behaviours are influenced by a patient's capacity to make decisions about their health, whether there are opportunities to access health care services/ treatment and the patient's motivation. For example, the COM-B Model suggests that even if someone has the capacity to make a decision and are motivated, they will not engage in positive health seeking behaviours if they lack the opportunity to access local health provision. This has been mentioned in earlier studies.

2.9.5 Gaps in Literature, Rationale and Research Question

To reiterate, what has been highlighted above, is that there are a number of gaps in the literature which led to the rationale for undertaking this research project. This study will attempt to close some of these gaps and include for example, how do these positive immigrant African mothers experience healthcare in the UK; how do they experience decision-making, in relation to their partners and child\ren; what the impact of disclosing their HIV status has on their role as a mother, wife and family member; how they adjust to their own HIV diagnosis and that of their child\ren and partner; how these immigrant women experience their diagnosis in the UK, in the context of their own cultural and religious beliefs from their home countries; a further gap in the literature was how these African mothers, when they are diagnosed HIV positive, experience the adjustment process for themselves and their family members whether HIV positive or negative. The research question for this paper focuses on the lived experience of HIV positive immigrant African mothers in the UK.

2.9.6 Summary

The literature reviewed above demonstrates the complex and multifactorial challenges faced by HIV positive African migrant women living in the UK. The role of religion/faith, culture, media, stigma and socioeconomic circumstances has been found to shape and influence the individuals lived experience. These have been shown to impact on their physical and mental wellbeing. The challenges faced by these women, include acceptance and adjustment to being HIV positive. This has a wider impact on intimate relationships, family dynamics and decision-making processes about whether to test child/ren for HIV. By understanding the lived experience of HIV positive immigrant African mothers in the UK, healthcare services can tailor their approach to increase adherence and engagement. To date, there is still a dearth of literature in this area, highlighting the importance of investigating this further. The aim of this research is to offer a more in-depth, richer, analysis than previous quantitative studies have provided. This particular study will investigate the lived experience of a small sample of HIV positive immigrant African mothers resident in the UK.

3. RESEARCH METHODOLOGY

3.1 Overview

This chapter will cover the link between qualitative research and counselling psychology, the rationale for employing qualitative research methods and more specifically the use of Interpretative Phenomenological Analysis (IPA). It will outline the theoretical framework from which IPA was founded, my epistemological position, reflexivity and how the validity was maintained in this study. This chapter will also include a description of the research procedure and methodology used to analyse 'the lived experience of HIV positive immigrant African mothers in the UK'.

3.2 Overview of research design

This research adopts a qualitative research design collecting data from 6 participants. Semi-structured interviews were employed to obtain information on 'the lived experience of HIV positive immigrant African mothers in the UK'. IPA, as described by Smith, Flowers and Larkin (2009) will be used to analyse the data.

3.3 Qualitative methods and Counselling Psychology

Over time there has been a shift of focus from a purely positivist empirical standpoint towards qualitative approaches within the field of psychology. These have offered an alternative perspective broadening not only the scope of research approaches that can be applied, but the type of knowledge that these approaches can generate.

Qualitative methods arguably draw parallels to counselling psychology. Drummond (1996), Bor and Watts (2006), propose that both counselling and qualitative research immerse themselves in observing and questioning the human experience. Smith, Flowers & Larkin (2009) and Willig (2016) describe qualitative methods as being concerned with the lived experience of particular phenomena, uncovering rich and in-depth data. Similarly, for example, Person-Centred therapy, founded by Carl Rogers (1961), proposes that the therapist should aim to 'walk in the shoes' of the client in order to gain as close an insight as possible to their world and how they lived and made sense of their world/experience. Galassi and Gersh (1993) further suggest that

qualitative research methodology and counselling psychology focus on the individual.

3.4 Rationale for Qualitative Methodology

Willig (2016) proposes that qualitative research is concerned with the process of 'how' participants experience and 'make sense of' phenomena as well as the 'meanings' attributed to events. Qualitative methodology specifically lends itself to investigating small sample sizes and extrapolating descriptive, textured and rich data (Smith and Dunworth, 2003) rather than exploring the relationship between cause and effect (Willig, 2016). Langbride (2007) suggests that such data provides a different perspective on phenomena. Qualitative methodology further enables the researcher to understand and capture phenomena within specific social, cultural and historical contexts. In light of the above, a qualitative research approach would seem an appropriate method in which to explore how and what it is like for HIV positive immigrant African mothers living in the UK. This includes capturing participants' sense and meaning-making attributed to these experiences.

3.5 Phenomenology

3.5.1 Overview of Phenomenology

Phenomenology lies in the discipline of philosophy and in particular focuses on the experiential world of individuals within a specific context and time. Phenomenology proposes the existence of multiple experiential worlds and that the same phenomenon can be experienced differently by different people. It is not concerned whether experiences are real or not.

Willig (2016) proposes that phenomenological research aims to generate data on texture and quality of an experience rather than explain it. It aims to answer what is it like to experience the phenomenon within a particular context?'; 'how it is experienced?'; 'what makes the experience what it is?'; 'what conditions make the experience possible to be experienced?'; and 'what is meaningful in an experience and how do these meanings appear?'

The two main approaches in phenomenological studies include descriptive and interpretative analysis. Descriptive phenomenology takes the account at face value, which in itself embodies the meaning of the experience. According to Smith, Flowers and Larkin (2009) the researcher should neither add nor subtract from the experience by minimising any interpretation achieved by 'bracketing' their assumptions. Giorgi (1992) suggest the researcher should stay as close as possible to the individuals account.

An interpretative approach to analysing the data urges the researcher to move beyond the descriptive and shift their focus to uncover the hidden meanings in the text (Smith, Flowers and Larkin, 2009). As described by Willig (2016) interpretative theorists believe that it impossible to remain entirely 'pure' to the account, there will always be some element of interpretation. The researcher may adopt the 'hermeneutics of suspicion', as described by Langdridge (2007). At the point of data collection, accounts are contextualised within cultural, social and psychological norms and deeper meanings are sought by the researcher drawing on their own experiences and interpretations.

3.6 Interpretative Phenomenological Analysis

3.6.1 Rationale for Choice of IPA

This study aims to investigate the 'specific' and 'lived' experience of HIV positive immigrant African mothers living in the UK. It is not an investigation which aims to generate data about social processes and developing theories. IPA is therefore an appropriate method in which to analyse the data as according to Smith, Flowers and Larkin (2009), IPA is suitable for capturing individuals sense and meaning-making that individuals attribute to their experiences. It was also chosen as it importantly 'gives voice' to the accounts of those who are 'marginalised' (Willig, 2016).

Willig (2016) proposes that the epistemological stance adopted by the researcher and research question, dictates the choice of analysis undertaken. My epistemological stance (which is discussed later in this chapter) is in line with IPA theory which includes the understanding that multiple experiential worlds exist; therefore, different people can experience the same thing in many ways. IPA allows the data analysis to capture and represent these

different realities, which this research aims to explore. IPA focuses on analysing each case with a focus on the particulars before moving on to identifying patterns of convergence and divergence between the accounts.

In this study the idea is that HIV positive immigrant African mothers in the UK might share and differ in 'what' and 'how' they experience phenomena. More specifically, 'how' they make sense of their world and what it is like being a HIV positive immigrant African mother in the UK (Willig, 2016). IPA is the preferred methodology as it is concerned with 'quality' and 'texture' of phenomena which encompasses thoughts, feelings and perceptions (Willig, 2016). It aims to understand how and what participants experience whilst taking into account their specific cultural, religious, economic and social backgrounds.

IPA was chosen because its theoretical approach concurs closely with my own ontological position. This posits that what type of knowledge we can acquire from participant's accounts include both explicit and implicit meanings about their experiences (Willig, 2016). IPA facilitates this and allows for the interpretation of data to occur on many levels (Larkin, Watts and Clifton, 2006).

Willig (2016) proposes that how the researcher approaches language is fundamental to the methodology selected for qualitative data. As my epistemological stance aligns closely with IPA theory concerning the role of language; this further supports my choice of methodology. My epistemological stance and IPA share the view that language is considered a fundamental aspect of how people 'capture' and express their experiences (Smith, Flowers and Larkin, 2009). Participant's communication of their meanings and sense making is dependent upon their linguistic ability to utilise words that best capture their experience (Willig, 2016). From an IPA conceptualisation, experiences are constructed through language including metaphors. Shinebourne and Smith (2009) suggest metaphors communicate unexplored, unexpressed and unrecognised meanings.
Finally, Willig (2016) suggests that IPA facilitates a reflexive process for both participants and researchers. Adopting this approach may benefit participants

in assisting them to make better sense of their experiences as an HIV positive immigrant African mother living in the UK and the meanings they attribute to these phenomena.

3.7 Phenomenological Origins and IPA Theory

IPA has its philosophical theoretical underpinnings in phenomenology, hermeneutics and ideography. These concepts are explored below.

3.7.1 Phenomenology

Phenomenology, proposed by Husserl (1927), contributes to the theory and practice of IPA. According to Husserl (1927), the researcher should step outside of the everyday lived experience in order to return to 'the things themselves', perceiving them as they occur and within their own right. 'Bracketing' assumptions of a lived experience enable us to capture the essential qualities of that experience as it unfolds (Smith et al 2009) and (Willig, 2016). Husserl (1927) referred to this as the 'experiential content of consciousness'. Through the process of reflexivity, researchers rid themselves of their *'taken for granted' attitude* (*Husserl, 1927)* and pre-conceived assumptions. This facilitates new understandings of participants' accounts to emerge. The researcher is able to identify and capture the richness of the lived experience (thoughts, feelings, values and meanings) by shifting their attention away from the physical experience to a more inward reflexive process.

3.7.2 Hermeneutics

Heidegger (1927, 1962) argued that experiences can never be fully understood in its entirety because it is dependent on the author's ability and openness to explicitly state their meanings attributed to their account. Heidegger (1927, 1962) proposed that these hidden meanings can be identified through interpretation, which is the basis of hermeneutics.

According to Smith et al (2009) the purpose of hermeneutic enquiry was to understand Biblical texts. In contrast to Husserl (1927), Heidegger (1927, 1962) postulated that bracketing limits the ability to understand an account in depth. Tentative interpretations of text help identify hidden meanings whilst

not assuming the existence of meanings that are not there.
Gadamer (1990) argues that meanings identified in texts using an interpretative approach is influenced by the moment in which these interpretations are made. Gadamer (1990) further proposes that the researcher cannot be truly objective or maintain a critical distance. This is because as researchers our own prejudices and beliefs influence the way in which we engage with the text. Despite making use of reflection, we are not always aware of our preconceptions until we embark on the interpretative process whether conscious or unconscious.

The process of 'bracketing' pre-conceptions aims to limit the influence of bias on the part of the researcher. Bracketing should be circular as described by Heidegger's (1927) hermeneutic circle, facilitating the movement of unconscious pre-conceptions into the conscious so that priority can once again be given to new encounters with data. This proposes that texts should be understood as a whole as well as the sum of its parts, moving in a circular motion. Gadamer (1990) suggests that analysis of the 'whole-part' relationship can occur on multiple levels offering different meanings and perspectives. Smith and Osborne (2003) describe double hermeneutics as when the researcher tries to make sense of the participant's sense-making, taking on a duel role in hearing the participants' experiences whilst simultaneously viewing the account from their own lens.

In contrast to Ricoeur's (1970) 'hermeneutics of empathy', Merleau-Ponty (1962) argues that experiences are unique to an individual, and our ability to understand that experience is limited to own experience of that phenomenon. Schleiermacher (1998) suggests during the process of interpretation, texts should be contextualised by the author's linguistic ability to communicate experiences as well as their intentions for how the account is received. Moustakas (1994) and Heidegger (1927, 1962) recognise the importance of how human experiences are based on their social, and cultural norms (Dasien concept), economic, political, historical (Dilthey, 1976) and environmental contexts.

3.7.3 Ideography

Another important influence in IPA is ideography. An idiographic method concentrates on the individual and proposes that everyone is unique and should be studied in their own right. Ideography involves both description and understanding, which is significant for scientific investigation and exploration? The significance of ideography is the idea of small, homogeneous sample sizes; detailed and in-depth analyses which as Smith, Flowers and Larkin (2009) illustrate has a commitment to the 'particular' while being thorough and systematic. 'What is it like for a specific individual to experience a particular phenomenon within a particular context'? By focusing on individual cases, the researcher is then able to examine the differences and similarities between explanations before being able to make general clarifications about the 'specific'. As Willig (2016) clarifies, ideography is concerned with the particular, rather than the general.

3.8 Limitations of IPA

IPA is concerned with an individual's unique experience as well as the particular, which according to Malim, Birch and Wadely (1992) propose limitations with regards to data being generalised to the population. Pringle, Drummond, McLafferty and Hendry (2011) further suggest that IPA, as discussed by Smith, Flowers and Larkin (2009) is subjective and intuitive, which may lead to problems in clarifying the important aspects of the experience.

As the nature of IPA is to describe rather than explain an experience (Willig, 2016), IPA is limited in that the data cannot be used to generate theories or provide answers to the questions such as 'what caused the phenomenon' or 'why a phenomenon occurs'.

IPA relies on the participant to convey their meanings through language (Willig, 2016). This in itself creates the potential for these to be missed or misrepresented when participants are unable to use the correct words to capture their meaning. This may be more prevalent with participants whose first language is not English.

According to Shinebourne and Smith (2009) meanings identified in texts, are limited by the researcher's ability to identify them, and represent them in a way that encompasses them in its original form.

3.9 Alternative Methods of Analysis Considered

Narrative analysis was one of the methodologies considered for this project. Gergen and Gergen (1988) suggest that this theoretical approach concerns itself with the 'structure' of a 'story' or the way in which the 'story' is told to understand life experience. Smith, Flowers and Larkin (2009) further describe this as a form of constructionist enquiry which is closely linked to discourse analysis.

Discourse analysis endeavours to investigate a person's experience by focusing on the structure of an experience. This includes a line of investigation which captures the structure of expression such as word order or the formation of a sentence.

Narrative and Discourse analysis were discounted because the purpose of the study was to understand cognitions as a 'sense making process' rather than an "isolated separate function" focused on structure as illustrated by Smith, Flower and Larkin (2009).

Grounded Theory (GT) founded by Glaser and Strauss (1967) was another methodological consideration as it aims to understand human experience. Similar to IPA, both approaches involve systematic analysis of data (Woolfe, Dryden and Strawbridge, 2006). GT was not deemed appropriate because its intention lies in generating new theories/explanatory concepts which offer a 'theoretical-level account of phenomena'. It also aims to identify social processes that can be applied to the wider population (Smith, Flowers and Larkin, 2009).

IPA and this study seeks to understand and capture the essence of individual lived experiences, which is understood initially on a micro and requires a more in-depth and subtle analysis (Smith, Flowers and Larkin, 2009). These authors further suggest that the micro processes can lead to developing 'enriched' macro accounts. In contrast GT analyses data on a macro level, looking at the convergence and divergence of emerging categories, rather than the specifics of individual accounts (IPA).

4.1 Epistemological Stance

Epistemology is the study of knowledge which seeks to answer the questions what is and how is knowledge acquired. It is an explanation of the way we think and is important to be able to determine true from false through the process of evaluation. The researcher's epistemology is based on the historical tension between a more traditional, experimental approach (quantitative) which is measurable; versus a critical, discursive (qualitative) approach which sees social reality as mutually constructed between people in the real world? As Willig (2001; 2016) illustrates, epistemology is a means for the researcher to identify their goal and justify choice, but also needs to be clear about the objectives of the research and a sense of what kinds of things (information) are possible to uncover. As Willig explains, questions that help establish the researcher's epistemological position include what are the aims of the research, what type of knowledge is generated through the methodology, what assumptions have been made about the world and how do we claim to know what we know?

4.1.1 Interpretative Phenomenology and Relativist Ontological Position

In this study, my aim was to create meanings from participant's accounts of their own experiences and understand how they made sense of these while keeping as close to the data as possible. In addition, by focusing on their inner world and staying close to the data I hoped to understand their cognitions and affect, and in turn how these thoughts and feelings helped obtain an 'inside' perspective of the participants 'world'.

Following Smith, Flowers and Larkin's (2009) IPA analysis methodology, I initially immersed myself within the data and focused on the descriptive element of the accounts. I progressed into interpretation as I adopt an interpretative phenomenological stance. By approaching the data from this standpoint, hidden meanings can be identified.

By asking the question, what is it like to be an HIV positive immigrant African mother in the UK, I adopted a strong interpretative phenomenological position and focused on their sense-making process. I hold a relativist ontological stance and concur with the view that people's realities are comprised of their lived experiences and these are subjective (Smith, Flowers and Larkin, 2009). Furthermore, these are shaped by our thoughts and lend itself to the philosophy that there are multiple worlds. The findings of this study reflect individual's subjective worlds, rather than focusing on whether the experience was real or not.

As part of my interpretative process, I believe that the meanings that participants attribute to their accounts are both explicit and implicit. Accounts may hold hidden meanings, which can be identified by interpretation as proposed by Heidegger. In order to extrapolate the meanings participants, attribute to their accounts, the researcher is required to be reflective and be aware of any bias or subjectivity they bring to the research process and analysis.

4.1.2 Hermeneutic/Phenomenological Epistemology

Reflecting on theory of interpretation (Hermeneutics) I adopt a similar view to Gadamer (1990), that researchers are unable to maintain full objectivity when interpreting implicit meanings. Data generated may be influenced by my own biases. I acknowledge that even with the use of bracketing, there may be preconceptions that I am unaware of. This may have influenced the analysis process and findings, with respect to identifying hidden meanings that do not exist. To minimise this, I asked a colleague to check that the meanings I identified, do in fact exist or those that exist were not overlooked. As there is a risk of some of my preconceptions not being in my conscious awareness I

engaged in reflective practice before, during and after reading the transcripts.

Heidegger's (1927) hermeneutic circle informed the way in which I analysed the data. I attempted to understand participant's accounts on different levels, looking at the whole of their account, as well as the sum of its parts, moving in a circular motion between the two.

As highlighted by Smith and Osborne (2003) I also analysed the data utilising the concept of double hermeneutics. This entails the researcher making sense of participant's sense and meaning-making (Smith, Flowers and Larkin, 2009).

I also share the view of Moustakas (1994) and Heidegger (1927, 1962) that the way that people make sense and directly experience phenomena are shaped by their cultural and social norms. I contextualised participants' accounts holding in mind their background and the influence this may have had on their sense-making. Treating the data in this way however has its limitations as I do not share the same backgrounds of the participants and cannot assume that my understandings or any possible assumptions were accurate. This meant that I drew upon reflective practice to minimise researcher bias.

Coyle and Lyons (2007) propose that contributors may use words/language in a different way to the researcher. Sharing this view, I attempted to make sense of/interpret how participants used a word to capture meaning. I acknowledge that my ability to fully capture these meanings is limited by my own use of language and the meanings I attribute to the words of participants. I accept that I may never completely understand or experience someone else's experience and that the findings are an attempt to get as close as possible to the participant's accounts.

4.2 Reflexivity

Reflexivity is the process whereby the researcher maintains both an awareness and critical stance towards the impact that his/her own role has on all aspects of the research. (Kasket, 2013) In addition, as counselling psychologists, there needs to be an awareness of how subjectivity impacts on

the work that they do (Orlans and Van Scoyoc, 2008). This means that when involved in a research undertaking, the counselling psychologist needs to be aware of their relationship to the topic, and this can be mediated through the process of reflexivity. These are some of the core values of counselling psychology research and practice, which involve the process of reflexivity.

Willig (2016) identifies two specific areas of reflexivity that pertain to the field of counselling psychology research. This includes both personal and epistemological reflexivity. IPA proposes that part of qualitative research is an acknowledgement and demonstration of the researcher's understandings and preconceptions about the topic being investigated (Finlay and Gough, 2003), including data collection and analysis. Willig (2016) highlights the difficulties in remaining impartial when doing qualitative research.

4.2.1 Epistemological Reflexivity

In trying to understand my own role in relation to this topic, I needed to as Willig (2016) says reflect on my own assumptions and biases, and how these may have impacted on the research process and the study findings. Professionally, my previous qualifications and training, as well as my role as a counselling psychologist, has exposed me to a number of different theoretical perspectives which have helped challenge my assumptions and beliefs. The current popularity of evidence-based research which originates from a positivist/post-positivist epistemological perspective is limiting in that it focuses on quantitative data, often to the exclusion of qualitative and interpretative explanations. On the other hand, the constructivist/interpretative paradigm emphasise the goal of understanding the 'lived experience' of the participant and these occur in a historical social reality. Sometimes these experiences may lie outside immediate awareness, but it can be argued that these can be brought into consciousness.

Larkin, Watts and Clifton (2006) argue that there are many levels of interpretation. I take the stance that data can contain explicit and implicit meanings which can be identified by adopting an interpretative phenomenological position. I adopt Heidegger (1927, 1962) idea that as a researcher I could never fully understand my participants experience and

therefore my findings do not claim to capture their experience entirely but rather offers an understanding of the participant's sense and meaning-making as closely as possible.

In IPA research the importance of linguistic elements cannot be overemphasised, as language is a core component of understanding culture. Fairclough (1995) has highlighted this by encouraging researchers to be aware of how they use language and the implications for findings in the research process. Although interviewees have lived in the UK for many years and had a level of proficiency in the English language, it was not necessarily their first language. For these participants their ability to capture meanings using precise words may have been limited. No assumptions can be made about the meanings they attributed to the questions, or my understanding of their use of language.

4.2.2 Personal Reflexivity

The idea of personal reflexivity for the counselling psychology researcher involves the way in which their own values, beliefs, culture, economic, political and social background influences their experiences and shaped the way they approached the research. In the following paragraphs I will focus on how I may have influenced this study.

I am an older, White South African woman who moved to the UK decades ago and had lived and worked in areas designated as 'townships' before moving countries. These resource poor environments saw extreme poverty and lack of medical facilities due to the Apartheid (separate development) system. Prior to HIV being identified and named, I was exposed to people living and dying from 'slimmer's disease' which later became medically understood as HIV/AIDS. This sparked my interest in working in this field and addressing what was, and remains today, a heavily stigmatised and marginalised condition.

I hoped that through this research process, participant's voices would be heard and that they would be able to make better make sense of their own experiences. Through sharing their stories, I also hoped that this may

contribute to a better understanding of what it is like to live with a HIV diagnosis. In part I wondered why in 2019 stigma was still so prevalent and how this research might help contribute towards challenging negative attitudes and addressing, in a small part, a gap in the literature.

My research question emanated from working with marginalised communities, particularly HIV African migrant mothers in the UK whose voices appeared 'in-visible' in the literature. The lived experience and challenges facing these women, including disclosure and testing of their children, are not fully understood or recognised. By addressing this specific research question, it was hoped that new information would emerge which might highlight gaps in service provision.
In this particular study, the choice of IPA seemed like a natural fit for investigating the lived experience of HIV positive African migrant mothers and provides an in-depth, rich understanding of data. This may have arisen as a result of my current practice as a counselling psychologist in a secondary care, large academic teaching hospital and the responsibilities I hold within the multidisciplinary team. After attending a meeting in December 2008 entitled 'Don't Forget the Children' my professional interest as a psychologist was triggered by the difficulties I noticed between both the medical team and HIV positive African migrant mothers when deciding whether to test their child\ren for HIV.

I had already experienced these problems first-hand as the psychologist responsible for trying to encourage these mothers to agree to this test. Why did it take some parents almost three years before they agreed to what is a relatively 'simple' medical test? I became increasingly curious about the processes, experiences and 'lived experience' for this relatively small, but significant cohort of adults. This led me to include questions about testing children in my interview schedule and how culture and religion played a role in their decision-making and overall experience about living as a HIV positive African immigrant mother in the UK.

I wanted to know more about the fears, obstacles and relationships involved. I noticed within the medical establishment a very pragmatic, 'matter of fact' type

of approach to an area that encompassed so much evident sensitivity and at times a conflictual relationship between provider and service-user. I was navigating the concerns of professionals, myself included, of possible undiagnosed HIV, and the impact on society and on the other hand as a psychologist the core values of our profession which includes working at a client (patient's) pace, offering a non-judgemental approach and facilitating therapeutic change rather than directing or forcing change.

So often, gender, and power dynamics need to be considered and influence the way that we approach research. As Kvale (1996) so clearly illustrated, reflexivity is one of the underlying threats to accuracy of research outcomes because of the relationship between interviewer and interviewee. It is the process of reflection, and in IPA research, the idea of 'bracketing', that allows us to reflect on this power dynamic and think about how race, socio-economic factors, cultural background, to name a few factors may influence the research process. It is Finlay's (2002) five approaches to reflexivity that helps address these possible biases. A reflexive journal is an important part of this process and can mediate too many preconceptions or prejudices informing the research process. In my own situation, being a white, older student who had been practising as a psychologist for many years needed to be considered when undertaking this research project. I was also someone directly involved in this form of HIV testing and wanted the opportunity to 'step outside' my current practice and focus on this from the point of view of the researcher. This was part of the reason for undertaking this project and influenced everything from the interview schedule through to the data analysis and subsequent findings.

My identity as a white, South African born, practising counselling psychologist, working in the area of HIV and Infectious Diseases inevitably would influence my interactions with participants. It is for this reason that the recruitment stage was considered in the way that it was, and a decision was made that I would not interview anyone that knew me in either my professional or voluntary capacity. I did not want this to impact on the IPA methodological process. As difficult as it was going to be, I wanted to 'bracket' my professional and personal knowledge as far as possible. My accent alone would usually tell

people that I was not born in the UK and as a white, South African, of my generation would also tell them that I was a product of a particular time in history. All of these important factors needed to be taken into consideration throughout this project and influenced my choice of methodology.

I offered participants a number of choices, such as whether they wanted to volunteer to be interviewed in the first place as they were either approached by a voluntary sector worker or they had seen the advertisement in the local community organisation, where this interview would take place, timing and venue was considered, amongst other areas. To address, for example, an area such as the power imbalance, this saw me travelling around the country at different times of day/night to facilitate the most participatory, collaborative approach as possible. The aim was also to help interviewee's feel more relaxed and provide an element of safety they may not have felt in a venue of my choosing. Interviews took place in both home environments (primarily) and in a few voluntary sector organisations. In one situation I drove around for hours as the house was not on any maps as it was a new housing estate. While the interviewee had a speech impediment, her teenage son had house music cascading from his bedroom and affecting my recording devices. All of this illustrates my attempts, at trying at all times, through the interview process to be aware of my position as a researcher and to facilitate an ease of process for the interviewee. Primarily this allowed me to embark on the role of the researcher, rather than the professional psychologist.

4.3 Validity

Validity can be defined as the degree to which the investigation measures, describes or explains what it intends to (Willig, 2016). Consulting Yardley's (2000) principles of assessment I have considered the validity of this research. 'Sensitivity to context' entails the detailed review of current literature about the subject of interest, of which there are limited studies. Given the subject matter it was important that questions were asked in a sensitive manner to ensure the way in which data was collected met these principles. I considered the social and cultural context and the role this played in the research when exploring parents' experiences of testing their child/ren for HIV.

I met the principle of ‘commitment and rigor’ by adopting a curious mind and by bracketing my assumptions during the analysis process as described by Gadamer (1990) to follow participants accounts as closely as possible.

To ensure rigor the study used a sample which was homogeneous with regards to all participants having experienced living in the UK as a HIV positive African mother, and decision whether to test their child\ren for HIV. To ensure this, I approached HIV voluntary sector organisations across the country to advertise the research. Rigor was further obtained by periodically checking my understanding of participant’s accounts in the interview process. The following principle of ‘transparency and coherence’ requires the researcher to be open and clear about the stages involved in the study. Transparency was facilitated by clearly outlining my research objectives, recruitment procedure, interview schedule and choice of analysis.

Throughout this time, I made use of a reflexive diary so as to be aware of my influence on meanings identified in the text. Peer reviews of the study findings (checking themes against transcripts to ensure their existence and accuracy at capturing meaning) were conducted at points during the analysis stage. This enabled the themes identified in the analysis to remain coherent and logical.

Yardley’s (2000) fourth principle ‘impact and importance’ requires the researcher to consider the impact of the study findings, which will be described in the discussion section.

4.4 Procedures

4.4.1 Participants

Samples were selected purposively as according to Smith, Flowers and Larkin (2009) they have experience and provide an insight into the phenomenon of interest. The sample size selected (6) was small because IPA is partly concerned with ideography (Willig, 2016). Participants were homogeneous in respect to all participants having the experience of being an HIV positive immigrant African mother living in the UK.

During the recruitment process I initially did not offer a financial incentive for participation. However, at the early stages of recruitment I was contacted by a service user/Director of a voluntary sector organisation where I was advertising, to insist that some remuneration needed to be provided. She felt this was the least I could do if people volunteered to come forward and be interviewed. We agreed that a small Mark's and Spencer's voucher, including reimbursing any travel costs, would suffice.

Subsequently I went back to all the organisations to inform them of the above. The remuneration did not appear to be the incentive for participation, as interviewees appeared to not only want to tell their story but went to great efforts to participate. For example, some participants called me back straight away after having missed my call in order to secure an interview and made further telephone calls until we spoke, they were also keen for me to interview them in their home environment or were flexible and met me at a suitable venue such as the organisations office. In either case this was in a place where they felt most comfortable.

4.4.2 Difficulties in Recruitment

The sensitive nature of this research topic caused me to wonder how easy it would be to recruit participants. I was surprised at how quickly people responded to my recruitment poster. In only one instance did a male participant who had contacted me on numerous occasions and arranged to be interviewed, fail to turn up or notify me. He subsequently did not make any further contact with me to facilitate this process.

4.4.3 Inclusion Criteria

Participants were required to be: (a) HIV positive parent; (b) experienced the decision making process as to whether or not to test their child\ren for HIV (c) their child\ren had not been through the UK antenatal system, or their diagnosis came after they had given birth and (d) they needed to live in the UK and be able to communicate in English.

4.4.4 Exclusion Criteria

The exclusion criteria included parents whose child\ren had been through the UK antenatal system, after they had been diagnosed HIV positive, and followed routine HIV antenatal screening procedures (therefore after eighteen months being aware of the child's negative HIV status). The parent could either have already known that they were HIV positive or been diagnosed during pregnancy.

4.4.5 Recruitment Procedure

Once I had been given and received my ethical approval from the University, I then contacted all the voluntary sector organisations in the UK working with HIV positive communities. I generally spoke to one of the senior, employed members of the organisation and explained the purpose of the research project and asked whether it was possible to send them my recruitment poster, and other information (including ethics approval) to help them make a decision as to whether they would support the recruitment process (please see Appendices A-F). I agreed to follow this up with a telephone call a couple of weeks later to hear their decision, which I did. I contacted over nine different organisations both within London, and also included Hertfordshire, Brighton, Eastbourne, Birmingham and Manchester.

Table of Participants						
Pseudonyms	Alison Interview 1	Yolanda Interview 2	Harriet Interview 3	Susan Interview 4	Eleanor Interview 5	Eve Interview 6
Age	38	34	37	41	35	54
Birth place (region)	West Africa	East Africa	West Africa	East Africa	Southern Africa	West Africa
Current country of residence	UK	UK	UK	UK	UK	UK
Ethnicity	Black African	Black African	Black African	Black African	Black African	Black African
Relationship Status	Single	Single	Married	Married	Married	Married
Country where HIV status diagnosed	UK	Europe	West Africa	UK	UK	UK
HIV status of child/ren	Negative	Positive and Negative	Negative	Negative	Positive	Negative

On the whole, the responses were very positive and supportive. Despite increasingly difficult funding situations the organisations were welcoming and helpful. They quickly put up my recruitment poster and also included this on their websites. Three organisations periodically contacted me to see whether I had heard from any of their service-users and if I needed more participants.

4.4.6 Final Sample

Six female participants, who ranged in age from 34 to 54 years old, all from East, West or Southern Africa. They had all been through the UK immigration process and were now settled and more secure in the UK. Their employment, marital status, and educational backgrounds all varied. There were also few cultural and religious differences amongst the group, despite my awareness that there are significant differences across and within African communities.

4.5 Research Procedure

Whether arriving at one of the participant's homes or at an organisational venue, I followed the same process. After introductions, I asked them to sign a consent form (Appendix B) having reiterated the purpose of the study and giving them a participant information sheet (Appendix A). I ensured that they still wanted to be part of the research and reminded them they could withdraw up until a certain date. I also had their voucher ready in an envelope which they were given with the information sheet. If they had travelling expenses these were paid at the same time. We discussed confidentiality and I reminded them that on the information sheet were my supervisor's name and contact details.

I showed them my recording devices and we found a place for these to remain (as unobtrusively as possible) for the duration of the recorded interview. Most of the interviews took just under one hour but ranged from twenty-five (first interview) to fifty-seven minutes. On completion they were given a debriefing form (Appendix C). The interview was focusing on the participant living with a life-threatening, stigmatising condition and the difficult area of their child/rens health. I was aware as a practising psychologist that although they may not have been aware of any emotional distress during our interview, this may

arise later, so during the debriefing I offered them options (Appendix C), if needed, and they had my contact details already.
Most of the recruitment materials had been included in my ethics form and were standard requirements of conducting qualitative research. Finally, the participants had an opportunity to ask questions and add any information that had not been covered during the interview.

4.5.1 Data Collection

4.5.2 Interview Schedule

Semi-structured interviews were used to explore parent's experiences of testing their child/ren for HIV. This interview schedule (Appendix F) was developed using both the guidance from the literature (Smith, Flowers & Larkin, 2009), attending an IPA workshop, supervision, presenting this to both my University colleagues as well as the London IPA Group. As a result, there were various iterations of this, until the final schedule which tried to move from the general to the specific. Although the first interview served as a form of pilot, minor modifications, were made which were primarily clarifying language, especially as most participants' first language was not English. Prompts were only used if more information was needed, to capture meaning and experience.

The idea was to interrupt participants as little as possible, while allowing for the flow of information. The semi-structure questions aimed at helping them to explore their experiences and express themselves in their own words, and for me to gain a better insight in to how they experienced and made sense of their experiences. Because English was generally not their first language, I tried to ensure that the validity of the data was not compromised, by my lack of comprehension of what was being shared, so sometimes I asked for clarification or checked my own understanding of what was being communicated.

Finally, at the end of each interview, I spent some reflective time thinking about both the pace and tone of each participant, my own responses to the experience, and whether this could have been conducted differently in any

way and on my role as both a researcher and whether I had enough ‘distance’ as a therapist.

4.5.3 Rationale for Choosing Semi-Structured Interviews

Exploring the participant’s world in IPA, involves trying to understand meaning and sense-making for the interviewee. By choosing semi-structured questions, the idea was for participants to ‘tell their stories in their own words’ and gain a deeper grasp of their individual experience(s) which in turn would facilitate my understanding of the phenomenon being explored. How did immigrant African mothers experience living in the UK with an HIV positive status? As part of this, how and what challenges did they face as an HIV positive woman and mother, such as making decisions around disclosing their status to their family, communities and deciding whether or not to test their child/ren for HIV?

Semi-structured interviews are less directive, more open-ended and encourage a bottom-up approach. Unlike quantitative, positivist approaches, they do not reduce participation to set categories but facilitate dialogue and a different form of exploration. Willig (2016) illustrates this by saying that by not pre-coding meanings, a phenomenon can be explored fully helping gain new perspectives and meanings.

In addition, as Coyle (1998) makes reference to the similarity between an interview and therapeutic practice in their structure and substance, the use of semi-structured interviews seemed appropriate. The balance between using my therapeutic skills and wanting participants to be able to share their experiences in an open manner were further encouraged. An important point made by Woolfe, Dryden and Strawbridge (2006) about the nature of interviews, was that they are reactive, and that the interviewee responds to the attitude and comments of the researcher which shape how and what a participant discloses during the interview

Environmental factors also impact on the interview process so as Smith, Flowers and Larkin (2009) highlight, this needs to be considered too. In this study, participants chose where the interview would take place giving them a certain level of control and flexibility.

4.5.4 Interview Limitations

While semi-structured interviews were seen as the most appropriate for this research project, there are of course also limitations which should be mentioned. According to Smith, Flowers and Larkin (2009), interviews are only a brief glimpse of participant's sense-making at that particular point in time and are not easily standardised. As already highlighted, the interviewer's skills and style can also influence the process (Hayes, 2000). Besides other possible limitations, interviews were chosen for this piece of research as most likely to be able to explore parent's experiences and obtain in-depth, rich data to be analysed.

4.6 Ethical Considerations

I obtained ethical approval from London Metropolitan University (See Appendix G). I adhered to the ethical standards of the BPS (British Psychological Society) and HCPC's (Health Care Professions Council) Code of Ethics and Practice. To reiterate, this was shared with organisations and participants throughout the recruitment stage and subsequent interviews.

The recruitment poster allowed participants to self-select and decide whether to participate in the first place. During introductions, further clarification was given that their recorded interviews would be stored securely, destroyed when no longer needed, as expected from the Data Protection Act (1998). While the study findings were to be used for research purposes it was also discussed that if later the research were published, anonymity would be ensured, and that transcriptions would be for the researcher and if requested seen by the research supervisor. Any transcriptions included in the final thesis would again be checked to ensure confidentiality and anonymity.

I was aware that the subject matter was of a sensitive nature and needed to be dealt with sensitively and ethically.

4.7 Transcriptions of Interview Recordings

I transcribed and anonymised the digital recordings. These were transcribed verbatim in order to capture the interviewee's tone and communication style. This also helped me to stay as close to the account as possible.

4.8 Analytical Procedure

The process of analysis in IPA is lengthy and requires close consideration be given to all aspects of the interview. This requires repeated listening to audio recordings, note-taking, attention to the meta-communication as in tone of voice, nuances, innuendo, and so on as well as a detailed focus on the nature of the relationship between the interviewer and interviewee. Once the first transcription has taken place, according to Smith & Osborn (2003) and updated in Smith, Flowers & Larkin (2009), a systematic process is followed, and this is repeated for each transcript.

4.9 Initial Notes

Detailed notes were kept from each of the six interviews. IPA focuses on a detailed exploration of each participant's views of the world, their thoughts (cognitions), meaning and sense-making processes and aims to enter the internal world of the interviewee. I noted descriptive comments including what the participant said; and moved on to linguistic elements that looked at their use of language; and finally concentrated on the participant's conceptual framework which had a focus on semantics that aimed to capture implicit meanings in the text through the process of interpretation. A former student offered a very helpful suggestion of reading my transcripts backwards to scan words/phrases as single units of meaning, which gave a very different view of my data and helped develop my understanding from a different perspective.

5.1 Emergent Themes

After re-reading transcripts many times, and considering all the notes already written down, on the other side a column was made where emergent themes were noted and regularly reviewed. This column represented emerging interpretative themes. Smith, Flowers & Larkin (2009) offer a clear and systematic way to analyse data in IPA and encourage the researcher to list all emergent themes while using a process of continual reflection and

re-examination to ensure that I was staying as close to the participant's account as feasible (i.e. the hermeneutic circle).

These emergent themes needed to be consistent with the interviewee's communication rather than me being too interpretative or extrapolating meanings that were not in a particular transcript. Certain themes were then dropped, and others could be expanded upon dependent on their relevance to the research question or whether they were an accurate representation of the specific transcript. These themes were later revisited in relation to whether they held any other meaning for the participant.

5.2 Emergent Themes: search across cases

As already mentioned, and reiterated by Smith, Flowers & Larkin (2009), this process was repeated for each transcript and master lists of themes were compiled. On completing each individual process, I checked for new emergent themes. By completing a table (Appendix H) I could look for similarities and differences and cross-reference these with across transcripts.

5.3 Developing Themes and Constructing a Master Table

This process involved grouping emergent themes in a number of different ways until it felt like they were in their correct place. Besides two colleagues from the London IPA Group, I also asked another qualified psychologist who had completed their training a few years previously to look at my clustering and comment on whether my emergent themes seemed to be true to IPA. Confidentiality was maintained at all times.

The super-ordinate themes came from comparing my master list of emergent themes and grouping these that were related in meaning. This again was a time-consuming process as I printed all the emergent themes out, cut each one separately and placed large sheets of flipchart paper on the wall. There were many emergent themes and with the use of blu-tac I was able to move them around and cluster them together. This process took place several times and finally a table of sub-themes and super-ordinate themes emerged, which will be illustrated in the analysis section.

6. Analysis

6.1 Introduction

The superordinate themes detailed in this chapter were generated from the analytic process as outlined in the methodology chapter (chapter 2). The themes identified encapsulate a proposed interpretation of the participants' sense of meaning-making of their experiences.

The following chapter consists of quotations from the interviewees' transcripts that aim to capture the meanings attributed to experiences. Quotations included in this section will be referenced by their line, page and transcript number. Pauses in accounts are represented by 3 dots i.e. text taken out is shown by three dots in brackets […].

6.1.1 Overview of Superordinate Themes

The Master Table of themes (see Appendix I) comprises of three superordinate themes and eleven sub-themes. Following the clustering of sub-themes, the following three **superordinate** themes were constructed:

1. **The quest for survival**
2. **Impact of diagnosis on identity**
3. **"It's there, but HIV is not me..."**

The table below represents the superordinate themes and their sub-themes. *Figure 1*

Superordinate Theme

Quest for Survival

Sub-themes

- *Negotiating Survival as an Immigrant*
- *Fear of Dying*
- *"...Take the virus out of me"*
- *"You'll be looked after"*

Superordinate Theme

Impact of Diagnosis on Identity

Sub-themes

- *Shame, Blame, Secrecy*
- *The struggle of life-long medicine taking*
- *HIV affected my family*
- *"My Faith is kind of shaken..."*

Superordinate Theme

"It's there, but HIV is not me..."

Sub-themes

- *With others strength and resilience is found*
- *Transitioning to a 'New Normal'*
- *Working through challenges as a positive African mother*

6.2 Superordinate theme 'Quest for Survival'

The superordinate theme 'Quest for survival' represents participant's (and/or family members) suspicions that they were unwell and how the fear of ill-health and death motivated their journey to seek medical treatment outside their country of origin in a bid to survive. As part of this, participants had to navigate different health care systems, which presented a number of challenges and obstacles. Participants experienced the need to seek medical help (treatment), whilst having to cope with the impact of an HIV diagnosis as an African Immigrant mother in the UK.

6.2.1 *Negotiating Survival as an Immigrant*

The participants' decision-making process to leave the country of their birth and live in the UK appeared to be partly driven by their experiences in their home country and assumptions about their survival.

The majority of participant's reported having entered the UK to visit relatives. It was during this visit, that their ill health became noticeable to family members who encouraged them to seek medical treatment. For other participants their ill-health was already evident and they had been encouraged to travel to the UK and seek medical assistance. The following extract from interview 3 captures the common theme across the majority of women, who once seen by medical providers in the UK, learn about their HIV.

"…I came here for my daughter's graduation, so I has on a short visit. …Then I got, a, it was cold, I got some sore throat, so my daughter took me to the GP…. the doctor told me, what happens if I tell you that you've got HIV? I told him, if you tell me I've got HIV, I'm here, I'm a visitor here and there is no medication for HIV" (in Africa) (8-16/2/3) [Harriet]

Participants who already had a diagnosis of HIV and were living in their home country were also encouraged by family member to enter the UK and seek treatment. There seemed to be an understanding that an individual's survival was better guaranteed if you came to a country like the UK and received HIV treatment. This is illustrated in the following quote, whereby the participant's mother had insisted she leave her country of origin.

"…and when I went inside the caravan (mobile health unit), they told me that I was infected, and that was, a shock. Because of the stigma in my country, my mum said, my mum made a good research....and I have heard that England is the best country in the world to get treatment. So I think you should go" (32-36/4/6) [Eve].

In Africa accessing healthcare involved financial costs and was laden with perceptions of stigma from others. When they arrived as immigrants in the UK they were worried about the cost of healthcare and feared exposure and valued anonymity because of these past experiences. When they realised this was 'free' and available they could relax and not worry as much as before. This is illustrated in the following extract.

"In Africa when they say you've got HIV, there's nothing you can do, just die. So when they told me when I was here and they tell me there's medication, I, I did, I couldn't believe it. I said I should go back in Africa and die because there is no medication [...] the doctor was convincing me there is medication" (176-180/17/3) [Harriet].

At this time this participant was going through the immigration process and feared this would affect their access to free HIV treatment in the UK.
The tone of this participant conveyed her sense of helplessness and belief that without finances to fund her HIV care in the UK, she may as well return to her home country where she feared she would die. She continued to express her worry about how would she survive if she could not fund her healthcare in the UK, like back home in Africa.

*"They [*her family member*] then decided to take me to their GP. But I told them, you want me to go in your GP, where would I get the money? No matter, we shall plan it." (212-219/21/3)* [Harriet].

This participant compared the availability and cost implications of receiving treatment for their HIV diagnosis between the UK and their home country. The financial burden of seeking HIV treatment in Africa is captured in the quote

below.

“And you know in Africa you have to work, get money, pay for everything, go to hospital have to pay, transport have to pay, everything’s for, we have to pay” (311-312/30/3) [Harriet].

These quotes capture a sense of uncertainty about how they will access treatment. The tone reflected the feeling of stress and worry which was shared across a number of participants.

The experience of comparing healthcare services between the UK and their home country was also shared with other participants as demonstrated in the quote below.

“I just feel for people back home actually because I’m being privileged, you know, I’m privileged to be here” (519-520/51/4) [Susan].

For this participant there seemed to be an internal conflict of emotions. On one hand a sense of relief they were in the UK being treated, whilst on the other hand a sense of guilt for their survival whilst others did not have the same opportunity.

As participants gained experience with the UK healthcare system, they became more knowledgeable about HIV testing and how to access treatment. As part of this, participant’s confidence in navigating the NHS also grew. They made comparisons between their own, and people in their country of origins knowledge, with respect to understanding the importance of HIV testing in new born babies, as well as the physical appearance of HIV symptoms.

As one interviewee explained, *“...I would say thanks for the UK doctors or whatever, because some country doesn’t have that knowledge, people would have pregnancy with the HIV and they start going home with the baby, and later on the baby will start sicking, doing...developing different type of sickness, they won’t know that it’s HIV” (26-30/2/1)* [Alison].

The quote below further illustrates that having knowledge enables people to negotiate their survival and make better decisions to promote good healthcare and change attitudes worldwide to HIV.

"...we don't have information...it's, it's wrong, government and everything, it's not only in UK, all over the world...all of this starts with education. Because there are people who are ignorant, they don't even know even how to write. And they get infected, they don't have information, so they will infect, because they think they are dying, and people get desperate, they get this depression, everything starts with education." (415-421/41/6) [Eve].

Eve's use of language, in particular the words *we* and *they,* indicate that now she is 'not ignorant' and by having this knowledge about her own HIV health diagnosis, she can make more informed choices. Eve judge's systems as 'flawed' and this is her moral judgment in relation to HIV, that somehow this is 'wrong' and more can be done to prevent the spread of HIV. Education is therefore an opportunity to gain knowledge and this knowledge will help others contracting HIV. This participant appears to value the knowledge she has gained and this has shaped how she has made sense of her experiences of the world.

This reflects the various ways that taking HIV medication is understood. Participants understood that taking medication prevented premature death and gave them a sense of being like other 'normal' mothers. When considering pregnancy, they also understood that adherence to medication was a protective factor for their unborn baby in that they were less likely to pass HIV on and be like any other mother who does not live with HIV.

The quote below illustrates that when an African HIV positive mother shared her diagnosis with her children and received their support, this was an additional motivation to keep taking her medication, as a means of protection to stay 'normal' and 'live long'.

"...we just want to be normal, we just want to be mummy, mummy will be okay, she's now taking medicine that means the medicine will help her live

long..." (547-549/51/5) [Eleanor].

Eleanor makes sense of her diagnosis by adopting the voice of her children and seeing her experience through her children's eyes. She appears to be striving for a 'normal' life as a mother which she perceives as her main priority and sense of being in the world.

On observation this participant was smiling when talking and indicated that this was her rationalisation for taking medicine to make her children happy and not to burden them. She saw medicine-taking (adherence) as a positive step to keeping her children happy.

6.2.2 *Fear of Dying*

This sub-theme encapsulates interviewee's suspicions about having HIV and what this might mean for themselves, their child/ren and other family members. Commonly, participants' understanding of what the indicators might look like for having HIV, involved primarily physical symptoms, that were evident to others. For example, being perceived as thin, coughing and recurrent chest infections. By not testing themselves, in spite of experiencing physical illness, maintained suspicion and kept their fear alive. In some cases, this reinforced their denial and avoidance to test for HIV.

"But in Africa, I sort of suspected that something wrong with me, because, uh, I had to be treated TB one after another, one after another, God knows I did around four times. You know those tablets, there are so many, for TB. So they, they never thought of testing me HIV, back home. But...my mum and me, we kind of thought maybe something wrong..." (10-15/2/2) [Yolanda].

The quote above reflects not only the interviewee's and their family's suspicion that there was something more seriously wrong with them, but the health care professionals approach to not investigate the possibility of their patient being HIV positive, in their home country. The repeated phrase *'one after another'* reflects this Yolanda's sense of how intense and overwhelming she found being tested and feeling frustrated that it was never for HIV.

This attitude also appears to have influenced some of the participants' decision-making regarding testing their child/ren for HIV or not in the UK. Some interviewees were discouraged from testing their child/ren because of perceptions of what constitutes good health for a child/ren by family members and themselves. In many cases where the child/ren had no illness or symptoms, testing was considered unnecessary. This highlighted the point that for these participants their experiences of living in the UK were still influenced by their country of origin. Their understanding of HIV transmission was carried over to the UK and for these mothers they had the same attitudes and understanding from their past lives when they had been living in Africa. The following quote illustrates this perception reportedly held by Eleanor's partner.

"He said he, he'd, he didn't mind, anything if I decided to test them its fine, if I didn't test them it's still fine, because as long as they're ok...because they were bouncy, and healthy, he said mmm...maybe there's no need but if it bothers you, then I'm, I'm, I'm with you to test them." (460-464/43/5) [Eleanor].

It appears from the above quote that the meaning Eleanor attributed to her husband's response, was that she was responsible for deciding about testing and was the gate-keeper for their health and wellbeing. The sense from how she described her husband's hesitancy is powerfully illustrated by the use of language *'...he didn't mind...if I decided to test them...'*

The understanding that children do not need to be tested if they are asymptomatic is also reported by participants to be echoed amongst the attitudes of their family members, which may have affected some participant's decision-making as to whether to test their child/ren or not for HIV. This is demonstrated in the following quote.

"My Mum was working in Sweden...she knew the, all the, the symptoms. So even if I didn't tell her she knew I was sick...she said no this, this child is okay. I can see that child is okay." (371-374/36/3) [Harriet].

The language here shows a lack of accurate knowledge and Harriet deferred to her mother's authority based on her mother's European experience. When she says, *"I can see...",* this demonstrates her belief that information her mother obtained while abroad, must be correct. In this quote, it can be interpreted that Harriet's sense of worry and looking for reassurance from her own mother was influential in her sense and meaning-making about the transmission of HIV.

Participant's fear of death not only referred to their own mortality but that of their child/ren despite living in the UK and accessing a very different healthcare system. In some cases, family members including children also reportedly expressed their fear for the participant's life as demonstrated in the quote below.

"...it's... it's a serious sickness that can kill if you don't treat it..." (25-26/2/1) [Alison].
The repetition of the word 'it's' conveys the emotional intensity. This is further illustrated in the following quote:
"...there is that fear of...you're gonna die...it's just a matter of time, you're gonna die" (315-317/29/5) [Eleanor].

Another interviewee said, *"I was just living in a worry land of what if this, when am I gonna die, what if this, what if my children are, how am I gonna cope with this..." (182-184/17/5)* [Eleanor].

This statement reflects how for this HIV positive immigrant African mother she was concerned about her child/rens health and linked this to her own mortality. What will happen if she dies before her child and how will they survive. The metaphor 'living in a worry land' reflected her state of mind that she could not stop worrying which had an impact over her thought processes and emotions.

Psychologically this reflects Eleanor's sense of helplessness and panic of inevitable death. She has an underlying sense that time is not on her side and that her life will end too soon.

Fears for children who tested negative never dissipate and appeared consistent across transcripts that there is an on-going emotional burden for the positive mother about their negative child becoming HIV positive through sexual activity. This is illustrated below in the reported reassurance from an adult child to their HIV positive mother that they are aware of how to protect themselves.

"...I know about this thing, that was you are saying is not serious like cancer, but to prevent myself I know I would do that. Don't worry about it...." (163-165/11/1) [Alison].

In the above quote, Alison, again makes sense of her own experience taking on the voice of her adult child and their perspective which was more relaxed about an HIV diagnosis. She's made sense of her child's response as them having a sense of agency and confidence in how they would approach a diagnosis of HIV if they had this medical condition.

Alison's use of language 'this thing' as opposed to naming HIV indicates her on-going struggle to adjust to her HIV status. A commonality amongst participants was similar semantics in relation to the naming of HIV, which was not to use the actual word HIV. Participants often referred to their diagnosis as '*this thing...'* rather than using the medical terminology which could be understood as either a form of psychological distancing themselves from this condition and the sense of stigma in not naming HIV. This depersonalisation process was common amongst all participants.

6.2.3 *"...Take the virus out of me"*

For many participants when they were tested and received their diagnosis they were alone. In many instances they kept this information private, including from their partners. Receiving an HIV diagnosis was emotionally difficult for these immigrant African mothers and found themselves having to negotiate their own survival psychologically. This is illustrated in the quotes below. From their accounts, it was apparent that participants had to process their HIV diagnosis first, before being able to move their focus onto their

child(rens) health, which is discussed later in this chapter.

"Then he tell me, you've got HIV. Oh, I fell, fell down. I stood and fell down. I stood, I said, then I said in my heart, these people they are lying." (276-277/27/3) [Harriet].

This quote illustrates simultaneously Harriet's experience of shock and denial. The language and the style in this short but dramatic sentence are captured by the repetition of *'fell down'* and *'stood'* and encapsulate the immensity of this emotional moment in her life. The use of the word *'lying'* further illustrates how overwhelming receiving this diagnosis was for this Harriet. One singular word says so much about the meaning she attached to receiving her diagnosis of HIV.

Another participant, Susan, further highlighted this point by saying "*...they just broke the news to me, I said, I was really shattered and I said I don't believe it. Why would I be HIV positive? ...I was really broken-hearted and I couldn't really get, I stayed, I stayed there in the hospital for over five hours, sitting down." (38-42/4/4)* [Susan].

Susan's use of language with respect to words used and repetition of phrases convey the emotional intensity and psychological impact of receiving an HIV diagnosis. I understood the words '*shattered'* and '*broken-hearted'* as an expression of their shock, disbelief and lack of knowledge about being susceptible to contracting HIV. The term *'shattered'* speaks to the fragmenting of her sense of self as she currently knew it and her world had irrevocably altered at this moment in time. The powerful impact of receiving a life-altering, life-changing diagnosis is further illustrated in the quote below

"...I was hopeless, I was better dead, and I wanted to take the virus out of me, I, I, I had suicidal thoughts and everything" (403-405/40/6) [Eve].

The phrase '*take the virus out of me'* might be interpreted as someone wanting to not have HIV anymore. The impact of hearing they were HIV positive had an emotional impact on their sense of self, their identity and the

meaning they could now attach to their lives. This tremendous impact on their identity is powerfully highlighted by the phrase *'I was better dead'*. Life no longer had the meaning it had prior to receiving an HIV diagnosis.

The quote below by Eleanor captures how she experienced increased anxiety prior to getting her HIV diagnosis, which sometimes prevents or delays testing taking place.

"...had another three days' wait, and that time I couldn't tell you how I lived those three days. I lived like I was in a trance or I was dead or half dead, I couldn't tell you, I didn't eat, I didn't, I didn't enjoy anything, I was just, I was just...it's like something bad had happened to me..." (96-100/9/5) [Eleanor].

The metaphor *'trance and half-dead'* was the idea of the physical manifestation of Eleanor's emotional distress at an HIV diagnosis. Life was over as she knew it and the shock of the diagnosis initially stopped her being able to function. The repetition of the phrase *'I didn't...'* illustrated the extent of the shock and paralysis that this diagnosis had on her physically and emotionally.

6.2.4 *"You'll be looked after"*

This sub-theme illustrates the idea that the UK has a better healthcare system and that immigrants with HIV will be 'looked after'. This was shared amongst most participants. These mothers reported feeling encouraged by the UK healthcare professionals in their decision-making process to test their child/ren or not for HIV.

The healthcare system was not seen as encouraging or identifying the need for HIV testing in most participants' country of origin. A shared view was that unless you had a certain level of severity of symptoms, both patient and healthcare professionals did not see the need to investigate further, in spite of suspicions that the participant and/or their child might have HIV. The participant's reported that you were more likely to treat the immediate illness and respond to symptoms. The UK healthcare system was seen as 'more advanced' and having better medical knowledge and access to treatment. On

one hand this dissipated participants fear of premature death, while on the other it created some fear and anxiety that if they had this diagnosis how would they survive.

"...look here we have medication, we have better healthcare, so you'll be looked after..." (170-171/16/5) [Eleanor].
The idea that the UK has better healthcare and that they will be 'looked after' is further echoed in the following quote:

"But he told me I should go ahead, to go, that they can handle it over there. I should not be afraid." (147-148/15/4) [Susan].

Susan's husband, who was already living in the UK when they were diagnosed HIV positive, encouraged her to go to the UK for 'better' treatment. Interviewee's also held a perception that the UK healthcare system showed kindness and helpfulness towards patients, which included financial assistance, reflected in the quote below:

"...this is very common here in Britain, people who are sick they, they go back to work, they they are so, they don't mind about it...here in Britain they can give you some small money to use, but in Africa people are dying." (471-475/47/3) [Harriet].
This quote also illustrates that in the UK there was an affordability factor that facilitated a different approach to HIV. These immigrant women made comparisons to living in Africa versus the UK as HIV positive mothers.

The quote below by Alison captures the dilemma for her, which was helped by the support and encouragement she received from this midwife. There was a sense of HIV being normalised and an on-going plan for her pregnancy which was reassuring.

"...I'm, I'm a midwife and we have many people there in your situation. The thing is that, the first thing on your mind now is, you will be thinking maybe you should abort the baby, or no, or that, that she can assured me that if I don't abort the baby, the baby will be fine with the treatment they are going to give

me..." (12-16/1/1) [Alison].

The support of the healthcare system was particularly important when participants had to decide whether to test their child/ren.

In four out six of the interviews, the reason given for testing (or not) their child/ren for HIV in the UK, was because of their own experience of being tested and diagnosed and understanding the consequences of not receiving treatment should their child/ren have an HIV diagnosis.

"So after me being diagnosed yeah I thought of that, it clicked in my head that, uh, I need my son to be tested...I thought it would be so selfish for me to be tested and he doesn't have tested and then, maybe I would end up losing him." (176-179/18/2) [Yolanda].

Yolanda appeared only to be able to consider testing her child once she had learnt about her own diagnosis. This was shared by all the participants. The language emphasised the emotional impact for these parent's and how difficult this decision-making was, and how alone they felt at the time of their diagnosis. They became reliant on the healthcare system in the UK for their support.

This quote reflected Yolanda's anxiety about the possibility of her child dying because of their HIV status. It also highlights her rationale and justification for testing her child, as she would see herself as a *'selfish'* mother, if she did not test her child after finding out her own HIV positive diagnosis. The meaning Yolanda attached to the word *'selfish'* could be understood to have changed once they had knowledge/education about HIV. Before this occurred the '*not knowing*' was perceived as a protective factor but once they had information about HIV treatment, it was seen as '*selfish*' not to test your child because you would deny them the opportunity to take medication that ensured longevity and correlated with being looked after by the UK healthcare system.

Participants sense of control and responsibility over the testing their child/ren and others were often split between themselves and the healthcare systems. The sense from most of the participant's, was that individual autonomy in their home country was not the same as in the UK. In their countries of origin, the perception was that the healthcare professionals held more authority and control over patient's decision-making. In the following quote a nurse reportedly tells Susan that she needs to make her husband get tested, following her positive result, and suggested withholding her own HIV result from her husband, until she brought him to clinic to test. This caused her distress.

"...this is the way I have to do it, that I should tell him, that they need to do his, do his blood test..." (46-47/5/4) [Susan].and she went on to say *"when we got there, I saw the nurse, and he called me outside and he said you need to make him..." (54-55/5/4)* [Susan].

In the UK, when participants describe or depict their experiences with the healthcare system, they experience a more shared decision-making approach than they had previously found in their countries of origin. There appears to be a sense of a paternalistic approach to healthcare in their home countries and the position held by men in society. This may have diminished her own sense of agency in relation to decision-making.

This is illustrated in the quote below

"It's just I think it's good now that they are making it [HIV testing] *routine though you can opt out" (373-374/35/5)* [Eleanor]. They went on to say, *"I think at the hospital once I found out, of course they said to me now we need to test the baby, because then if the baby is there is some treatment we can give straight away." (413-415/39/5)* [Eleanor].

The experience of an opt-out rather than opt-in service for antenatal testing was perceived by this participant as positive, as well as the testing of new-borns, because of her HIV diagnosis. For these immigrant African mothers, decision-making was jointly held, helping to alleviate some of their burden in the UK around testing of child/ren for HIV.

For a number of these participants the control and responsibility to test their child/ren was perceived as shared with the UK healthcare system and that the UK was a place of support, information obtaining and a place where they could make individual choices and decisions is further illustrated below,

"But I thank my midwife that has said, look, if you want to do all this, you have to bring all your children to be tested, and I did." (46-47/3/1) [Alison].

When participants were faced with the choice and responsibility to test older children by the UK healthcare provider some participants experienced a dilemma, as on one hand knowing a child's HIV status enables the parent to seek treatment for that child if needed, but on the other hand if the child is positive it raises issues over coming to terms with and managing their child's HIV.

"...I would like children to be, to be tested, so that this thing will stop spreading and we stop killing people..." (210-211/14/1) [Alison].

Once again in the above quote you can sense the burden and responsibility for Alison with the use of the words *'this thing…'* There was a strong meaning attached to the idea that HIV challenges parenthood, in relation to the concept of life and death.

The sense for some of these mothers that they were somehow to blame for their child/ren dying (from mother to child transmission of HIV) was shared by other participants.

"...it would be unfair if I get tested and my son would die...he is not the one who brought it, it's you. So you're just killing innocent soul." (481-482/47/2) [Yolanda].

The shift of language from 'I' to 'you' captures in this sentence how the participant's language depicts a sense of depersonalisation and psychologically distances herself from the emotional impact and guilt she experiences around whether she had transmitted HIV to her child.

In some cases, being given the responsibility to test their child/ren was left to the mother, whilst for others it was a decision made by both parents, who did not always agree with one another. There is a sense that the responsibility was also the mothers because they tested positive as depicted in the quote below:

"I, I think we... we all, both went in different directions, for he was thinking like, oh, if he stays untreated its then less bad enough worrying...he didn't want to know..." (260-264/24/5) [Eleanor].

6.3 Superordinate theme *'Impact of Diagnosis on Identity'*

This superordinate theme reflects the impact of having an HIV diagnosis on the participants emotionally, psychologically, physically, culturally and in some instances spiritually. Interviewees sense-making in relation to their own and their child/rens diagnoses, have in part been shaped by norms, attitudes and values based on their individual backgrounds and experiences, which they brought with them from Africa to the UK.

6.3.1 *'Shame, Blame and Secrecy'*

Shame, Blame and Secrecy were interpreted to be repeating themes across the data-set. This sub-theme captures the stigma participants faced from having an HIV diagnosis and the feeling they had to hide this, to avoid shame and blame for their positive status.

"Oh God, it's...stigma, its so many things to say...my elder sister, we can't even tell her about, that I'm, I'm infected because she thinks only prostitutes, drug addicts and...um...yeah and she sees HIV positive's as rats" (236-241/24/6) [Eve].

The quote above offers a poignant illustration of the interconnectedness between secrecy and stigma. In addition, this quote shows the experience for Eve of people with HIV being compared to *'…rats'* which infers you are less than human, like 'vermin'. This could also convey how Eve experienced being perceived as 'dirty' and 'infectious' and therefore to be avoided.

Eve described being HIV positive meaning *"...you are always in a dark side, you are hidden." (484/47/6)* [Eve]. The sense of being ostracised for being positive is illustrated through the metaphor of *'you are hidden'.*

The blame element of this sub-theme was captured in the following sentence, *"No, even though men at times, the husbands can have two wives, or even three or with a mistress, they will always blame the woman who is...they will always blame, it's you who has found, who has brought it." (280-283/26/5)* [Eleanor].

Male partners were also thought to blame females for transmitting the virus and this was repeated by other participant's and highlighted in the next quote.
"...the same day when I was tested I called my partner...I said listen, I got tested, I'm infected, I think you should come. He went and he was positive, he was also positive. And inside...he was trying to blame me, it was you, it was you, but I was certain that I wasn't..." (38-42/4/6) [Eve].

The experience of stigma, blame and shame for HIV positive immigrant African women living in the UK today has not really changed from their experiences of living in their country of origin. Still there are negative associations for these women of being HIV positive, which remain a burden and a challenge. This demonstrates the power of cultural perspectives that the male partners of these women are entrenched in and despite these mothers being more knowledgeable they still appear to be blamed by their partners and themselves if their child tested HIV positive as demonstrated in the following quote:

"...cause it's something that you would never forgive yourself, you know, knowing that you're HIV and passing it to your child. It's something that I would never forgive myself for." (357-359/35/4) [Susan].

This quote reflects the shared experience amongst participants of self-blame and guilt and lack of any form of self-compassion. Once more, the repetition of words and phrases *'would never forgive yourself...'* emphasised the emotional

content, and for Susan the issue of the transmission of HIV, in this case to their child, was viewed as a burden. Susan shifts her terminology from 'you' to 'I' indicating a shift towards accepting and adjusting to their HIV diagnosis. This highlights a move from 'depersonalisation' to 'personalisation'.

The quote below illustrates the participants *'burden'* of not knowing their child's HIV status and how this might psychologically affect her. There is also worry about what would happen if their child tested HIV positive.

*"I think I try to find their [*other mothers] *reasons of not wanting, because many people say oh no I don't think they are [*the child/ren] *and I'm like, what makes you certain...I think I use my own experience, I say look, I don't know about you but for me, it was some kind of a weight on my shoulders not knowing. It was another worry, worry factor for me, not knowing." (470-474/44/5)* [Eleanor].

Participants experienced cultural rules and assumptions about how HIV is transmitted and the types of behaviours and people that would be more likely to have HIV. These social and cultural *'rules and assumptions'* were also held by the participants, who believed that 'virtuous, moral and good' people, do not contract HIV. This caused some participants a sense of confusion as they could not comprehend how someone like their partner, who slept with other women, tested negative while they tested positive. This led to an inner conflict which challenged their *'rules and assumptions'* about life and the transmission of HIV.

"...they told him that he's negative, it was like a shock to me actually, I said why would he be negative and I'm positive? And he was looking, and he was like, I just, you know that he is a bad boy, because he played really rough, why would be be negative and me, they know that it is just their...I'm just a saint, he sees me as a saint, being the positive one...totally difficult for us..." (63-67/6/4) [Susan].

For this recently diagnosed HIV positive mother, it was difficult to comprehend how she had tested positive, whilst her husband tested HIV negative. He had

reportedly been having extra-marital relationships. The terms *'bad boy'* and *'saint'* represent her disbelief at her HIV positive status. Susan's comments reflected many of the other accounts in relation to moral judgements about the transmission of HIV, such as the belief that only people who have multiple partners contract HIV. This behaviour of extra-marital relationships was considered unacceptable. The stigma and moral judgement about being HIV positive affected people's decisions about whether to disclose their own and their families' HIV status. This is explored below.

Participant's faced the dilemma of once they had been diagnosed HIV positive whether to share this information with partners and/or family members. Decision-making was influenced by a number of different factors, including would they be 'judged' and accepted by the person they disclosed this information to. Other areas affecting this were their own moral 'compass' and value system as well as what they understood to be their legal responsibility. All participants experienced fears associated with disclosing their HIV status to others based on their own attitudes and background knowledge and experience. Most of the interviewee's shared a common experience from UK healthcare professionals involved in their HIV care who encouraged them to disclose this to partner's to ensure they get tested and if necessary treatment.

The following extract speaks to the shock of this for one participant,
"...I have to get my partner, if, for him to be aware, for them to know the...I was really broken-hearted and I couldn't get, I stayed I stayed there in the hospital for over five hours, sitting down. I didn't know what to do, because I didn't know how to disclose to him." (40-43/4/4) [Susan].

The emotional intensity and struggle to process their diagnosis influenced their decision in relation to disclosing to their partner. This process was complex and evoked a sense of helplessness in not knowing how to disclose to their partner. The shock of this appeared to remain present for participants for many years. For a number of these participants who had been diagnosed many years before, the trauma attached to receiving their diagnosis still resonated, and raised the same feelings as if they were being transported back in time, to when they were given their own HIV diagnosis. As the

following quote illustrates,

"...this is the way I have to do it...that they need to do his blood test. I should not tell him about HIV. In fact, I was very sick for one week, I couldn't tell him anything, I was really sick, I became more sick..." (45-48/5/4) [Susan].

The physical manifestation of feeling sick illustrates Susan's emotional response to being diagnosed HIV positive and the impact this had on her life and the trauma she felt about disclosure to her partner. The repetition of the word 'sick' captures the emotional intensity she felt contemplating disclosing her status to her partner. It appeared she felt anxious and worried about her partner's reaction and feared the outcome of this disclosure.

This linked to the sub-theme *'transitioning to a new normal'.* For participant's who had children, they wanted them to be tested, but had concerns about sharing their HIV diagnosis with older children in their family for fear of their response and not being able to keep the information within the family. The impact of their child being HIV positive was a burden they did not want to have to consider. Once they had been tested this became a gateway for parents to have difficult conversations around sex, sexual health prevention and transmission of the virus.

The idea of disclosure as a process rather than as a once-off event was highlighted by Eleanor in her struggle to find the right words and tone with her husband.

"...when I disclosed, I didn't disclose one day, I kept on saying like, I want to tell you something then I don't say it because I couldn't bear what, what do I, even I remember saying what words do I need to say?" (534-536/50/5) [Eleanor].

The repetitive use of the word '*I*' in this sentence highlights the difficulty for many of the participants when thinking about the disclosure process. For Eleanor, the hesitancy in her language reflects the challenge disclosing her HIV status felt and the paralysis she experienced in doing this.

Almost all of the participants were aware of the life-changing impact of disclosing their HIV status to partner's, children and significant others and struggled with the disclosure process. The meaning they attributed to disclosing their HIV status was greater than fears around their own mortality, but also was linked to the fear of the sense of loss of their relationship with both partners and family members. Once they disclosed their HIV status there was a sense of a loss of innocence and a change in their identity in the eyes of those they disclosed to.

Before being given a medically confirmed diagnosis of HIV, participant's described their life as if they were HIV negative, despite at times experiencing ill health and their own suspicions of being positive. Interviewee's described the life altering impact of this diagnosis. Not only had their perceptions changed that now they were different, but the belief that the life they could lead had irrevocably altered. This removed a layer of innocence and changed their sense of identity.

"...when you see your colleagues I see there's something different about them, you still feel very inferior...you have this HIV" (256-258/25/4) [Susan].

This quote illustrates that for this positive participant, you are no longer seen as an equal but as less worthy than other people. Her use of the word 'you' as opposed to 'I' initially reflects her psychological distancing and sense of being separate or different to her colleagues.

The following extract by Eleanor may be considered to reflect a level of naivety about testing for HIV, and hints at a sense of innocence on the part of Eleanor when being asked to test for HIV.

"So then they talked with me and I was happy and then nothing was coming to my mind that it's bad to do this test or that there are consequences of the test." (59-61/6/5) [Eleanor].

Her self-esteem and sense of identity was now different since she was

diagnosed HIV positive. Her phrase '...I was happy' indicated a shift towards 'unhappiness' on receiving her HIV diagnosis. The test was considered negative and the reason for her shift in emotional wellbeing.

Like many immigrant populations, the experiences of this group of HIV positive African mothers, meant that they often brought cultural and religious beliefs about health from their home country to the UK, especially in relation to the role of God. The evident impact of the uncomfortable juxtaposition of these two paradigms and belief systems, might leave them internally conflicted. Sometimes providing reassurance but at other times this may cause conflict with their faith.

Participant's sense of shame and blame was also influenced by the media's portrayal of HIV and their cultural understanding of how HIV is perceived in their communities. Their experiences of the role of media in shaping social attitudes and norms about HIV, were primarily negative and heavily stigmatised in both Africa and the UK as illustrated below.

"The TV programme that normally talk about HIV, they show, they show people of the world like...if you have HIV then you are loose." (74-75/5/1) [Alison].

This was not the only participant whose experience was based on stigmatised views of HIV. In the UK a mother described how her son's arrest was portrayed in social media *"...I think the police are not educated enough, they, their lack of private and confidentiality...one time it was on facebook that my son is taking medicine..." (328-330/32/2)* [Yolanda]
For this mother realising that her son's HIV status was being spoken about on social media caused her distress, pain and empathy towards her son who she felt was negatively emotionally affected by this event.

On the other hand, for one mother media advertising campaigns to test for HIV encouraged her to be tested.
"...HIV has now made public... [...] in the buses I could see some advert had been done... [...] it has really helped." (302-350/23/5) [Eleanor].

A common thread across participants was the emotional impact of the media's approach and attitude towards HIV. If the message was positive this was construed as helpful, but when these media portrayals were negative, this caused pain and upset.

6.3.2 *'The struggle of life long medicine-taking'*

Many barriers to treatment adherence can be understood as a consequence of social and economic difficulties, health beliefs and side-effects of medication. For some participants their religious leaders also discouraged them from taking medication which was counteracted by support groups attended by participants, and/or their reframing of their illness in line with their religious beliefs.

One barrier to taking medication is that it is daily and life long, leading to treatment fatigue, as illustrated by their use of the repetitive phrase 'every day, every day...' in the quote below.

"...but this medication, taking them every day, every day, every day. It's not easy...I'm taking it on and on and on." (564-568/56/3) [Harriet].

Taking medication daily further acted as a reminder of people's HIV status, and in some cases how they contracted HIV, which resulted in some emotional distress including depression and fear.

"Mentally I think that HIV is not just a virus, it's everything because you get depressed, you still think it's the medication, medication scares everyone...it's when you, when you just acknowledge that I, I'm actually positive." (92-95/10/6) [Eve].

The quote above illustrates poignantly that for this participant life had irrevocably changed and along with this was a change in her identity. The shift in language from 'you' to 'I' reflects the move from depersonalisation to personalisation with the recognition of her HIV status.

The physical side-effects of the medication and concern that it would not work

were also influencing factors for treatment adherence. To quote, *"...he started me on medication straight away...it was terrible..." (35-36/4/3)* [Harriet].

6.3.3 *'HIV Affected My Family'*

Many of the participants' had the view that HIV meant suffering and death for both themselves and their children if they tested positive.

"I, I pity them, because me, I had it when I was old. But how can you be in such a life like that since you are born, you've got HIV." (596-597/59/3) [Harriet].

Harriet's use of language indicates the heavy burden she felt for children who were born with HIV and how they will cope if their child tested HIV positive which was shared amongst many participants.

Closely linked to the previous sub-theme, it was not only the parent(s) whose innocence was affected pre-diagnosis. These HIV positive immigrant African mothers were aware that some of their children's lives were irrevocably altered. The children had increased responsibilities and took on a carer's role in relation to their parent such as reminding or encouraging them to take their medication.

"...my child has been fantastic 'cause she's the one that remind me about my medication...she will even give it to me." (549-551/54/4) [Susan] and goes on to elaborate, *"she knows, she knows which is which but she doesn't know the name, she doesn't even know what it's about, but she knows I'm supposed to take my medication every day..."" (556-558/55/4)* [Susan].

This loss of childhood and taking on a parental role is also illustrated in the following quote whereby the child tells the parent how to behave socially and morally.

"...you don't, you dare not tell this to your friends, or else they don't come to visit our house and they'll be thinking our mum is gonna infect everybody...we just want to be normal..." (542-544/51/5) [Eleanor].

This was the voice of Eleanor's primary school age child, from her own perspective.

This was shared by others as illustrated in the next quote, *"I was living a*

double life at home...I made a decision and I told him [her child]*. It was a very good response apart from he said that, um...I shouldn't lie to him, it's bad." (297-301/30/6)* [Eve]*.*

Parent's usually discourage children from telling lies and in this interview Eve recalls that her young son reminded her that it was not good for her not to tell him the truth and that she should have shared her diagnosis earlier.

For these mothers, there was a shift in their own identity as a parent with their child knowing and taking on a caring role. This parental reversal of roles caused some distress for many of these mothers as they did not want to 'burden' their child/ren.

Having an HIV diagnosis also had an impact on some of these women's sexual/romantic relationships. For some participants who tested positive while their partners tested negative, this impacted on their intimacy and expectations within their relationship. Some partners, primarily husbands, reportedly sought sex outside their primary relationship which was tolerated rather than accepted by participants after their HIV diagnosis.

".... I said you've got to use condoms with who you are sleeping with...it was terrible and like I was heartbroken actually...if I wasn't HIV I don't think he would go that far, I'm not saying that men don't cheat but I don't think he would go that far." (165-167/16/4) [Susan]*.*

For Susan, she blamed HIV for her husband's infidelity and interpreted his subsequent behaviour as him using her HIV status as a justification for his choices. This statement might reflect a loss of power for Susan in her relationship with her husband. This could also indicate sadness for the loss of the relationship prior to the HIV diagnosis. Her phrase *"...I was heartbroken..."* captures her grief and despair at the perceived change in their relationship.

Other partners were able to adjust to this and continued their sexual relationship with their spouse as illustrated below.

"Yeah, yeah we are still together and it didn't even change our, everything was ok as a family." (204-205/20/2) [Yolanda].

For some, their sexual relationship ended as a result of the HIV diagnosis as illustrated in the following quote, *"He didn't want to use condom and I wasn't really comfortable, so I never since then actually I have not enjoyed sex. Yeah I don't enjoy sex anymore, it's as if...this sexing is not in me as if I've got a dead cell here." (178-180/17/4)* [Susan].

This quote illustrates the impact of Susan's diagnosis on her sex life and sexuality, with sex no longer being pleasurable or desirable. The phrase "...*dead cell*..." illustrates that her sexual enjoyment was now over and she cannot envisage any form of pleasure in future.

This reflects difficulties interviewee's who had older children at home experienced when thinking about how to talk to them about their own diagnosis and their own protection. For some participant's, conversations focused on helping their child to understand the need to keep taking their medication, without disclosing the parent's HIV status, or the adolescent's own diagnosis. Other parent's found this too emotionally challenging and tried to avoid explanations.

"...it was the right time since he was becoming a teenager, we were afraid that he need to be using condom and knowing the right way of sex otherwise he end up passing it on, yeah...because it was a long way for me to give him tablets...a long long way...he was a very naughty boy, sometimes he doesn't come home when he was a teenager... (246-251/24/2) [Yolanda].

In this instance the young person was positive so the parent's concern was exacerbated by the fact that her child was unaware of their own HIV diagnosis. For this positive parent, her experience of her adolescent child who stayed out all night and did not come home caused her distress as he missed doses of his medication. The use of the word 'we' suggest that her husband shared this concern.

The impact on adolescent children who have learnt their parent's HIV diagnosis was also illustrated by participants in the following quote, *"...the*

thirteen-year-old, became depressed and next morning didn't want to go to school...I had to seek counselling for him, for some time, he he couldn't cope..." (553-555/52/5) [Eleanor].

While this child was not positive, he had recently learnt about his mother's HIV diagnosis and was reportedly worried that she would not survive. This mother tried to alleviate the impact of her HIV diagnosis on her child.

6.3.4 *"My Faith is kind of shaken..."*

Nearly all of the interviewee's made reference to God. They made sense of their diagnosis and that of their child/rens as something given to them by God for a deeper, spiritual reason. Those who had children that tested HIV negative, praised God for 'not giving/sparing' their child from this burden. It was significant to note in some of the interviews that the word God was repeated multiple times to emphasise difficult and emotional experiences. This *'calling on God'* for some participants was to provide them with the necessary strength and support they needed to cope with their HIV diagnosis.

"...I started praying and I believe in my God, that he will be there for me, he said I should call on him... And to God be the glory, they are negative..." (146-153/10/1) [Alison].

This participants' sense and meaning-making was a dialogue with God and her religious beliefs were reinforced with her children testing negative and she could maintain her faith and rationalise what had happened to her rather than her children.

Another participant was taken back to the time of her diagnosis when she had to consider testing her own children and she called on God to help her with her decision-making.

"...it took me back, from that time that I was diagnosed and then I was think, oh my God what am I gonna do, I've got, I've got children, I'm pregnant what should I do?" (383-384/38/6) [Eve].

Once more faith was called upon to help cope and manage the burden of the

decisions she faced. This was replicated by many of the participant's in their respective interviews when they sought the help of God to help them make sense of their diagnosis and felt they were at God's mercy. In this context they were both helpless and safe at the same time in the belief that whatever occurred was not in their power and part of God's plan for them.

Alison stated, *"...And I said to my God yes I have this thing...I know you know the reason for why this thing happened to me...I just don't want my children to have this thing...: (149/10/1)* [Alison].

As previously explored Alison repeats the phrase *'this thing'* rather than mentioning the word HIV which seems to distance her from the experience of being HIV positive and allows her to remain connected to her faith while not having to feel responsible for or blamed if her children are diagnosed HIV positive. This quote also demonstrates for this interviewee the role of God as a protector and understanding of people's circumstances while not being judgmental.

This reflected a tension between religion and modern medicine in the treatment of HIV. Some interviewee's described the belief that 'God gives' and 'God takes away/cures HIV'. The idea that God will take away HIV if you pray and repent for your sins was experienced by a number of participant's. The message that HIV was given to those who 'sinned' was reportedly delivered by religious leaders. This directly contradicted the message from modern medicine delivered by healthcare professionals. The medical staff in turn explained that there was no cure, but good health could be maintained by taking medication. In turn modern medicine offered an alternative 'scientific' understanding of how HIV was contracted and could be treated.

The following quote highlights the role of religion and faith when seeking medical care in their countries of origin.

"...before they give you your medication...there will be a pastor that will come and preach, preach, preach, preach, preach, preach. It will take about one and a half hour, it's like everybody has to listen to the pastor...and they say you don't have to take your medication..." (109-112/11/4) [Susan].

For this interviewee attending an HIV clinic abroad meant you had to listen to a Pastor preaching before receiving treatment. The repetition of the word *'preach'* highlighted the negative experience for this participant and the stigmatisation and marginalisation she felt being trapped in this situation.

Unexpressed anger was evident, and her use of language emphasised the powerlessness she felt. Susan, as an immigrant African mother, made sense of her HIV diagnosis from her experiences of the Church in her country of origin, which she carried with her to the UK and influenced her sense and meaning-making processes .

The following quote highlights the perceived tension experienced by some between their faith and medicine-taking. This is eloquently captured by Eleanor who described her understanding of why her friend had passed away from HIV, attributing the Church's doctrine as having influenced her friend not to take medication but put her faith in God.

"...my faith is kind of shaken...I come across many people having negative experience from the Church...of course I'm not saying a Church is bad, but I felt she died because they made her stop her medicines...she did tell me, I'm cured..." (585-592/55/5) [Eleanor].

With others, God and medicine were more complementary (to go alongside rather than to praise) and participant's thanked God for their child remaining well, despite erratic adherence. The following quote about a participant's HIV positive child who does not always take his HIV medication, illustrates this point, *"...one time it will catch him being sick but we thank God and he was never in bed with it." (261-262/26/2)* [Yolanda].
Although her child was missing doses of his medication, she understood that God had a role and was looking after her child and preventing him becoming unwell.

6.4 Superordinate Theme "It's there, but HIV is not me..."

This superordinate theme captures participant's movement towards accepting

their own and their child/rens HIV diagnosis as well as their adjustment to living a life being HIV positive. Drawing on various support networks, these interviewees were gradually able to come to terms with their *'new sense of normal'* and regain their *'sense of duty and responsibility'* as an HIV positive immigrant African mother in the UK.

6.4.1. *With Others, Strength & Resilience is found*

This sub-theme reflects how participants came to have a better understanding of their HIV diagnosis, through UK support groups, which they were encouraged to attend by their healthcare professionals. Acceptance and adjustment was not an automatic process but something that developed over time. For many of these participant's it was their healthcare professional that encouraged them to attend support groups in the hope that this would help with acceptance and adjustment. On the other hand, one interviewee explained in the following quote how the *process of adjustment* takes time and was experienced differently by participants.

"The support groups, I don't really know why because each time we, we discuss, I still see some people reminding themselves about, cause I have moved forward, you know...but some they still hold back, so I think it's an individual difference..." (582-586/57/4) [Susan].

For Susan the support group had helped her move on with her life and find meaning, while others remained '*held back'* indicating their struggle to adjust and accept their HIV diagnosis. Susan is using social comparisons to enable her to identify the progress she has been able to make. Another mother found that over time support groups helped the process of adjustment and through them learnt how to cope being HIV positive.

"...you educate yourself, living better, eating better, sleeping better so it's maybe, for me it was a, a beginning of a new life, for three years I couldn't see that" (395-397/39/6) [Eve].

The phrase '*a beginning of a new life'* captures Eve's sense of acceptance and adjustment. She again highlights the progress she has made and links this to the education that was referred to earlier, as part of her process of

adjustment.

The strength found in numbers was illustrated by the following interviewee who shared *"...when I came here I see a lot of people like 250 people that have this sickness and we are like family, we, we shower together, we eat together, we...whatever problem you have you speak..." (114-117/8/1)* [Alison].

The meaning that Alison attributed to the support group she attended was highlighted by the use of the word *'we'*, identifying the feeling of togetherness rather than being alone with her feelings since being diagnosed HIV positive. The groups became a place where some of the participants could feel safe and accepted, without fear of judgment. This helped create a new sense of self and belonging going from feelings of 'I' to 'we'. This appeared to highlight her new sense of belonging. This was a felt sense of unity and similarity through their shared experiences *'we are like family…we shower together; we eat together…'*

In some situations, where silence was promoted by partners, this was perceived as protecting the positive individual and the family. This is illustrated in the quote below:

"So my husband, in a way he was protecting me, he said look, let's not share this, but for me I was thinking like, we either face this thing together, or, it's like I felt like I was being put in a corner, like, you can't talk about your HIV..." (283-285/26/5) [Eleanor].

In some cases, where participant's initially sought support from their own family members i.e. mothers, later they experienced concern about this person worrying about their health, and regretted feeling they were the cause of this worry. Despite needing emotional and physical support, one participant highlighted this in the following quote, *"but I remember sharing it with my mother...she went through a phase when she was always beeping me and saying, I was just checking on you, are you in hospital..." (294-297/27/5)* [Eleanor]. On the other hand, this quote could reflect the loving concern and

worry from her own mother about her health and wellbeing.

Most of the participant's had accessed support from Charities (NGO's) in the UK during the process of adjustment. They also received support from healthcare professionals in the UK. These organisations helped participant's in a number of different ways including encouraging participants to speak to their partner's about their diagnosis; test their child/ren; and in some instances encouraged the discussion about HIV with family other members.

"...I don't have the will within to...that is why this support group they, they have the will there to do it.... yeah, they're able to like, disclose it to your and like, know how to, you know." (542-546/53/4) [Susan].
Susan illustrates the deep sense of emotional difficulty in trying to make sense of how to disclose to their loved ones an HIV diagnosis.

Susan's use of language ("*...I don't have the will within...*") reflects the emotional intensity and meaning that being diagnosed HIV positive had on participants. She was not alone in this struggle and as Eleanor said,
"...he [her husband] *said to me, why don't you go to the groups, in the group there you're gonna meet people who are also positive, who are, who have been positive for some time, they might you some support or information that can encourage you. And indeed he was right." (172-175/16/5)* [Eleanor].

This quote further captures the role that other individuals in the same situation gained from one another, through sharing experiences and knowledge when attending HIV organisations in the UK.

6.4.2 '*Transitioning to a 'New Normal'*

Interviewee's appeared to initially make a transition from a state of depersonalisation ('outside of oneself'), which reflected a lack of *acceptance or adjustment* to their HIV diagnosis. This was juxtaposed to the process of personalisation, which was the process of adjusting to their HIV status, where participant's appeared more accepting and took 'ownership' of their situation and made sense of their diagnosis only once they moved and had settled in the UK. Some felt it was something that has been given by 'God' which was

explored earlier in this chapter. Through personalisation, participants were better able to look after themselves and make decisions about testing their child/ren.

The process of moving from a state of *depersonalisation* to that of *personalisation* was illustrated by one participant who described their new found approach to their diagnosis. This can represent how their reflections across time suggest this shift in meaning-making for this particular participant.

"…own up and just be responsible, and be ready, to face the future, and like discuss it, because the more you discuss it, the more you tell people about it, the more you have this relief..." (590-592/58/4) [Susan].

The sense of taking ownership of their and their child/rens health is further illustrated in the following quote.

"I think the starting point is once you know your own status that makes you think about your children...unless you've been tested yourself you're feeling like what, what makes me think my children are at risk?" (395-398/37/5) [Eleanor].

Even after their journey to the UK and involvement with HIV support organisations (NGO's/Charities), these HIV positive African immigrants experienced challenges as mothers. The above quote highlights a sense of external focus which could help illustrate an internal adjustment process.

A further aspect of acceptance and adjustment was how participant's seemed to create a new sense of *normality.* Linguistically, interviewee's language shifted from avoiding using the word HIV to being able to mention the word. This was often in the context of participants talking about the importance of testing. The meaning behind this seemed to suggest that they had now accepted their HIV diagnosis.

Participant's appeared to be able to normalise their healthcare condition and their treatment. As already mentioned for many of the participants the groups played an important role in helping this process. An additional aspect of the adjustment process was acknowledging that HIV was a part of their life but it

did not define who they were as a person.

"...I was able to use my confidence to fix that oh life is beyond this you know. It's there, but HIV is not me. I am above HIV you know, so that is just it." (259-261/25/4) [Susan].

The above quote links to innocence before diagnosis and further illustrates Susan's journey from diagnosis to acceptance, as does the quote below.

"...now I can...I wasn't fearing to die but I was just like, at least I don't have to bury my children, they will bury me which is, should be normal...more of these medicines are coming...which was to me was reassuring like, wow, there's a future." (617-618/58/5) [Eleanor].

The above quote captured a sense of hope which occurred once the transition to accepting their HIV positive diagnosis took place in the UK.

6.4.3 'Working Through Challenges as a Positive Immigrant African Mother'

Participant's faced dilemmas throughout their HIV journey. These included whether to test themselves, who to disclose to; whether to test their own children; or when to disclose a child's own HIV diagnosis to them; and with some interviewee's whether to continue with a pregnancy or not once they found out their diagnosis.

The quote below illustrates Alison's dilemma as to whether to disclose her HIV status to her child or not.

"...if I went to tell her, she may, she may not know how to handle it and she have this...this is that, they normally call depression..." (176-178/12/1) [Alison].

Whereas Yolanda faced the dilemma of when to disclose to her child that she was HIV positive;

"that time he was only, when we talked before he was just taking tablets, to be honest, until when he was twelve or fourteen when we decided to tell him." (230-231/23/2 and she went on to say *"...yeah of course it was hard, especially, for me it was better especially when I wanted to tell my son. It was*

really hard, but I had to do it, so that he would know..." (223-225/22/2) [Yolanda].

The above quote illustrates how difficult decision-making was, as on one hand she knew what she *'had to do…',* but on the other hand wanting to protect him from any distress that disclosing his HIV diagnosis would cause her son.

For some of these participants their sense of nurturing and caring for their child/ren was illustrated by a decision to test their child and find out their HIV status. This was so that they could access the necessary healthcare, in order for them to survive. This 'need to know' was driven by knowing their own diagnosis and their parental sense of duty and responsibility, as well as love and care for their own children. The quote below reflects the sense-making for these participants around testing of their own child/ren and attributes the importance they attach to testing for HIV.

"...it's better to know, I think it's unfair. ...I wouldn't like anyone to [do that] to my children. So I think it's important to test young people. I think it's important to test adolescents and everyone should do it as a duty, as a social, as human being, they should be tested." (229-232/23/6) [Eve]. Much later on in this same interview she reiterates this earlier point saying, *"...if you are positive and you don't take your children to be tested, you are being selfish. Because you are taking the opportunity for your children to have a better and healthy life." (495-497/49/6)* [Eve].

The wording in this quote suggests a mother has a moral obligation or duty to test their child for HIV. The linguistic concept of *'being selfish'* implies that mothers who do not test their child/ren are in turn 'bad' parents. Previous participants have also referred to the idea of 'being selfish' as part of their sense and meaning-making illustrating their move towards acceptance and adjustment to being HIV positive.

The idea that a mother's honesty encourages future honesty in their child's sexual relationships is illustrated in the following quote by Eleanor. *"Because I believe if you lie [about being HIV positive], then it's like that lie then makes*

them think negative of you, but if you're open and truthful they'll be grown, they're gonna confront these issues themselves." (651-653/61/5) [Eleanor].

Part of this process is parents instilling in their children good values and life lessons to help them navigate their own sexual relationships in future. The emotional intensity and sense-making for many of these participants is further highlighted in the strong use of the word *'lie...'* that is used repetitively in the above quote, almost as a sense of their own guilt for times when they were not open and honest with their child/ren.

Participants experienced a sense of wanting to 'protecting their child'. In the first instance participant's act of testing their child/ren offered a form of protection. This is because a formal diagnosis of HIV leads to the seeking of medication which protects them from ill health while living with HIV. The parental instinct to protect their child/ren from contracting HIV in negatively tested children was demonstrated by these mothers talking to their child/ren about safe sex.

"...to my knowledge, I think it is very important, because knowing earlier is better than, rather than late knowing...it's...it's a serious sickness that can kill if you don't treat it." (24-26/2/1) [Alison]. This same mother goes on to say, *"...so I think it's a good idea to me, it secures the baby, it secures the mother from suffering for a long time in sickness..." (31-32/2/1)* [Alison].

In another quote, a parent tries to approach the subject of prevention with her adult child. *"So, when I telled her, why don't you use these condoms? She said but Mum, you know what she told me? But why should we, if we use condom we use them, if we don't use them, we don't care, there is medication here, we don't mind about it...I said but it's not only the HIV, there are so many diseases." (510-513/53/3)* [Harriet]

For Harriet, she wanted to approach the issue of responsibility based on her own experience of being diagnosed HIV positive and protect her child from contracting this virus. She was trying to help her adult child understand her experiences but found it difficult to find the language. For Harriet, she was

trying to be emotionally more open and honest but still found it difficult to make sense and convey meaning *"...when I telled her, why don't you use condoms..."*. The emotional impact was in both her explicit language and in her implicit underlying meaning.

Further on in the interview she again tried to reiterate the earlier point she had been saying to her adult child when she explained, *"I told them, the life is in your hands...this medication, taking them every day, every day, every day, it's not easy." (563-565/56/3)* [Harriet]. Once again the use of repetition in the phrase, *'every day'* is emotionally laden and emphasises how difficult these mothers found to share their experiences of being diagnosed HIV positive with others, even members of their own families as well as the burden they felt living with HIV.

7. Discussion

7.1 Introduction

This chapter will explore the themes identified in the previous section within the context of empirical literature. A review of how the study findings either support or differ from this, including unique findings will be highlighted. The limitations of this study, implications of the findings specifically relevant for counselling psychology and the wider context for HIV Positive Immigrant African Mothers Living in the UK. Finally, areas for future research will be proposed.

7.2 Overall Findings

Several main findings appeared to emerge from the analysis which are reflected in the superordinate themes.

The first of these was the *'Quest for Survival'* which captures these HIV positive African mothers sense of fear about their own mortality and challenges as an immigrant in the UK. On receiving a diagnosis of HIV, many participants experienced psychological distress which included concerns about how they would survive and what this would mean for themselves and their families. Initially they were worried that they would not be able to access the UK healthcare system and would have to return to their home country where being HIV positive meant eventual death if treatment was not accessible or available. Over time, they made sense of their experiences of the UK Healthcare system as a place where they were looked after physically and emotionally. This process involved them in decision-making around healthcare outcomes which was experienced as different to what they were used to in their countries of origin, especially in relation to issues around disclosure and testing of children and partners.

The superordinate theme '*impact of diagnosis on identity'* reflects how participants initially made sense of their diagnosis as something associated with shame. Most of them felt a need to hide their HIV status from others because of the stigma attached to this condition and because of the fear that they would be blamed for any transmission of HIV to family members including

partners and child/ren. Receiving an HIV diagnosis had somehow changed their sense of identity and for some, how their partner's viewed them (no longer perceived as innocent). Participant's experiences were influenced by their *cultural and religious* understandings which perceived HIV as a punishment from God, or caused by sexual behaviour that held negative connotations for communities. Despite living in the UK and accessing 'modern' medicine, participants often seemed to initially make sense and approached their HIV diagnosis from a traditional perspective based on their early childhood. This was based on their past experiences of religion and traditional views passed down the generations. For the majority of these HIV positive immigrant African mothers, the outcome of their own and their child/rens HIV test was perceived to be in God's hands.

The superordinate theme *'It's there but HIV is not me'* captures individuals shift towards *'coming to terms'* with their diagnosis which enabled them to eventually consider testing their child/ren for HIV. This was largely due to the support and encouragement of healthcare professionals and the Charity/NGO sector, which ran education programmes and were instrumental in communities accessing HIV testing and challenging stigma and marginalisation. Through attending support groups, many participants felt that they found an inner strength to combat their fear around having an HIV positive child/ren. They made sense of their own and their child/rens diagnosis as something beyond their control which meant they were not to 'blame' and no longer viewed HIV as pertaining to the 'I' and moving towards the 'we'.

This process allowed participants the opportunity to not feel so alone but part of a wider 'community' which shared a common sense of purpose and meaning. A new sense of 'normal' was attained and helped participants move on with their lives. They viewed HIV as part of who they had become and not their sole identity. These immigrant African mothers had multiple identities that they were now able to embrace as mothers, partners, family members and friends. They still maintained the role of the protective and nurturing mother, which happened to include their HIV positive status.

For some mothers their protective role involved educating and encouraging safer sexual practices to prevent them contracting HIV. For others who had a positive child, their focus became ensuring that their child engaged in HIV treatment and learnt to live well with their positive status.

7.2.1 Unique Findings

To date there are no studies on the experiences of HIV positive immigrant African mothers in the UK. The few studies that do exist focus on the experiences of HIV positive African women and not specifically on mothers. The focus is different for these other studies, either addressing questions of identity such as what it means to be a black woman in London (2004); or how women engage in care when they are diagnosed with a long-term health condition (2013); or experiences of antenatal care and pregnancy (2011; 2013; and 2017).

A unique finding included child/ren taking on a parental/caring role after their mother shared her HIV status. They ensured that medication was taken and in some instances they emphasised how 'normal' this was to help their mother remain adherent. The mother's HIV diagnosis had an impact on family roles with the child taking on a parental role.

For some of the participants they wanted to protect their child (ren) and had conversations they did not expect to have around sex to try protect them from contracting HIV. This was a part of accepting and adjusting to their own diagnosis and wanting to safeguard their child's health and wellbeing.

Testing your child for HIV moved from an area of fear/worry (and stigma) to one of being 'selfish' if you did not test them, which reflected some of these mothers process of adjustment.

Another unique finding was the absence of a father's voice in the decision-making around testing of their child/ren for HIV; which seemed to be in direct contradiction to the literature which placed men/father's as the prime decision-maker, in particular in participant's countries of origin.

After the process of adjustment, many of these mothers seemed to develop a greater sense of purpose in relation to their HIV diagnosis and became part of a wider community. They may have found their voice in relation to either becoming public health advocates or promoting HIV testing and/or started to challenge stigma associated with the diagnosis.

A further finding was that for this group of women, their adjustment included merging traditional beliefs with those of modern medicine, and accepting the complementary relationship between the two.

Another unique finding was the role of religion and God, moved from previous views that HIV was either a result of your sins or a punishment from God, to in the UK their sense-making changed to either you had been sent to UK by God and you no longer had to make a choice between religious practices and modern medicine. You could pray and take medicine. Their identity as an African Christian women was not questioned when they were able to reframe their HIV and integrate it into self (part of identity, not only part of who they were).

This study found that when a woman tested HIV positive and a man was negative, the sexual behaviour of men (for example having extra-marital relationships) was not ‘allowed’ to be questioned by the wife but expected to accept this behaviour because of their HIV status.

From the literature reviewed, the language that is used by these participants, reflected the move from depersonalisation (use of words like ‘sicking’, ‘this sickness’, etc.) to being able to use the word HIV which indicated their adjustment to being diagnosed HIV positive and a more internalised process of acceptance.

7.2.2 Discussion of Themes and Sub-themes in relation to the literature review

The superordinate theme *'Quest for Survival'* represents the importance of participant's journey to the UK and how they came to access the UK health service. Their experiences of the healthcare service and their sense-making of being tested and treated for HIV, in part influenced their decision making to test their child/ren. Whilst there is no literature that found that HIV positive immigrant African mother's experiences of HIV healthcare services influence their decision-making over their children's health, studies such as Lorenz, et al (2016) and Arun, et al (2009) support that mothers did not want to test their child/ren for HIV because of their own experiences of stigma. This can be argued to support the finding that mothers tend to make decisions about their children's healthcare based on their own experiences.

In this study, participants appeared to justify or make sense of why they felt the need to access medical assistance while on holiday in the UK. Primarily their physical symptoms became noticeable and family members encouraged them to seek medical help. The understanding that unless you were physically unwell you would not go to a doctor, was also found in several studies including Baugh, et al (2014) who found that this was one of the reasons given by parents for not earlier seeking help. This approach was also applied when considering testing their own child/ren for HIV. Mothers could not conceive of their child/ren being HIV positive unless they had physical symptoms of illness. This supports the findings of Rwemisisi, et al (2008) that highlighted the complex array of underlying reasons why parent's decision-making was often confused by contradictory advice given by healthcare providers. This often reinforced their own fear, cultural and family beliefs about HIV, and the dilemma about the presence of 'physical versus non-physical' symptoms remain a problem today for mothers' decision-making about HIV whether in the UK or abroad.

The findings from this study support that of Lorenz et al (2016); and the WHO (2016), who found that in resource limited settings people were less likely to access healthcare unless they had financial means. Affordability did not only refer to having economic means to pay for treatment but to being able to pay for transport to and from clinics. The wider economic impact of receiving HIV treatment in developing countries was uniquely captured in the current study. Participant's expressed the difficulty of not having enough financial resources to pay for both treatment and the food required when taking their medication. This was essential for their overall wellbeing. There was a wider impact, with respect to, being able to afford food for your immediate and extended family. Across participants they made frequent reference to the differences between their country of origin and the UK in relation to 'free' health care and support to stay well. This in part, facilitated their decision-making in relation to their child/rens health needs and whether to test them for HIV.

Another unique finding generated from this study, was the stigma attached to attending clinics in participant's country of origin, which they managed to avoid, if they could afford for their medication to be brought to them discretely. It could be proposed from these interviewee's, that confidentiality of their own and their child/rens HIV status, is an important consideration in mothers decision-making about whether they will test themselves and their child/ren for HIV, and seek treatment. Studies such as Adeniyi et al (2015); Simbayi, et al (2007); & Parker, et al (2003) have also shown that mothers fear their children being stigmatised which influenced their decision-making about disclosing their own and their child/ren HIV status.

It can be extrapolated from this that decisions about HIV testing would be affected too, and limit their attendance at clinics/healthcare facilities. Although stigma was a concern found amongst the participants in this study, a unique finding was that mothers fear of their own and their child/rens mortality in part motivated them to test and seek treatment. Amongst these participants, their quest for survival was encapsulated by their journey to the UK. This was both an implicit and explicit outcome of their fear of death. This was mirrored by their family members who encouraged and supported this journey.

As already mentioned previously, in the UK, HIV testing and treatment remains free via the National Health Service (NHS). While the UK approaches healthcare decision-making in a fairly collaborative manner between patient and healthcare provider, this was not always the experience for participants especially when thinking about their experiences from their countries of origin. Rwemisisi, et al (2008) found the advice offered, differed, affecting parent's decision-making. Two recent studies by Fearnley et al (2017) & Bluebond-Langner, et al (2016) found that parent's looked to healthcare providers for assistance in their decision and sense-making especially with regard to information gathering and sharing.

It was primarily the decision-making process that differed for participants when they had settled in the UK. For most participants who were diagnosed abroad, they described having some of their decision-making removed by the healthcare system especially in rural, traditional areas. This was reiterated by Simbayi et al (2007) & Parker et al (2003) who highlighted the role that healthcare providers played for many communities including the fear experienced by those who accessed their services. What has been previously highlighted is the feeling that sometimes the choice has been taken away and while already trying to cope with a new HIV diagnosis, being 'strongly' encouraged to inform partners/husbands, or other family members felt different when they engaged with their HIV care in the UK. Findings from this research support the work of Wagner et al (2016) who found that when healthcare services encouraged and offered parents the opportunity to test their child/ren there was an uptake in testing.

In this research, some participants described being prompted to discuss testing their older child/ren for HIV, during their routine antenatal appointment which offered antenatal 'opt out' HIV screening in the UK. This draws parallels with the work of Kulzer, et al (2012) who found that by raising the question of HIV testing with families, concomitantly increased testing uptake. Although participants were offered testing in the UK, this did not independently result in the decision to test. They were better able to make this decision when having confidence in the UK healthcare system and a positive relationship with the

healthcare clinician. Rwemisisi, et al (2012) shared these findings, highlighting the importance of people's confidence in the healthcare available to them and treatment efficacy.

The second superordinate theme '*Impact of Diagnosis on Identity*' reflects how these immigrant African mothers experienced living with HIV. This incorporated the impact that this diagnosis had on their own identity and their interpersonal relationships within the family. As previously mentioned above, the fear of stigma led to participants hiding their diagnosis and they appeared reticent to find out their child/rens diagnosis in case they also were stigmatised and marginalised. This also applied to participants' partners. This was found in the study by Arun, et al (2009) & Gyamfi, et al (2017) who reiterated these findings. Even when participants made the decision to test their child/ren, they wanted to keep their own and their child/rens diagnosis a secret. Stigma for the mother included being blamed by society for this diagnosis. HIV was negatively viewed by participant's communities and resulted in feelings of shame and secrecy because of the associations attributed to this diagnosis. These included views that only 'sexually promiscuous' women contracted HIV and it was their fault when a child or partner contracted HIV. This was found in the article by Adeniyi et al (2015) previously highlighted in the literature review. Some participants in this study experienced fear and anxiety that their partner would blame them for their child/rens HIV diagnosis, which occurred amongst some of those interviewed.

For many of the African immigrant mothers mentioned by Proudfoot (2017), their disbelief about their HIV diagnosis was in part due to their assumptions that they did not fit the profile of someone who would contract HIV. Interestingly many participants did not blame or mention their partners when considering who was responsible for the transmission of HIV, and seemed to take responsibility for contracting HIV and had a marked impact on these participants.

A shared commonality among these positive immigrant African women living in the UK was the impact this diagnosis had on their personal relationships. In most instances, they found partners blaming and shaming them for testing

positive. There was an accusatory nature to these interactions, which had a negative emotional impact on participants. The psychological impact for these women of receiving an HIV diagnosis had a marked impact on their sense of self-worth and identity. For many of these mothers there was a sense of innocence before their diagnosis. This supports the findings of Gyamfi et al (2017) that people with HIV were vilified and 'engaged in bad behaviour'. Despite coming from different countries the participants shared these views towards themselves and others. The findings from this study revealed that there were changes to the dynamics in these immigrant African mothers relationships after receiving their HIV diagnosis and disclosing this to their partners. The power dynamic shifted in their relationship and for some of their partners, they became verbally abusive, distant in their marital relationship and conducted sexual relationships outside marriage. These findings give further weight to the report by the National AIDS Trust which found that women feared disclosing their HIV status to their partners, and had to contend with challenging behaviour from their partners.

The impact of this diagnosis on a mother's relationship with her child/ren involved in some of the cases, the child taking on the caring role and worrying about their mother remembering to take their medication according to a number of participants, who made sense of this, as their child caring for them and taking on a parental role. This was not found in any of the other literature. Although the mothers in this study reported being cared for by their children, they also described being protective of their child/ren and worried how their child/ren would react to news that they too were HIV positive. This supports the work of Wiener et al (2007) who found that HIV positive African mothers delayed testing their child/ren for HIV because they were concerned about the negative psychological and emotional impact that this diagnosis could cause their child.

The findings from this study showed that once participants had accepted their own HIV diagnosis they were confronted with the dilemma whether to test their child/ren. This was experienced as a psychological burden. On one hand not knowing allowed the participant to remain 'innocent' and unencumbered with dealing with an HIV positive child. While knowing their HIV status raised

worries of how they would cope, and fears about the impact of the outcome if positive.

For others, the test result gave a sense of relief and ended rumination and worry. Part of the influence around decision-making, was shaped by participant's experiences of receiving their own HIV diagnosis. For some, this decision-making took them back in time to when they were first diagnosed. These evoked difficult emotions which needed to be processed before they could consider their decision. The emotional and cognitive aspects of the dilemma around testing, has not been found to be documented previously in the literature. Interestingly, whilst Birdthistle et al (2008) found that men and male elders have a large influence over decision-making regarding healthcare for themselves and their family, many of the participants in this study had to make the decisions for their own and their family's health on their own.

Religion appeared to play a critical role in how these HIV positive immigrant African mothers in the first instance, made sense of their own and their family's HIV diagnosis. Similarly, to the works of Gyamfi et al (2017) these women perceived their HIV diagnosis as a punishment from God and only through repentance could you 'rid yourself' of HIV. This study supports the work of Gyamfi et al (2017) in that these participants 'called on God' for 'protection' and to take control of their health.

The third superordinate theme '*It's there, but HIV is not me…'* represents the transition that positive mothers made with respect to coming to terms with not only their diagnosis but the need for their child/ren to be tested and the anticipated outcome of their child/rens test. These HIV positive immigrant African mothers had to make sense of their own experiences of being tested and diagnosed HIV positive in the first instance before they could emotionally reconcile considering testing their child/ren and acknowledging the outcome.

There was an additional aspect to the adjustment process, which involved the immigrant African mother developing a new identity which involved integrating their HIV status into their sense of self. Similar to the work of McLeish and

Redshaw (2016) the participants found new meaning to being HIV positive and embraced this new identity as a health advocate and 'good mother'. The meaning of what contributed to being a 'good mother' according to Lingen-Stallard (2016) was that these mothers kept physically and emotionally well so they could remain alive to be part of their child's life. For the participants in this study, being a 'good mother' meant testing their child/ren for HIV and ensuring they engaged in positive health behaviours around either being HIV positive or protecting themselves from contracting HIV.

Participant's quest for survival motivated them to eventually engage in the UK healthcare system and NGO's. This helped them to develop a better understanding of their chronic condition and shift from a state of fear to that of confidence with managing their own and their child/rens health as well as giving them hopes for the future. As part of this, healthcare professionals and charities played a role in reducing the sense of stigma, shame and blame attached to a HIV diagnosis. They also helped to normalise the concept of testing, while emphasising and promoting its relevance. This in part, helped mothers decide to test their child/ren. The importance of removing stigma as a barrier to testing was also found in the work of Bolsewicz, et al (2015).

Charities played a role in participants taking on a 'new identity'. Being a member of a group of people who shared the same diagnosis harnessed a sense of 'us' and 'we' rather than 'I'. They no longer felt so alone or isolated but could share their narrative and seek support and encouragement to disclose their HIV status to their partners and child/ren. They also found courage to test their partners and child/ren and manage the outcome. This was not found in any other study, the process of moving from depersonalisation to personalisation in this context.

As part of this new identity, it appeared that once mothers accepted responsibility for their own testing and that of their child/ren, they were now part of something that held a greater import than themselves. This gave them meaning and purpose, as advocates and champions, for raising HIV awareness, educating the public and encouraging testing. It can be

argued that the phenomenon of becoming a public advocate is not isolated to HIV, but can be found in other chronic health conditions. For example, Charities such as Cancer Research, often use people who have a diagnosis of cancer in their campaigns for testing/ and promoting screening. While in HIV, one of the most notable exponents became 'Magic' Johnson when he disclosed to the public that he was HIV positive. He is still often referred to in public health campaigns focusing on HIV testing.

As already mentioned, contributors sense of what it means to protect their child/ren as a mother and a parent, shifted when they were able to accept and cope with their own diagnosis. Prior to their own adjustment, participants described shielding their child/ren from stigma, as a form of parental protection, and this was illustrated in the work of Adeniyi et al (2015). The understanding of what it meant to protect their child/ren seemed to undergo other changes. Interviewee's later described disclosing their HIV status to their child/ren as a means to educate them about HIV and sexual health. They either spoke to their child/ren about the importance of taking precautions, such as using condoms, to protect against contracting HIV or about ensuring their positive child took their medication. Participants felt that they were better able to talk to their child/ren about how to protect themselves from illness, through the skills and knowledge they had gained from charities as well as from healthcare professionals. This was highlighted in Fearnley, et al (2017) who found that mothers sought guidance from healthcare professionals on how to talk to their children about chronic ill-health.

As participants moved towards a sense of adjustment, God's role in their contracting HIV was perceived to be an act of divine intervention and had meaning and served a spiritual purpose which corroborates McLeish and Redshaw (2016) findings. It was commonly shared amongst participants that they entered a dialogue with their 'God', requesting help and pleading for a negative HIV result for their child. There was a belief amongst those interviewed that their child/rens diagnosis was dependent on God's will and that if their child tested negative, this was a result of God's mercy and a testament to the strength of their faith. Array et al (2016) also found that

similar to these participants the role of religion and faith provided emotional strength and helped them develop resilience. Whilst on one hand, some parents felt powerless by acknowledging God as the ultimate decision-maker, others found comfort and solace for God being responsible, rather than themselves, for a child's HIV diagnosis. This enabled them to be free of the guilt and burden they primarily held for their child's physical and emotional well-being. Contradictory and complex aspects relating to religion and spiritual belief systems were illustrated by participants when thinking that a child might be HIV positive, and mothers felt they could cope by asking God for strength to manage the burden of this diagnosis.

7.3 Limitations of IPA

The limitations of IPA include the small sample size, which prevents generalisability of findings to the broader population and it involving one in-depth interview. The findings are limited by participant's sense-making at the time of the interview.

Willig (2013) describes the role of language, suitability of accounts and explanation versus description as further limitations of IPA. This will be explored as well as how participants experience their world and reality (Kvale, 1996).

7.3.1 Language

According to Willig (2013) language captures and communicates experiences. Accounts are limited to participant's ability to use language that accurately represent the meanings and sense making they try to convey. Participant's ability to do this is restricted to their knowledge of vocabulary and understanding of language. In this study, although English was not participant's first language, they had all been living in the UK for many years. It is possible that certain meanings were lost or not fully understood. An additional influence may be the possibility that meanings attributed to words are different for the researcher and participant. In an attempt to minimise this, checking with participants what they meant was necessary.

Language constructs rather than describes reality and experiences can be described in several ways through language. The researcher is limited to understanding how participants describe their experience through language rather than directly accessing that experience. To accurately capture how participants made sense of their experiences the interview questions and prompts encouraged the exploration of participant's feelings and sense-making.

Lakoff and Johnson (1980) propose that metaphors are meaningful representations of what is difficult to directly express. Metaphors are visual images that may offer a more accurate expression of emotional meaning (Levitt, Korman, and Angus, 2000). Metaphors were used by participants in this study as a means to convey the depth of their distress when finding out their HIV diagnosis and having to make decisions around the testing of their child/ren.

7.3.2 Suitability of Participant's

As described earlier, the findings identified in an IPA study depend on participant's ability to capture and convey their experience through language. When screening participants for suitability, it was important that they were able to express themselves in English.

The participants in this study all self-selected and were linked to HIV organisations such as Charities/NGO's. They were all born abroad, immigrated and had been living in the UK for several years. They were also predominantly from Christian, African backgrounds and were all female. Although the participants were homogenous in these ways, the study findings are limited in terms of understanding how other ethnicities, religions and genders may have experienced the same phenomena. Despite these findings not being transferable or representative of UK born and raised HIV positive parents, the participants are suitable as the majority of positive HIV mothers in the UK were born abroad.

The contributions are also limited in that these participant's accounts were recorded sometime after they and their child/ren, had been tested and

diagnosed HIV positive. The meaning and sense-making may have been different had these been conducted prior to their own HIV testing or that of their family members.

It is relevant to note, that this particular cohort appeared to want their narratives to be heard, and utilised the interview as a platform to have their voices heard. This was demonstrated by some participants whose comments made reference to the importance of others learning from their experiences.

7.3.3 Explanation versus Description

Willig (2013), explains that IPA focuses on meanings and perceptions for individuals who help them make sense of the world. While this lived experience is important in phenomenological research it does not try and explain these experiences, or how or why they occur, but focuses on describing and documenting perceptions of those interviewed. This too is a limitation of the research findings and as IPA is idiographic it does not purport to offer definitive answers but rather as Smith et al (2009) explains, attempts to make sense of individual experiences and contribute towards a developing knowledge base, for instance in this study, understanding the lived experience of HIV positive immigrant African mothers in the UK. The themes that have been discussed are based on this researcher's understanding, rather than that of anyone else who may have found different themes that they thought relevant from the data.

According to Smith et al (2009), IPA is a creative process. While quality and validity need to be empirically understood, criteria for validity needs to be applied flexibly as what works for one piece of research might not work for another study. In addition, the researcher's own knowledge and experience in the field may have been a limitation in that it could have influenced the interpretative aspect of the analytic process. Kvale (1996) promulgates the importance of researchers 'bracketing' their prior knowledge and experiences. This is to ensure that accurate description of the phenomena being investigated are captured and that implicit messages identified belong to the interviewee not the researcher.

7.4 Implications of Study Findings

It can be argued that the study findings may contribute towards establishing UK guidelines and pro-formas to help encourage the disclosure and testing of individuals, their partners and their child/ren. Participant's described the impact a positive diagnosis had on family dynamics and relationships. They shared their experiences of the fear associated with this diagnosis such as stigma and their feelings of guilt and worry about a child testing HIV positive. These findings highlight the importance for on-going psychological interventions for pre and post-test counselling to be included as part of any pro-formas that are developed. In addition, this corroborates the BHIVA recommendations for specialist HIV psychological support (counselling psychology) as participants have complex psychological and physical needs.

The types of psychological and practical decisions faced by this cohort often involve challenging health beliefs for behavioural change. This study supports the need for specialist training for healthcare professionals who work with this patient group in the context of their cultural and religious backgrounds. Training might cover topics such as the adjustment process for patients and how culture and religious beliefs shape and influence their engagement with modern health care services. This in turn may enable healthcare professionals to gain a deeper understanding of how to identify and manage the challenges this cohort face.

This study highlights the important role that healthcare professionals including doctors, nurses and midwives have on patient's experiences and their level of engagement with the UK healthcare system. Training this group of professionals should include addressing the psychological impact involved in HIV testing and the impact of a positive diagnosis for both the parent and other family members. Considerations should be made for the patients cultural, religious and personal beliefs which might influence their decision-making around testing and treatment. Working in collaboration with patients and their families seemed to help this cohort foster agency in their health management. This is supported by the participant's accounts of the professional relationship being supportive and encouraging which helped

them with the decision to disclose their HIV status to their partners and to test their child/ren.

It could be argued, that the findings from this study support previous literature which demonstrates that for many African immigrants living abroad, their religious and cultural norms influence their attitudes and approaches towards HIV and its management. The participants reported that they found outreach programs provided a sense of community and helped them adjust and accept their HIV diagnosis. The findings give weight to the important role religious institutions (e.g. churches) play with respect to helping de-stigmatise HIV and challenge the perceived reticence at times, of African immigrant communities to test themselves and their child/ren for HIV.

Stigma and lack of resources amongst the participants were reported to be some of the main reasons why mothers were hesitant to test themselves or their child/ren for HIV. These findings highlighted the need for support groups to help HIV positive immigrant African mothers to manage their diagnosis by normalising HIV and encourage continued testing. In an era of austerity and cutbacks in the NHS, there is a risk that HIV testing and support becomes less available which may lead to an increase in undiagnosed HIV in the UK.

The children of these HIV positive immigrant African mothers have been demonstrated in this research to have in some instances become corers. This particular finding highlights the need for this role to be explored in more depth so that the impact on their childhood is better understood. It also suggests that there may be a need for these children to receive support from social services or other community organisations.

As an IPA study, the findings contribute to closing the gap in the literature which to date has largely been quantitative in nature. This research project offers in-depth, rich and unique insights into how someone makes sense and experiences being an HIV positive immigrant African mother living in the UK. It tentatively offers an understanding of how these participants attributed meanings both implicitly and explicitly to their experiences.

It could be argued that the study findings offer deeper insights into the barriers to engagement within the UK healthcare system for these HIV positive immigrant African mothers, which may not have been captured through other research methods.

7.5 Implications of Study Findings on Clinical Practice

It may be proposed that the study findings highlight the importance of counselling psychology in helping HIV positive immigrant African mothers in the UK adjust and accept their own and their child (rens) HIV status. Participant's accounts offer insights into the therapeutic work that counselling psychologists might undertake when working with this client group. The role of a counselling psychologist might involve helping these mothers with their decision making to test themselves, partners and their child/ren for HIV. Clients might need therapy around working through their fears around receiving an HIV diagnosis and the possibility of a premature death. Through the therapeutic relationship, they might develop an improved sense of agency and coping strategies to face any stigma and marginalisation they may experience. Working through any felt sense of shame, blame or guilt can lead to normalising and accepting a heavily stigmatised health condition. As part of this, therapy might involve helping people reframe their diagnosis in the context of their cultural norms and spiritual/ religious beliefs and move towards an improved engagement with the healthcare system.

Whilst face to face therapy for individuals has been more widely used to address difficult experiences for individuals, the study findings suggest that there may be value in adopting alternative therapeutic approaches which could be appropriate for this patient cohort. An example might include family therapy and/or couples counselling in order to address the impact that a HIV diagnosis has on family dynamics and interpersonal relationships. Cognitive Behavioural Therapy and third-wave approaches such as Compassion Focused and Acceptance and Commitment Therapy might be particularly useful to work through feelings of shame and guilt towards acceptance and adjustment. Alternatively, Motivational Interviewing might be better placed to facilitate healthcare engagement.

Given the complex and diverse issues that this cohort of patients might experience, counselling psychologists may need to undergo further training, as listed above, to ensure that they are able to meet the needs of these HIV positive immigrant African mothers. This might also include learning about how Health Psychology models can be used to promote good health and prevent illness.

Participants highlighted the influence of education and attending support groups in normalising a HIV diagnosis, increasing their understanding of the need for testing and the importance of treatment. Counselling psychologists might facilitate this through a series of psycho-educational groups or workshops.

7.6 Recommendations for future research

The HIV positive immigrant African mothers in this study were not UK born, and were interviewed some years after testing themselves and their child/ren for HIV. Future research might include investigating the experiences of UK born positive mothers, pre and post testing, from various other religious and ethnic backgrounds. This might help identify other aspects that influence decision-making around HIV health at different stages. This may reveal similarities and/or differences for these particular groups.

Future research might also attempt to address the gap in the literature and investigate the experiences of HIV positive immigrant African fathers living in the UK to better understand if there are similarities or differences. This study might focus on the role that men play in the decision-making process of testing their partners and their child/ren for HIV. It is important to understand, if and how, men and women experience these phenomena differently, and if so, how this affects their decision-making around their own and their family's healthcare.

In light of the study findings, which illustrate the important relationship between patient and healthcare provider, how clinicians perceive their role and responsibilities in encouraging African immigrant HIV positive parent's to test their partners and their child/ren needs further exploration.

Further research could explore the lived experiences of the children of HIV positive immigrant African mothers.

Finally, another researcher may wish to utilise a different qualitative theoretical approach such as grounded theory, narrative, or thematic analysis to study the same phenomena. By employing a different research approach, unique findings might be identified and generated.

7.7 Final Reflexivity, the Role of Counselling Psychology and IPA Research

Reaching the latter stages of this research project raised a number of reflexive thoughts and questions. Without repeating too much of the methodology chapter, as Willig (2013) reminds the novice researcher, qualitative research accepts and understands the role of both the person and theoretical perspective they adopt, and the influence of this on the study findings. Reflexivity begins early on and continues throughout the research process. Through the use of reflexive journals, supervision, and the iterative nature of undertaking qualitative work, and in this instance IPA as a theoretical framework, meaning and sense-making evolves.

In a recent article Tomkins and Eatough (2018), discuss hermeneutics and remind us what one of the original proponents, Schleirmacher raised about the hermeneutic circle connecting whole to parts. For this study, I adopted an interpretative approach which meant that IPA data needs to be considered in the first instance at 'face value' and secondly moved towards an interpretative position where 'hidden' or implicit meanings exist. Heidegger (1962) raised the question about whether and how understanding is possible in the first place, as we start with pre-conceptions and it is difficult to start as a 'blank canvass'.

In my particular situation, the challenges were based on the fact that I was working as a Chartered Counselling Psychologist for the past seventeen years in the field of HIV, in a secondary care setting, and was concerned that this may have influenced my interpretation of participant's decision-making;

affected my objectivity; and that my research question and interview schedule would have been impacted by my role as a Practitioner Psychologist due to my particular work setting. To try and counter-balance any preconceived ideas, I checked for understanding by using prompts with interviewee's, 'bracketed' assumptions, used a reflexive journal, relied on supervision and conversations with others, to ensure that I was not confusing or conflating my role as a psychologist with that of my role as a qualitative researcher. This took a long time as I became focused on whether my knowledge of the topic, closeness to the subject due to the client's I have seen therapeutically and histories they have shared, might unknowingly have meant that during the process I had gone in to therapist mode, rather than that of the IPA researcher.

My role as a Counselling Psychologist is to understand peoples' experiences, and hence make therapeutic inferences and formulations and I needed to concentrate on not inadvertently becoming a therapist, as opposed to being a researcher, making sense of participant's sense-making. Ethically this was something I was mindful of, and had to remind myself of periodically, which was helped by immersing myself in IPA theoretical texts and the transcripts. In addition, I questioned my own practice, which was facilitated by attending the London IPA group, and further sharing this concern. During the interviews, I was conscious of not colluding with participant's when they discussed their experiences about HIV as a result of my practitioner psychology role and I attempted to follow the guidance for undertaking IPA research as discussed previously, proposed by Smith et al (2009) & Willig (2013). For example, due to my own ethnicity being different to those of my participants, this may have affected the way participant's explained their own culture in their interview, assuming difference.

7.8 Conclusion

The aim of this research was to undertake an Interpretative Phenomenological Analysis (IPA) of the Lived Experience of HIV positive Immigrant African mothers in the UK. There is a dearth of literature in this area, in particular when focusing on the particular experiences of HIV positive immigrant African mothers. Current thinking, in particular in the developed world, where

medication is readily available is that HIV is now considered to be a chronic, manageable health condition. Why then do parents seem to struggle to make the decision to test their older child/ren for HIV? In clinics it is not uncommon to hear the refrain, “but Doctor, they are not unwell...” and reluctance, fear and avoidance remain prevalent in 2018. Willig (2013) reminds us that it is qualitative research that provides the researcher with the chance to study meanings. The health field is where Smith et al (2009) found the opportunity to develop IPA and focus on how patient’s made sense and meaning of their illness experiences. The traditional medical field with its notion of ‘hard’ science, and facts and figures, were a stark contrast to the perspectives and interpretations offered by qualitative methodology, and evaluating this, are not easy. (Willig, 2013).

HIV testing is evocative and can be controversial, whether in children or adults. There are global health campaigns which promote testing and offer an educative function. Silence is challenged and the decision moves from the individual, to a larger one, of finding a voice for the disenfranchised and stigmatised communities. HIV can still be life-limiting and without medication, illness and death is inevitable. This study, found that the journey these participants had taken were impacted by stigma, rather than the actual fear of death. This was unique in relation to many other childhood illnesses and in future could be correlated with other childhood chronic conditions. A screening tool might be a way of supporting individuals and families while normalising some of the feelings associated with an HIV diagnosis.

There was additional information generated such as the role of infidelity from partner’s, expectations of sex and relationships after an HIV diagnosis, and the impact of gender such as the women taking on shame and blame for a positive status that was not directly related to the research question and could offer future areas of exploration. What did become evident as the research process progressed was that the journey for these HIV positive African immigrant mothers were physically and emotionally challenging and years later despite being settled in the UK, is still having a marked impact on their lives.

.

8. REFERENCES

Acheampong, A. K., Naab, F., & Kwashie, A. (2017). Qualitative exploration of psychological reactions and coping strategies of breastfeeding mothers living with HIV in the Greater Accra Region of Ghana. *International breastfeeding journal*, *12*(1), 28.

Adeniyi, V. O., Thomson, E., Ter Goon, D., & Ajayi, I. A. (2015). Disclosure, stigma of HIV positive child and access to early infant diagnosis in the rural communities of OR Tambo District, South Africa: a qualitative exploration of maternal perspective. *BMC paediatrics*, *15*(1), 98.

Afulani, P. A., Torres, J. M., Sudhinaraset, M., & Asunka, J. (2016). Transnational ties and the health of sub-Saharan African migrants: The moderating role of gender and family separation. *Social Science & Medicine*, *168*, 63-71.

Ahmed, S., Kim, M. H., Sugandhi, N., Phelps, B. R., Sabelli, R., Diallo, M. O., ... & Child Survival Working Group of the Interagency Task Team on the Prevention and Treatment of HIV infection in Pregnant Women, Mothers and Children. (2013). Beyond early infant diagnosis: case finding strategies for identification of HIV-infected infants and children. *AIDS (London, England)*, *27*(0 2), S235.

AIDSinfo (2017). *Preventing Mother-to-Child Transmission of HIV.* Retrieved from: https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheetss/24/50/ preventing-mother-to-child-transmission-of-HIV

AIDSinfo (2018). *HIV Treatment: The Basics*. Retrieved from: https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/21…AIDSinfo&utm_medium=email&utm_campaign=2-9-18-HIV_Treatment_FS

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. Washington, D.C.: American Psychiatric Association.

Anderson, J., & Doyal, L. (2004). Women from Africa living with HIV in London: a descriptive study. *AIDS care*, *16*(1), 95-105.

Arun, S., Singh, A. K., Lodha, R., & Kabra, S. K. (2009). Disclosure of the HIV infection status in children. *The Indian Journal of Pediatrics*, *76*(8), 805.

Bandason, T., McHugh, G., Dauya, E., Mungofa, S., Munyati, S. M., Weiss, H. A., & Ferrand, R. A. (2016). Validation of a screening tool to identify older children living with HIV in primary care facilities in high HIV prevalence settings. *AIDS (London, England)*, *30*(5), 779.

Bantjes, J., & Kagee, A. (2018). Common mental disorders and psychological adjustment among individuals seeking HIV testing: a study protocol to explore implications for mental health care systems. *International journal of mental health systems*, *12*(1), 16.

Baugh, A., Pammi, M., Butler, S., Cliffe, L., Ahmed, I., & Smyth, A. R. (2014). Testing children of HIV-positive parents: a multidisciplinary approach. *Archives of disease in childhood*, *99*(8), 789-790.

Becker, M. H. (1974). The health belief model and personal health behaviour. *Health education monographs*, *2*, 324-473.

Beima-Sofie, K. M., Brandt, L., Hamunime, N., Shepard, M., Uusiku, J., John-Stewart, G. C., & O'Malley, G. (2017). Paediatric HIV disclosure intervention improves knowledge and clinical outcomes in HIV-infected children in Namibia. *Journal of acquired immune deficiency syndromes (1999)*, *75*(1), 18.

Blair, J. M., Paxton, L. A., & Kamb, M. L. (2013). HIV and AIDS in women. In *Women and health* (pp. 505-522). Academic Press.

Bluebond-Langner, M., Hargrave, D., Henderson, E. M., & Langner, R. (2016). 'I have to live with the decisions I make': laying a foundation for decision making for children with life-limiting conditions and life-threatening illnesses. *Archives of disease in childhood*, *102*(5), 468-471.

Boland, L., Kryworuchko, J., Saarimaki, A., & Lawson, M. L. (2017). Parental decision making involvement and decisional conflict: a descriptive study. *BMC paediatrics*, *17*(1), 146.

Bolsewicz, K., Vallely, A., Debattista, J., Whittaker, A., & Fitzgerald, L. (2015). Factors impacting HIV testing: a review–perspectives from Australia, Canada, and the UK. *AIDS care*, *27*(5), 570-580.

Boon-Yasidhi, V., Naiwatanakul, T., Chokephaibulkit, K., Lolekha, R., Leowsrisook, P., Chotpitayasunond, T., & Wolfe, M. (2016). Effect of HIV diagnosis disclosure on psychosocial outcomes in Thai children with perinatal HIV infection. *International journal of STD & AIDS*, *27*(4), 288-295.

Bor, R., Miller, R., & Goldman, E. (1992). *Theory and practice of HIV counselling: a systemic approach*. Routledge.

Brinkmann, S., & Kvale, S. (2008). Ethics in qualitative psychological research. In C. Willig & W. Stainton Rogers (Eds.), *The Sage handbook of qualitative research in psychology*. London: Sage

British HIV Association, British Association for Sexual Health and HIV, & British Infection Society. (2008). *UK national guidelines for HIV testing 2008*. British HIV Association.

British Psychological Society. (2014). *Code of Human Research Ethics.* Leicester: The British Psychological Society

Bundock, H., Fidler, S., Clarke, S., Holmes-Walker, D. J., Farrell, K., McDonald, S., & Foster, C. (2011). Crossing the divide: transition care services for young people with HIV—their views. *AIDS patient care and STDs*, *25*(8), 465-473.

Byrne, L., Sconza, R., Foster, C., Tookey, P. A., Cortina-Borja, M., & Thorne, C. (2017). Pregnancy incidence and outcomes in women with perinatal HIV infection. *AIDS (London, England)*, *31*(12), 1745.

Cal, S. F., Sá, L. R. D., Glustak, M. E., & Santiago, M. B. (2015). Resilience in chronic diseases: A systematic review. *Cogent Psychology*, *2*(1), 1024928.

Carmassi, C., Corsi, M., Bertelloni, C. A., Pedrinelli, V., Massimetti, G., Peroni, D. G., ... & Dell'Osso, L. (2019). Post-traumatic stress and major depressive disorders in parent caregivers of children with a chronic disorder. *Psychiatry research*, *279*, 195-200.

Carter, M. (2019). Rate of undiagnosed HIV remains high among black African heterosexuals in London. Retrieved from https://www.aidsmap.com/news/may-2019/rate-undiagnosed-hiv-remains-high-among-black-african-heterosexuals-london

Casey, M. K., Allen, M., Emmers-Sommer, T., Sahlstein, E., Degooyer, D. A. N., Winters, A. M., ... & Dun, T. I. M. (2003). When a celebrity contracts a disease: The example of Earvin" Magic" Johnson's announcement that he was HIV positive. *Journal of health communication*, *8*(3), 249-265.

Chan, Z. C., Fung, Y. L., & Chien, W. T. (2013). Bracketing in phenomenology: Only undertaken in the data collection and analysis process?. *The qualitative report*, *18*(30), 1.

Chhagan, M. K., Kauchali, S., Arpadi, S. M., Craib, M. H., Bah, F., Stein, Z., & Davidson, L. L. (2011). Failure to test children of HIV-infected mothers in South Africa: implications for HIV testing strategies for preschool children. *Tropical Medicine & International Health*, *16*(12), 1490-1494.

Chilongozi, D., Wang, L., Brown, L., Taha, T., Valentine, M., Emel, L., ... & Brown, E. R. (2008). Morbidity and mortality among a cohort of human immunodeficiency virus type 1-infected and uninfected pregnant women and their infants from Malawi, Zambia, and Tanzania. *The Pediatric infectious disease journal*, *27*(9), 808.

Chirilă, O., & Petrea, S. (2014). Disclosure of diagnosis–Adherence–Couple or future of the past. *BMC infectious diseases*, *14*(S7), O6.

Chulach, T., Gagnon, M., & Holmes, D. (2016). The Lived Experience of Pregnancy Among HIV-Positive Refugee Women. *Advances in Nursing Science*, *39*(2), 130-149.

Churchill, R., Moore, T. H., Davies, P., Caldwell, D., Jones, H., Lewis, G., & Hunot, V. (2012). Psychodynamic therapies versus other psychological therapies for depression. *The Cochrane database of systematic reviews*, (9).

Clayden, P (2013) *Guide to HIV, pregnancy & women`s health.* UK: HIV i-base

Cobb, S. C., Etkins, L., Nelson, M., Egleston, B., & Sweeney, C. W. (2016, May). Caregiver Reactions in Oncology and Other Chronic Illnesses. In *Oncology nursing forum* (Vol. 43, No. 3, p. 321). NIH Public Access.

Collins, I. J., Foster, C., Tostevin, A., Tookey, P., Riordan, A., Dunn, D., & Collaborative HIV Paediatric Study (CHIPS) Steering Committee. (2017). Clinical status of adolescents with perinatal HIV at transfer to adult care in the UK/Ireland. *Clinical Infectious Diseases*, *64*(8), 1105-1112.

Cooper, M., & McLeod, J. (2007). A pluralistic framework for counselling and psychotherapy: Implications for research. *Counselling and Psychotherapy Research*, *7*(3), 135-143.

Cooper, V., Clatworthy, J., Youssef, E., Llewellyn, C., Miners, A., Lagarde, M., ..& Sabin, C. (2016). Which aspects of health care are most valued by people living with HIV in high-income countries? A systematic review. *BMC health services research*, *16*(1), 677.

Coyle, A. (1998). Qualitative research in Counselling Psychology: Using the counselling interview as a research instrument. *Counselling psychology: Integrating theory, research and supervised practice*, 56-73.

Coyle, A., & Lyons, E. (Eds.). (2007). *Analysing qualitative data in psychology*. Los Angeles. London: Sage.

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions.* London: Sage.

Dahab, M., Spiegel, P. B., Njogu, P. M., & Schilperoord, M. (2013). Changes in HIV-related behaviours, knowledge and testing among refugees and surrounding national populations: a multi-country study. *AIDS care*, *25*(8), 998-1009.

Delara, M. (2016). Social determinants of immigrant women's mental health. *Advances in Public Health*, *2016*.

Dibb, B., & Kamalesh, T. (2012). Exploring positive adjustment in HIV positive African women living in the UK. *AIDS care*, *24*(2), 143-148.

Doyle, K. L., Woods, S. P., Morgan, E. E., Iudicello, J. E., Cameron, M. V., Gilbert, P. E., ... & HIV Neurobehavioral Research Program (HNRP) Group. (2017). Health-related decision-making in HIV disease. *Journal of clinical psychology in medical settings*, *23*(2), 135-146.

Eatough, V., & Smith, J. A. (2008). Interpretative phenomenological analysis. *The Sage handbook of qualitative research in psychology*, *179*, 194.

Eccleston, C., Fisher, E., Law, E., Bartlett, J., & Palermo, T. M. (2016). Psychological interventions for parents of children and adolescents with chronic illness. *The Cochrane database of systematic reviews*, (*4*).

Eisen, M., Zellman, G. L., & McAlister, A. L. (1992). A health belief model-social learning theory approach to adolescents' fertility control: Findings from a controlled field trial. *Health Education Quarterly*, *19*(2), 249-262.

Elmahdi, R., Ward, H., Cooke, G., & Fidler, S. (2014). Implementation of HIV testing is patchy in the UK. *BMJ*, *349*, g4842.

European Centre for Disease Prevention and Control. (2009). Migrant health: Access to HIV prevention, treatment and care for migrant populations in EU/EEA countries.

Evangeli, M., Pady, K., & Wroe, A. L. (2016). Which psychological factors are related to HIV testing? A quantitative systematic review of global studies. *AIDS and Behavior*, *20*(4), 880-918.

Evans, C., Turner, K., Suggs, L. S., Occa, A., Juma, A., & Blake, H. (2016). Developing a mHealth intervention to promote uptake of HIV testing among African communities in the UK: a qualitative study. *BMC public health*, *16*(1), 656.

Fairclough, N. (1995). Critical discourse analysis. The critical study of language. London: Longman

Fakoya, I., Álvarez-Del Arco, D., Monge, S., Copas, A. J., Gennotte, A. F., Volny-Anne, A., ... & Darling, K. E. (2018). HIV testing history and access to treatment among migrants living with HIV in Europe. *Journal of the International AIDS Society*, *21*, e25123.

Falola, T., & Heaton, M. M.(2007) Overview to HIV/AIDS, Illness and African Well-being. *HIV/AIDS, illness and African well-being*, 3-15.

Favarato, G., Bailey, H., Burns, F., Prieto, L., Soriano-Arandes, A., & Thorne, C. (2017). Migrant women living with HIV in Europe: are they facing inequalities in the prevention of mother-to-child-transmission of HIV? The European Pregnancy and Paediatric HIV Cohort Collaboration (EPPICC) study group in EuroCoord. *The European Journal of Public Health*, *28*(1), 55-60.

Fearnley, R., & Boland, J. W. (2017). Communication and support from health-care professionals to families, with dependent children, following the diagnosis of parental life-limiting illness: A systematic review. *Palliative medicine*, *31*(3), 212-222.

Fenn, K., & Byrne, M. (2013). The key principles of cognitive behavioural therapy. *InnovAiT*, *6*(9), 579-585.

Fielden, S. J., Sheckter, L., Chapman, G. E., Alimenti, A., Forbes, J. C., Sheps, S., ... & Frankish, J. C. (2006). Growing up: perspectives of children, families and service providers regarding the needs of older children with perinatally-acquired HIV. *Aids Care*, *18*(8), 1050-1053.

Finlay, L. (2009). Debating phenomenological research methods. Phenomenology & Practice, 3 (1), 6-25.

Fish, R., Jungmann, E., Judd, A., & Foster, C. (2013). mortality amongst HIV-infected young people following transition to adult care: an HIV Young Persons Network (HYPNET) audit: 06. *HIV Medicine*, *13*, 3.

Flowers, P., Davis, M., Hart, G., Rosengarten, M., Frankis, J., & Imrie, J. (2006). Diagnosis and stigma and identity amongst HIV positive Black Africans living in the UK. *Psychology and Health*, *21*(1), 109-122.

Focà, E., Cavaglià, G., Rusconi, S., Cascavilla, A., Cenderello, G., Re, A., & Di Perri, G. (2018). Survival in HIV-infected patients with lymphoma according to the choice of antiretroviral treatment: an observational multicentre study. *HIV medicine*.

Frieden, T. R., Foti, K. E., & Mermin, J. (2015). Applying Public Health Principles to the HIV Epidemic--How Are We Doing?. *The New England Journal of Medicine*, *373*(23), 2281.

Gage, E. A. (2013). The dynamics and processes of social support: families' experiences coping with a serious paediatric illness. *Sociology of health & illness*, *35*(3), 405-418.

Ghimire, S., Hallett, J., Gray, C., Lobo, R., & Crawford, G. (2019). What Works? Prevention and Control of Sexually Transmitted Infections and Blood-

Borne Viruses in Migrants from Sub-Saharan Africa, Northeast Asia and Southeast Asia Living in High-Income Countries: A Systematic Review. *International journal of environmental research and public health*, *16*(7), 1287.

Glanz, K. (1997). Theory at a glance: A guide for health promotion practice. *NIH Publication*, 97-3896.

Glanz, K. E., Lewis, F. M. E., & Rimer, B. K. (1990). *Health behaviour and health education: Theory, research, and practice*. Jossey-Bass.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: strategies for qualitative theory*. New York: Aldine

Goodman, L. A., Liang, B., Helms, J. E., Latta, R. E., Sparks, E., & Weintraub, S. R. (2004). Training counselling psychologists as social justice agents: Feminist and multicultural principles in action. *The counselling psychologist*, *32*, 793-837.

Greenhalgh, C., Evangeli, M., Frize, G., Foster, C., & Fidler, S. (2013). Intimate relationships in young adults with perinatally acquired HIV: partner considerations. *AIDS care*, *25*(4), 447-450.

Gyamfi, E., Okyere, P., Enoch, A., & Appiah-Brempong, E. (2017). Prevalence of and barriers to the disclosure of HIV status to infected children and adolescents in a district of Ghana. *BMC International Health and Human rights*, *17*(1), 8.

Hallfors, D. D., Iritani, B. J., Zhang, L., Hartman, S., Luseno, W. K., Mpofu, E., & Rusakaniko, S. (2016). 'I thought if I marry the prophet I would not die': The significance of religious affiliation on marriage, HIV testing, and reproductive health practices among young married women in Zimbabwe. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, *13*(1), 178-187.

Hayes, N. (2000). *Doing Psychological Research. Gathering and Analysing Data.* Buckingham: Open University Press

Health and Care Professions Council. (2016*). Standards of Conduct, Performance and Ethics.* London: Health Professions Council. Retrieved from:www.hcpcuk.org/assets/documents/10004EDFStandardsofconduct.performanceandethics.pdf

Health and Care Professions Council (2015). *Standards of proficiency: Practitioner Psychologists.* Retrieved from: www.hpc-uk.org/assets/documents/10002963SOP_Practitioner_psychologists.pdf

Hefferon, K., & Gil-Rodriguez, E. (2011). Interpretative Phenomenological Analysis. *The Psychologist*, 23(10), 756-759

Hegazi, A., Forsyth, S., & Prime, K. (2015). Testing the children of HIV-infected parents: 6 years on from 'Don't forget the children'.

Heidegger, M. (1927/1962). *Being and time.* Oxford: Blackwell.

Higginbottom, G. M. A., Evans, C., Morgan, M., Bharj, K. K., Eldridge, J., & Hussain, B. (2017). Interventions that improve maternity care for immigrant women in the UK: protocol for a narrative synthesis systematic review. *BMJ open*, *7*(7), e016988.

HIV and Black African Communities in the UK. (2014). Retrieved from https://www.nat.org.uk/sites/default/files/publications/NAT-African-Communities-Report-June-2014-FINAL.pdf

Hough, E. S., Brumitt, G., Templin, T., Saltz, E., & Mood, D. (2003). A model of mother–child coping and adjustment to HIV. *Social Science & Medicine*, *56*(3), 643-655.

Howitt, D. (2010). *Introduction to qualitative methods in psychology*. Harlow: Prentice hall.

Husserl, E. (1927). Phenomenology. In Smith, J.A, Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Research and Practice.* London: Sage.

Jackson, C., Eliasson, L., Barber, N., & Weinman, J. (2014). Applying COM-B to medication adherence: a suggested framework for research and interventions. *European Health Psychologist*, *16*(1), 7-17.

Jones, C. L., Jensen, J. D., Scherr, C. L., Brown, N. R., Christy, K., & Weaver, J. (2016). The health belief model as an explanatory framework in communication research: exploring parallel, serial, and moderated mediation. *Health communication*, *30*(6), 566-576.

Jones, E. (1949). *What is psychoanalysis?*. International Universities Press.

Judd, A., Doerholt, K., Tookey, P. A., Sharland, M., Riordan, A., Menson, E., & Duong, T. (2007). Morbidity, mortality, and response to treatment by children in the United Kingdom and Ireland with perinatally acquired HIV infection during 1996–2006: planning for teenage and adult care. *Clinical Infectious Diseases*, *45*(7), 918-924.

Kalichman, S. C. (1998). *Preventing AIDS: A sourcebook for Behavioural Interventions*. Psychology Press.

Kasket, E. (2012). Being-Towards-Death In The Digital Age. *Existential Analysis: Journal of the Society for Existential Analysis*, *23*(2), 249-261.

Katz, I. T., Leister, E., Kacanek, D., Hughes, M. D., Bardeguez, A., Livingston, E., & Tuomala, R. (2015). Factors Associated with Lack of Viral Suppression at Delivery among HAART-Naïve HIV-Positive Women in the International Maternal Pediatric Adolescent AIDS Clinical Trials Group (IMPAACT) P1025 Study. *Annals of Internal Medicine*, *162*(2), 90.

Kearney, J. A., Salley, C. G., & Muriel, A. C. (2015). Standards of psychosocial care for parents of children with cancer. *Pediatric blood & cancer*, *62*(S5), S632-S683.

Kernberg, P. F., Ritvo, R., Keable, H., & of Child, T. A. A. (2012). Practice parameter for psychodynamic psychotherapy with children. *Journal of the American Academy of Child & Adolescent Psychiatry*, *51*(5), 541-557.

Klein, D. N., Arnow, B. A., Barkin, J. L., Dowling, F., Kocsis, J. H., Leon, A. C., & Wisniewski, S. R. (2009). Early adversity in chronic depression: clinical correlates and response to pharmacotherapy. *Depression and Anxiety*, *26*(8), 701-710.

Kouyoumdjian, F. G., Meyers, T., & Mtshizana, S. (2005). Barriers to disclosure to children with HIV. *Journal of tropical pediatrics*, *51*(5), 285-287.

Kulzer, J. L., Penner, J. A., Marima, R., Oyaro, P., Oyanga, A. O., Shade, S. B., & Bukusi, E. A. (2012). Family model of HIV care and treatment: a retrospective study in Kenya. *Journal of the International AIDS Society*, *15*(1), 8.

Kvale, S. (1996). *Interviews. An Introduction to Qualitative Research Interviewing.* London: Sage Publications.

Kvale, S. (1996). The 1,000-page question. *Qualitative inquiry,* 2(3), 275-284

Lako, G., & Johnson, M. (1980). *Metaphors we live by.* Chicago: University of Chicago Press.

Lancet, HIV (2015). Celebrity, the media, and HIV--not always easy bedfellows. *The Lancet. HIV*, *2*(12), e501.

Landry-Dattée, N., Boinon, D., Roig, G., Bouregba, A., Delaigue-Cosset, M. F., & Dauchy, S. (2016). Telling the truth… with kindness: retrospective evaluation of 12 years of activity of a support group for children and their parents with cancer. *Cancer nursing*, *39*(2), E10-E18.

Langdridge, D. (2007). *Phenomenological psychology: Theory, research and method*. London: Pearson Education Limited.

Langdridge, D., & Hagger-Johnson, G. (2009). *Introduction to research methods and data analysis in psychology*. Harlow, England: Pearson Education.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, *3*(2), 102-120.

Latif, Z. (2014). The maternal mental health of migrant women. Retrieved from https://www.gmmh.nhs.uk/download.cfm?doc=docm93jijm4n895.pdf &ver=1674

Laughton, B., Cornell, M., Boivin, M., & Van Rie, A. (2013). Neurodevelopment in perinatally HIV-infected children: a concern for adolescence. *Journal of the International AIDS Society*, *16*(1), 18603.

Lawrence, S., & Cross, M. (2013). Life transition with HIV: Some observations of the phenomenon of growing older with the infection. *Counselling Psychology Review*, *28*(1), 25-36.

Lindenmeyer, A., Newall, D., Phillimore, J., Redwood, S., Griffith, L., & Allybocus, A. et al. (2016). Health Across Borders: Recent migrants' experience of managing their health and wellbeing in the UK and the implications for health policy and practice. Retrieved https://www.birmingham.ac.uk/Documents/college-social-sciences/social-policy/iris/2016/health-histories-report-final.pdf

Lingen-Stallard, A., Furber, C., & Lavender, T. (2016). Testing HIV positive in pregnancy: A phenomenological study of women's experiences. *Midwifery*, *35*, 31-38.

Lipstein, E. A., Brinkman, W. B., & Britto, M. T. (2012). What is known about parents' treatment decisions? A narrative review of pediatric decision making. *Medical Decision Making*, *32*(2), 246-258.

London Metropolitan University. (2014). Code of Good Research Practice, *Research and Enterprise Committee*. Retrieved from: www.londonmet.ac.uk/media/london-metropolitan-university/londonmet-documents/professional-service-departments/researchoffice/handbooks/ Code-of-Good-Research-Practice.pdf

Lorenz, R., Grant, E., Muyindike, W., Maling, S., Card, C., Henry, C., & Naz-arali, A. J. (2016). Caregivers' attitudes towards HIV testing and disclosure of HIV status to at-risk children in rural Uganda. *PloS one*, *11*(2), e0148950.

Mayor, S. (2017). Routine HIV testing when registering with GP is cost effec-tive shows UK study. *BMJ: British Medical Journal*, *358*.

Manu, A. A., Mba, C. J., Asare, G. Q., Odoi-Agyarko, K., & Asante, R. K. O. (2015). Parent–child communication about sexual and reproductive health: evidence from the Brong Ahafo region, Ghana. *Reproductive Health*, *12*(1), 16.

McLeish, J., & Redshaw, M. (2016). 'We have beaten HIV a bit': a qualitative study of experiences of peer support during pregnancy with an HIV Mentor Mother project in England. *BMJ open*, *6*(6), e011499.

McLeod,S.A.(2014). Carl Rogers. Retrieved from: www.simplypsychology.ord/carl/rogers.html

Mengesha, Z. B., Perz, J., Dune, T., & Ussher, J. (2018). Challenges in the provision of sexual and reproductive health care to refugee and migrant wom-en: AQ methodological study of health professional perspectives. *Journal of immigrant and minority health*, *20*(2), 307-316.

Merleau-Ponty, M. (1962). *Phenomenology.* Humanities Press.

Michie, S., Ashford, S., Sniehotta, F. F., Dombrowski, S. U., Bishop, A., & French, D. P. (2011). A refined taxonomy of behaviour change techniques to help people change their physical activity and healthy eating behaviours: the CALO-RE taxonomy. *Psychology & health*, *26*(11), 1479-1498.

Michie, S., Atkins, L., & West, R. (2014). The behaviour change wheel. *A guide to designing interventions. 1st ed. Great Britain: Silverback Publishing*.

Michie, S., Van Stralen, M. M., & West, R. (2011). The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implementation Science*, *6*(1), 42.

Miller, J. and Abell, C. (2018). *Family/Systemic Therapy*. [online] Counselling Directory Connecting you with Professional Support. Retrieved from: http://www.counselling-directory.ordg.uk/family-therapy.html

Miller, R. M., Chan, C. D., & Farmer, L. B. (2018). Interpretative phenomenological analysis: A contemporary qualitative approach. *Counselor Education and Supervision*, *57*(4), 240-254.

Millum, J., Campbell, M., Luna, F., Malekzadeh, A., & Karim, Q. A. (2019). Ethical challenges in global health-related stigma research. *BMC medicine*, *17*(1), 84.

Milton, M. (Ed.). (2010). *Therapy and beyond: Counselling psychology contributions to therapeutic and social issues*. John Wiley & Sons.

Moradmand-Badie, B., Moayedi-Nia, S., Foroughi, M., Dejman, M., Nikzad, R., Akhlaghkhah, M., ... & Mwanri, L. (2014). HIV Positive Patients' Experiences on Receiving an HIV Positive Test: An Iranian–Qualitative Study. *Am J Epidemiol Infect Dis*, *2*(1), 47-5.

Moustakas, C. (1994). *Phenomenological research methods*. London: Sage.

Mullins, L. L., Cushing, C. C., Suorsa, K. I., Tackett, A. P., Molzon, E. S., Mayes, S., ... & Chaney, J. M. (2016). Parent illness appraisals, parent adjustment, and parent-reported child quality of life in pediatric cancer. *Pediatric hematology and oncology*, *33*(5), 314-326.

Munabi-Babigumira, S., Glenton, C., Willcox, M., & Nabudere, H. (2019). Ugandan health workers' and mothers' views and experiences of the quality of maternity care and the use of informal solutions: A qualitative study. *PloS one*, *14*(3).

Murnane, P. M., Sigamoney, S. L., Pinillos, F., Shiau, S., Strehlau, R., Patel, F., & Violari, A. (2017). Extent of disclosure: what perinatally HIV-infected children have been told about their own HIV status. *AIDS care*, *29*(3), 378-386.

Murphy, D. A. (2008). HIV-positive mothers disclosure of their serostatus to their young children: a review. *Clinical child psychology and psychiatry*, *13*(1), 105-122.

National Institute for Health and Care Excellence. (2007). *Behaviour Change at Population, Community and Individual Levels (NICE Public Health Guidance 6).* London: National Institute for Health and Care Excellence.

Ndirangu, E. W., & Evans, C. (2009). Experiences of African immigrant women living with HIV in the UK: implications for health professionals. *Journal of Immigrant and Minority Health*, *11*(2), 108-114.

Ndumbi, P., Del Romero, J., Pulido, F., Velasco Arribas, M., Dronda, F., Blanco Ramos, J. R., ... & Álvarez-del Arco, D. (2018). Barriers to health care services for migrants living with HIV in Spain. *The European Journal of Public Health*, *28*(3), 451-457.

Nemade, R., Staats Reiss, N. and Dombeck, M. (2007). *Psychology of Depression-Psychodynamic Theories*. Retrieved: https://www.mentalhelp.net/articles/psychology-of-depression-psychodynamic-theories/.

Nevin, P. E., Frey, S., Lipira, L., Endeshaw, M., Niemann, L., Kerani, R. P., & Rao, D. (2018). “You are always hiding. It's the worst way to live.” Exploring Stigma in African Immigrants Living With HIV in a Large Northwest US Metropolitan Area. *Journal of the Association of Nurses in AIDS Care*, *29*(3), 417-425.

Newell, M. L., Coovadia, H., Cortina-Borja, M., Rollins, N., Gaillard, P., & Dabis, F. (2004). Mortality of infected and uninfected infants born to HIV-infected mothers in Africa: a pooled analysis. *The Lancet*, *364*(9441), 1236-1243.

Nichols, S. L., Brummel, S. S., Smith, R. A., Garvie, P. A., Hunter, S. J., Malee, K. M., ... & Chernoff, M. C. (2015). Executive functioning in children and adolescents with perinatal HIV infection. *The Pediatric infectious disease journal*, *34*(9), 969.

O'Connor, A. M., Bennett, C. L., Stacey, D., Barry, M., Col, N. F., Eden, K. B., & Llewellyn-Thomas, H. (2008). Decision aids for people facing health treatment or screening decisions. *Cochrane database of systematic reviews*, (3).

Oldson, L. (2013). *The Psychological Impact of HIV/AIDS.* Retrieved from: www.sexualhealth.com/the-psychological-impact-of-hivaids/

Orza, L., Bass, E., Bell, E., Crone, E. T., Damji, N., Dilmitis, S., ... & Kenkem, C. (2017). In Women’s Eyes: Key Barriers to Women’s Access to HIV Treatment and a Rights-Based Approach to their Sustained Well-Being. *Health and human rights*, *19*(2), 155.

Pannetier, J., Lert, F., Roustide, M. J., & Du Loû, A. D. (2017). Mental health of sub-Saharan African migrants: the gendered role of migration paths and transnational ties. *SSM-population health*, *3*, 549-557.

Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social science & medicine*, *57*(1), 13-24.

Peters, H., Francis, K.,Collins, I.J.,Judd, A., Thorne, C. (2018). Current Trends in Children with HIV Diagnosed in the UK and Ireland. *National Study of HIV in Pregnancy and Childhood and Collaborative HIV Paediatric Study*.

Proudfoot, D. (2018). Frozen in a Moment in Time: The Experiences of Mothers Being Diagnosed with HIV Infection. *Journal of the Association of Nurses in AIDS Care*, *29*(2), 323-329.

Punpanich, W., Lolekha, R., Chokephaibulkit, K., Naiwatanakul, T., Leowsrisook, P., & Boon-Yasidhi, V. (2014). Factors associated with caretaker's readiness for disclosure of HIV diagnosis to HIV-infected children in Bangkok, Thailand. *International Journal of STD & AIDS*, *25*(13), 929-935.

Rafalin, D. (2010). Counselling psychology and research: Revisiting the relationship in the light of our 'mission'. *Therapy and beyond: Counselling psychology contributions to therapeutic and social issues*, 41-55. Oxford: Wiley- Blackwell.

Reid, K., Flowers, P. & Larkin, M. (2005). Exploring lived experiences: An introduction to Interpretative Phenomenological Analysis. *The Psychologist*, 18, 20- 23

Ricoeur, P. (1970). *Freud and philosophy: an essay on interpretation.* New Haven: Yale University Press.

Rogers, C. (1961). *A therapist's view of psychotherapy. On Becoming a Person.* London: Constable.

Rosenstock, I. M. (1974). Historical origins of the health belief model. *Health education monographs*, *2*(4), 328-335.

Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1994). The health belief model and HIV risk behavior change. In *Preventing AIDS* (pp. 5-24). Springer, Boston, MA.

Ross, J., Cunningham, C. O., & Hanna, D. B. (2018). HIV outcomes among migrants from low-and middle-income countries living in high-income countries: a review of recent evidence. *Current opinion in infectious diseases*, *31*(1), 25.

Rwemisisi, J., Wolff, B., Coutinho, A., Grosskurth, H., & Whitworth, J. (2008). 'What if they ask how I got it?'Dilemmas of disclosing parental HIV status and testing children for HIV in Uganda. *Health Policy and Planning*, *23*(1), 36-42.

Schleiermacher, F. (1998). *Hermeneutics and Criticism and other Writings. Cambridge Texts in the History of Philosophy. (Eds.).* Cambridge: Cambridge University Press

Shinebourne, P., & Smith, J. A. (2009). Alcohol and the self: An interpretative phenomenological analysis of the experience of addiction and its impact on the sense of self and identity. *Addiction Research & Theory*, *17*(2), 152-167.

Sierra, R., Selvadurai, V., & Zhou, J. (2016). P142 Challenges and opportunities of a 'Look Back'exercise on child testing. *Western Sussex Foundation NHS Trust*

Simbayi, L. C., Kalichman, S., Strebel, A., Cloete, A., Henda, N., & Mqeketo, A. (2007). Internalised stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. *Social science & medicine*, *64*(9), 1823-1831.

Simoni, J. M., Yang, J. P., Shiu, C. S., Chen, W. T., Udell, W., Bao, M., & Lu, H. (2015). Nurse-delivered counselling intervention for parental HIV disclosure: Results from a pilot randomised controlled trial in China. *AIDS (London, England)*, *29*(Suppl 1), S99.

Smith, J. A. (1995) *Semi-structured interviewing and qualitative analysis*, *Rethinking methods in psychology*. London: Sage

Smith, J. A. (2003). *Qualitative Psychology. A Practical Guide to Research Methods.* London: Sage

Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health psychology review*, *5*(1), 9-27.

Smith. J.A., & Dunworth, F. (2003). In J.A. Smith., P. Flowers & M. Larkin. (2009). *Interpretative Phenomenological Analysis: Theory, Research, Practice.* London: Sage

Smith J.A. and Eatough, V. (2006). Interpretative phenomenological analysis. In G, Breakwell, C., Fife-Schaw, S., Hammond and J.A. Smith (Eds) *Research Methods in psychology* (3rd ed). London: Sage

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, method, and research*. Los Angeles: SAGE

Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. Qualitative psychology: A Practical Guide to Methods. London: Sage

Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. Smith, qualitative Psychology: A Practical Guide to Research Methods, London: Sage

Smith, R., Chernoff, M., Williams, P. L., Malee, K. M., Sirois, P. A., Kammerer, B., & Garvie, P. (2012). Impact of human immunodeficiency virus severity on cognitive and adaptive functioning during childhood and adolescence. *The Pediatric Infectious Disease Journal*, *31*(6).

Spiers, J., Smith, J. A., Poliquin, E., Anderson, J., & Horne, R. (2016). The experience of antiretroviral treatment for black west African women who are

HIV positive and living in London: an interpretative phenomenological analysis. *AIDS and Behavior*, *20*(9), 2151-2163.

Steele, R. G., Forehand, R., & Armistead, L. (1997). The role of family processes and coping strategies in the relationship between parental chronic illness and childhood internalizing problems. *Journal of Abnormal Child Psychology*, *25*(2), 83-94.

Stein, J. A., & Nyamathi, A. (2000). Gender differences in behavioural and psychosocial predictors of HIV testing and return for test results in a high-risk population. *AIDS care*, *12*(3), 343-356.

Strawbridge, S., & Woolfe, R. (2010). Counselling psychology: Origins, developments and challenges. In Woolfe, R., Strawbridge, S,. Douglas, B. & Dryden, W. (Eds). *Handbook of counselling psychology*, *3*, 3-22. London: Sage
Tait, E. (2013). *An investigation into the lived experiences of HIV-positive African women living in the UK*

Tariq, S., Elford, J., Chau, C., French, C., Cortina-Borja, M., Brown, A., ... & Tookey, P. A. (2016). Loss to Follow-Up After Pregnancy Among Sub-Saharan Africa-Born Women Living With Human Immunodeficiency Virus in England, Wales and Northern Ireland: Results From a Large National Cohort. *Sexually transmitted diseases*, *43*(5), 283.

Tariq, S., Elford, J., Tookey, P., Anderson, J., de Ruiter, A., O'Connell, R., & Pillen, A. (2016). “It pains me because as a woman you have to breastfeed your baby”: decision-making about infant feeding among African women living with HIV in the UK. *Sexually transmitted infections*, *92*(5), 331-336.

The British Psychological Society. (2009). *Code of Ethics and Conduct*. The British Psychological Society. Retrieved from: https://beta.bps.org.uk/sites/beta.bps.org.uk/files/Policy%20-%20Files/Code%20of%Ethics%20and%20Conduct%20%282009%29.pdf

The British Psychological Society (2013). *Becoming a counselling psychologist*. Retrieved from: https://careers.bps.org.uk/area/counselling/where-do-counselling-psychologists-work

The British Psychological Society (2014). *Standards for the accreditation of doctoral programmes in counselling psychology*. Retrieved from: http://www.bps.org.uk/system/files/Public%20files/PaCT/counselling accreditation2014_web.pdf

The British Psychological Society, British HIV Association and Medical Foundation for AIDS and Sexual Health (2011) *Standards for psychological support for adults living with HIV.* Retrieved from: http://www.medfash.org.uk/uploads/files/p17abjjlhe7as89k45i1icg1f121.pdf

The Joint United Nations Programme on HIV/AIDS (2016). *How many people living with HIV access treatment (UNAIDS report).* Retrieved from: http://www.unaids.org/en/resources/documents/2016/how-many-people-living-with-HIV-access-treatment/

The National Institute for Health and Care Excellence. (2018). *Shared Decision-Making.* Retrieved from: www.nice.org.uk/what-we-do/our-programmes/nice-guidelines/shared-decision-making/

Tickle, A., & Rennoldson, M. (2016). Systemic Family Therapy.

Timothy, R. (2019). 9 ways racism impacts maternal health. Retrieved from http://theconversation.com/9-ways-racism-impacts-maternal-health-111319

Townsend, C. L., de Ruiter, A., Peters, H., Nelson-Piercy, C., Tookey, P., & Thorne, C. (2016). Pregnancies in older women living with HIV in the UK and Ireland. *HIV medicine*, *18*(7), 507-512.

Tuffour, I. (2017). A critical overview of interpretative phenomenological analysis: a contemporary qualitative research approach. *Journal of Healthcare Communications*, *2*(4), 52.

Van Lerberghe, W. (2005). *The World Health Report 2005: Make every mother and child count*. World Health Organization.

Vitale, A., & Ryde, J. (2018). Exploring risk factors affecting the mental health of refugee women living with HIV. *International journal of environmental research and public health*, *15*(10), 2326.

Wagner, A., Wachira, C. M., Njuguna, I. N., Maleche-Obimbo, E., Sherr, K., Inwani, I. W., ... & Slyker, J. A. (2016). Active referral of children of HIV-positive adults reveals high prevalence of undiagnosed HIV. *Journal of acquired immune deficiency syndromes (2016)*, *73*(5), e83.

Watson, H., Harrop, D., Walton, E., Young, A., & Soltani, H. (2019). A systematic review of ethnic minority women's experiences of perinatal mental health conditions and services in Europe. *PloS one*, *14*(1).

Whembolua, G. L., Conserve, D. F., Thomas, K., & Handler, L. (2017). A systematic review of HIV serostatus disclosure among African immigrants in Europe. *Journal of immigrant and minority health*, *19*(4), 947-958.
Wiener, L., Mellins, C. A., Marhefka, S., & Battles, H. B. (2007). Disclosure of an HIV diagnosis to children: history, current research, and future directions. *Journal of developmental and behavioral pediatrics: JDBP*, *28*(2), 155.

Wiener, L., Viola, A., Kearney, J., Mullins, L. L., Sherman-Bien, S., Zadeh, S., & Lone Parent Study Group. (2016). Impact of caregiving for a child with cancer on parental health behaviors, relationship quality, and spiritual faith: Do lone parents fare worse?. *Journal of Pediatric Oncology Nursing*, *33*(5), 378-386.

Willig, C. (2008). Introducing qualitative research methods in psychology. *Maidenhead, England: McGraw Hill*.

Willig, C. (2013). *Introducing qualitative research in psychology*. McGraw-Hill Education (UK).

Willig, C., & Rogers, W. S. (2008). *Handbook of qualitative research in psychology*.

Woolfe, R., Dryden, W., & Strawbridge, S. (2003). *Handbook of counselling psychology*. London: Sage.

Woolfe, R, Dryden, W., & Strawbridge, S. (2006). *Handbook of Counselling Psychology. (2nd ed.)*. London. Thousand Oaks: Sage

Woollett, N., Cluver, L., Bandeira, M., & Brahmbhatt, H. (2017). Identifying risks for mental health problems in HIV positive adolescents accessing HIV treatment in Johannesburg. *Journal of Child & Adolescent Mental Health*, 1-17.

Woollett, N., Cluver, L., Hatcher, A. M., & Brahmbhatt, H. (2016). "To be HIV positive is not the end of the world": Resilience among perinatally infected HIV positive adolescents in Johannesburg. *Children and Youth Services Review*, *70*, 269-275.

World Health Organization (2018). *Psychosocial Support.* Retrieved from: http://www.who.int/hiv/topics/psychosocial/support/en/

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and health*, *15*(2), 215-228.

Yardley, L. (2008). Demonstrating validity in qualitative psychology. *Qualitative psychology: A practical guide to research methods*, *2*, 235-251.

Zeligman, M. (2018). Medical Trauma: Assessing Trauma and Growth Following an HIV Diagnosis. *The Journal of Humanistic Counselling*, *57*(1), 14-30.

9. APPENDICES

Appendix A - Participant Information Sheet

To Whom It May Concern

I am currently doing my Doctorate at London Metropolitan University, and my research is focused on how parents decide whether to test their child\ren for HIV.

Although most people who are pregnant in the UK are routinely tested for HIV as part of their antenatal screening, older children or children who have not been born in the UK will not have been tested antenatally.

Currently there is very little known about how parents reach their decision. I am hoping you will be interested in helping me explore this further by participating in an interview where you can have an opportunity to share your experiences. This interview would last approximately one hour and will be voice recorded. Data from the interview will be used for my dissertation.

Participation is voluntary and if you decide to participate you are free to withdraw at any point (up until December 2014). Interviews will be voice recorded and strictly confidential. Recordings will be kept securely and destroyed once the project is completed. Pseudonyms will be used in writing up the research and any identifying information removed so that no one who reads the research can identify you.

Before you decide to participate it is important that you understand that the interview will be discussing an emotive topic and may evoke some distressing and difficult feelings for you. Please take your time in deciding whether or not you wish to take part. You will have the opportunity to discuss any feelings that have come up during the interview after the interview has finished with the researcher and given information on appropriate organisations that you may wish to contact, if necessary, for further emotional support.

Thank you in advance for considering participating and making time to read this information sheet. If you have any further enquiries, please do not hesitate to contact me on 07958676711 (pay as you go) or email XX.

I look forward to hearing from you.

Yours faithfully

Debbie Levitt

Appendix B - Consent Form

Understanding parents' decision-making whether to test their child\ren for HIV: An Interpretative Phenomenological Analysis

Description of Procedure: In this research you will be asked a number of questions regarding your own experience of being diagnosed HIV positive and the decision-making process around the testing of your own child\ren using a voice-recorded interview. This will be a private, semi-structured interview.

*I understand the procedure to be used will be an interview.

*I understand I am free to withdraw from the study without question; however, all the data will be aggregated by Jan 2015; therefore, if I wish to withdraw this has to be done by December 2014.

*I understand that participation in this study is anonymous. My name will not be used in connection with the results in any way and a pseudonym will be used on the digital voice recording and all information that may otherwise identify me (e.g.: address, friend's names, etc.) will be changed prior to transcription. There are limits to confidentiality however confidentiality will be breached if any information is disclosed that indicates a risk to safety.

*I understand that the results of the study will be accessible to others when completed and excerpts from my interview (minus explicit identifying information) may be used within the study.

*I understand that I may find this interview upsetting and that it may evoke a number of difficult and distressing feelings for me. I will be offered access to appropriate organisations or information that offer emotional support post interview with the researcher, if needed.

*I understand that I have the right to obtain information about the findings of the study and details of how to obtain this information will be given in the debriefing form.

*I understand that the data will be destroyed once the study has been assessed.

Signature of Participant: Signature of Researcher:

Print Name: Print Name:

Date: Date:

Appendix C- Debriefing Form

Thank you for taking part in this research study. This is part of a Doctoral project that the researcher is conducting.

If you are interested in the results of the study, or if you have any questions or wish to withdraw, please contact the researcher on the following email address _____ (this email address is checked regularly).

Please remember that if you wish to withdraw from this study it should be done by December 2014, as it may not be possible to do so at a later stage in the research process. Please do not hesitate to ask questions at any time during the study.

If you have any complaints regarding the way you have been treated during the course of this study please contact my research supervisor, Dr _____ on _____

If participation has raised any concerns or issues that you wish to discuss further, listed below are a number of organisations/agencies that may be of assistance:

1. *Samaritans-08457 909090 (talk to someone at any time)*
2. *Terence Higgins Trust Direct-0808 802 1221 (10am-8pm) Support, Advice and Information*
3. *Body and Soul Charity-0207923 6880 Supports Children, Teenagers and Families Living with or Affected by HIV as well as Individuals*
4. *Positively UK-0207713 0444 Support for People living with HIV*
5. *Herts Aid-01920 484 784 Another HIV Support Charity*
6. *Your local GP Surgery*
7. *Your nearest Accident and Emergency Department (A&E Department)*

Appendix D - Distress Protocol

Protocol to follow if participants become distressed during participation/during the interview:

This protocol has been devised to deal with the possibility that some participants may become distressed during their involvement in this research project. The researcher is an experienced Counselling Psychologist with many years working with people living with chronic health conditions and managing all levels of distress. Detailed below is a proposal for how to manage any evident distress that emerges during the research and in particular during the interview process. The protocol covers all eventualities although it is not expected that these interviews will cause extreme distress for participants.

As the researcher is a trained and practising Counselling Psychologist, any interview would be terminated where an interviewee showed signs of severe or extreme distress.

Mild Distress

Signs to look out for: tearfulness; voice filled with emotion and difficulty speaking; participant becoming restless/distracted.

Steps to take: ask participant if happy to continue; offer time to pause and compose themselves; remind them they can stop at any time if they feel too upset/emotional.

Severe Distress

Signs to look out for: uncontrolled crying/wailing/inability to talk coherently; panic attack e.g.: hyperventilating; flashbacks/intrusive thoughts.

Steps to take: researcher to stop interview; debrief; relaxation; recognise distress; accept and validate distress, discuss with mental health professionals; not therapeutic encounter so refer on; details of counselling/therapeutic services; etc.

Extreme Distress

Signs to look out for: severe agitation; verbal/physical aggression; psychotic breakdown.

Steps to take: safety of participant/researcher important; call GP or 999; A&E; Police; May need to seek appropriate help. Don't manage on own.

Appendix E

Interview Schedule

An IPA Study of the Lived Experience of HIV Positive African Immigrant Mothers in the UK

Thank you for agreeing to participate in this research project. The interview should be around one hour (or a little longer) ... *Theme: Beliefs/Self*

Theme: Decision-Making

1. Please tell me about your experience of how you learnt you were HIV positive/about your diagnosis?
    a. *Prompt: can you tell me more about when you were diagnosed?*
    b. *Prompt: what led to your diagnosis?*

2. In your opinion, is it important for a person to know their HIV diagnosis?
    a. *Prompt: why would this be helpful?*
    b. *Prompt: why would this be unhelpful?*

3. Did religion or other spiritual (kinship) practices feature/play a role in your childhood?
    a. *Prompt: and now?*
    b. *Prompt: can you tell me more about this.*

4. How has the media such as newspapers, magazines, or television influenced your decision about testing your child? *Theme: Testing*

5. Can you tell me when you were first introduced to the idea of first testing your child?
    a. *Prompt: who first suggested/how did you feel?*
    b. *Prompt: what went through your head at this time?*

Theme: Resources

6. What made you decide to test/not to test?
    a. *Prompt: do you remember how this made you feel?*
    b. *Prompt: how do you feel about this now?*

Theme: Sex/Sexuality

7. Is sex a factor in making this decision?

Prompt: how will you explain HIV to your child/ren?

8. Do you think there is anything else I should be aware of/or know about?...

AMENDMENTS

9. Can you share how your experiences of living as an HIV positive African Immigrant mother in the UK differs from living in your home country?

10. Can you tell me about your experiences of coping/managing with your HIV diagnosis and that of your child/ren?

Appendix F- Example of literature search strategy

Results Generated From:

Ovid AutoAlert <autorun@ovid.com>

Your autoalert was checked against the latest changes but no relevant documents were found.

Total documents retrieved: 0

Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>

Ovid MEDLINE(R) Revisions (updates since 2017-03-20)

Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>

Ovid MEDLINE(R) <2013 to March Week 3 2017> (updates since 2017-03-20)

Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>

Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations <March 27, 2017> (updates since 2017-03-20)

#	Search History	Results
1	exp HIV INFECTIONS/	40670
2	exp DIAGNOSIS/	1222039
3	(diagnosis or test*).ti,ab.	991246
4	2 or 3	1902074
5	1 and 4	20886
6	exp HIV INFECTIONS/di	5211
7	((hiv* or "human immunodeficiency virus" or AIDS or "acquired immunodeficiency syndrome" or "sexually tran! smitted disease*" or "sexually transmitted infection*") adj9 (diagnosis or test*)).ti,ab.	12708
8	5 or 6 or 7	27292
9	exp MATERNAL BEHAVIOR/	1755
10	exp PATERNAL BEHAVIOR/	252
11	exp PARENT-CHILD RELATIONS/	8239
12	exp CAREGIVERS/	8912
13	exp PARENTING/	3916
14	exp PARENTS/	21787
15	(parent* or guardian* or caregiver* or carer*).ti,ab.	111457
16	12 or 13 o! r 14 or 15	121264
1 7	exp ADAPTATION, PSYCHOLOGICAL/	19732
18	exp CULTURE/	25255
19	exp ATTITUDE/	60742
20	exp SOCIAL BEHAVIOR/	47559
21	exp SOCIAL CLASS/	6065
22	exp ANXIETY/	16566
23	exp FEAR/	6117
24	exp ATTITUDE TO HEALTH/	81583
25	exp HEALTH BEHAVIOR/	36789
26	(barrier* or behaviour* or behaviour* or fear* or attitude* or belief* or knowledge* or underst! anding* or socioeconomic or prejudice* or value* or stigma*).ti,ab.	1217428
27	17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26	1329404
28	16 and 27	53494
29	9 or 10 or 11 or 28	58233
30	8 and 29	380
31	limit 30 to "all child (0 to 18 years)"	249
32	limit 31 to updaterange="medc(20170320110646-	

20170308162820],medl(20170320110646-
20170322183939],prem(20170320110646-20170327115727]" 0

Appendix G – Ethics Certificate

LONDON metropolitan university

London Metropolitan University,
School of Psychology,
Research Ethics Review Panel

I can confirm that the following project has received ethical approval to proceed:

Title:	An IPA of parent's meaning-making of deciding whether or not to test their child(ren) for HIV
Student:	Deborah Levitt
Supervisor:	*Dr Esther Murray*

Ethical clearance to proceed has been granted providing that the study follows the ethical guidelines used by the School of Psychology and British Psychological Society, and incorporates any relevant changes required by the Research Ethics Review Panel. All participating organisations should provide formal consent allowing the student to collect data from their staff.

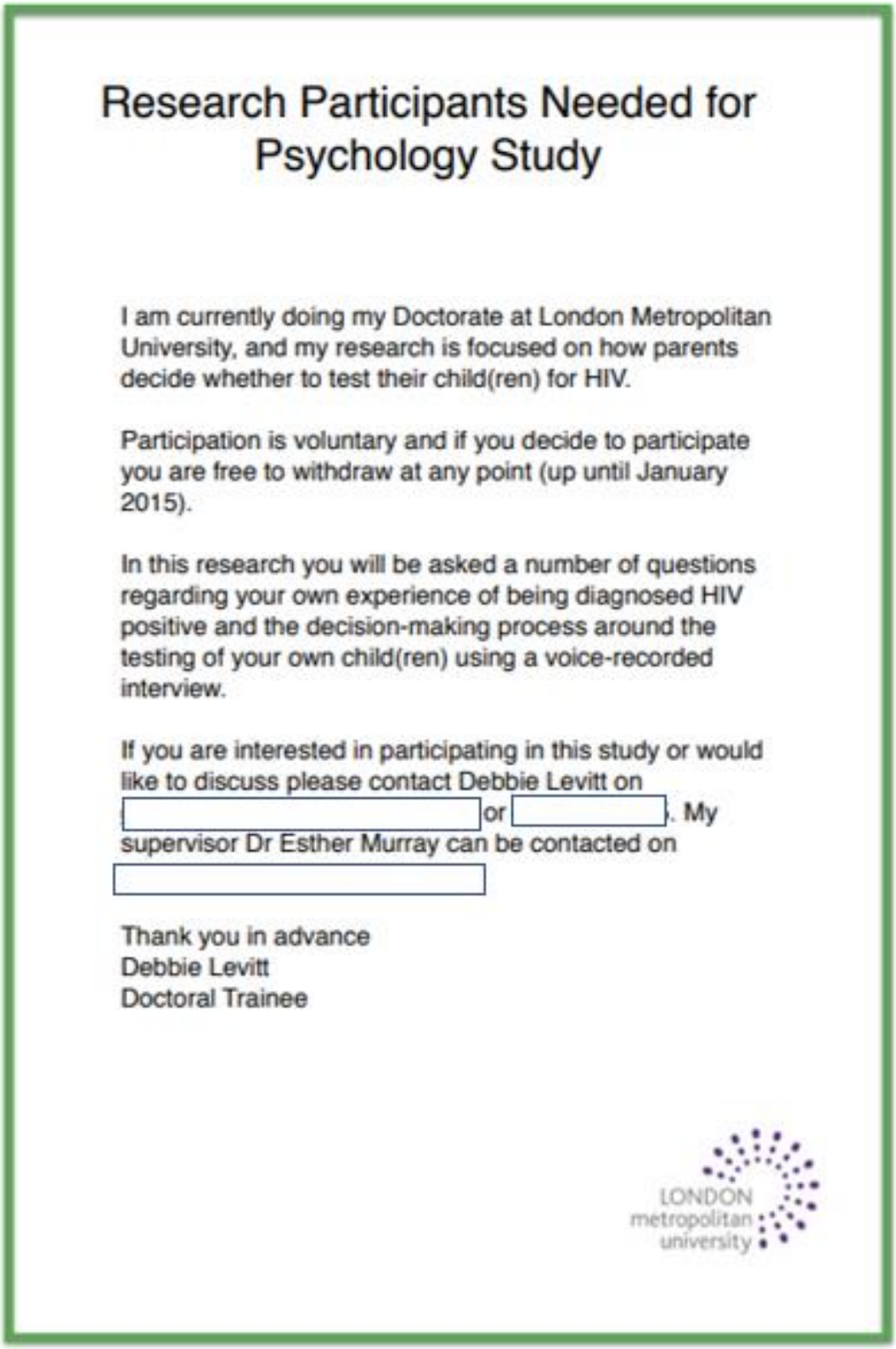
The researcher is also responsible for conducting the research in an ethically acceptable way, and should inform the ethics panel if there are any substantive changes to the project that could affect its ethical dimensions, and re-submit the proposal if it is deemed necessary.

Signed:

Date: 07/08/2014

Dr Chris Chandler
(Chair - School of Psychology Research Ethics Review Panel)
chandler@staff.londonmet.ac.uk

Appendix H – Recruitment Poster



Research Participants Needed for Psychology Study

I am currently doing my Doctorate at London Metropolitan University, and my research is focused on how parents decide whether to test their child(ren) for HIV.

Participation is voluntary and if you decide to participate you are free to withdraw at any point (up until January 2015).

In this research you will be asked a number of questions regarding your own experience of being diagnosed HIV positive and the decision-making process around the testing of your own child(ren) using a voice-recorded interview.

If you are interested in participating in this study or would like to discuss please contact Debbie Levitt on [ ] or [ ]. My supervisor Dr Esther Murray can be contacted on [ ]

Thank you in advance
Debbie Levitt
Doctoral Trainee

LONDON metropolitan university

Appendix I

Super Ordinate 1 **Quest for Survival**	Negotiating Survival as an Immigrant	Journey for survival
		Buying better health
		Receiving own HIV Diagnosis
		Through knowledge comes confidence to access treatment
	Fear of Dying	Suspicions of being unwell
		Worry for self and others health
	"…Take the virus out of me"	Treatment as a protector
	"You'll be looked after"	Experiences of different attitudes and approaches from healthcare systems
		The influence of healthcare systems on parents decision- making to test child/ren
		Who controls and is responsible for testing child/ren and others
Super Ordinate 2 **Impact of diagnosis on Identity**	Shame, Blame, Secrecy	Fear of finding out diagnosis
		Knowing vs. not knowing your HIV status
	The struggle of life-long medicine taking	Rules and Assumptions about being HIV positive

		Decisions to disclose or not to disclose
	HIV affected my family	Child as a carer
		Sex and relationships
		Impact on the adolescent family member
		Calling on God
	"My faith is kind of shaken…"	The tension between religion and modern medicine
		The experience of media on shaping attitudes towards HIV
		Identifying with others
Super Ordinate 3 "It's there, but HIV is not me"	With others strength and resilience is found	Encouragement from family and friends
		Gaining strength from organisations
		Transitioning from depersonalisation to per-sonalisation
	Transitioning to a 'New Normal'	The 'new normal'
		The dilemmas of a positive parent

	Working through challenges as a positive African mother	The positive parent's experience of being a nurturer/ carer
		The instinct to protect your child

Overview of Superordinate Themes and Themes

The Master Table of themes (see Appendix I) comprises of three super-ordinate themes 'The quest for survival', 'Impact of diagnosis' and 'The process of adjustment'.

The super-ordinate theme **'The quest for survival'** *was* composed of four main themes. Participant's effort to survive their HIV diagnosis and search for treatment outside their country of origin is the commonality amongst these themes.

'Impact of Diagnosis on Identity' as the second super-ordinate theme identified, included four themes. The common link between these was how a HIV diagnosis affected participants psychologically, physically, financially and spiritually as well as the impact on family life. These are influenced cultural and social norms.

The third superordinate theme **"It's there, but HIV is not me…"** is
comprised of three themes. What they share is the process of slowly coming to terms with their HIV diagnosis and managing not only their physical health but moving towards an improved state of mental wellbeing.

Appendix J – Example of Annotated Transcript: Participant 5

DESCRIPTIVE
LINGUISTIC

CONCEPTUAL

"I believe if you lie, that lie makes them think of you..."

Lie vs Truth
↓
open & honest

651 B: Because I believe if you lie, then it's like that lie then makes them think
652 negative of you, why would you...but if you're open and truthful they'll be
653 like...because as they grown, they're gonna confront these issues themselves.

654 I: And that, that's amazing, and do, do you talk about relationships and their
655 relationships with them?

656 B: Yeah, yeah. So of course now my sons, I'm sure they have girlfriends, so
657 this...when they started telling me, mummy I'm gonna bring my girlfriend I said
658 wow, okay. So, you know when we bring somebody to your parents that's a
659 serious relationship! *(Laughter)*. You know because I'm not gonna see many of
660 your friends, so if you bring someone to me it means this is serious, so these are
661 the relationship that probably you are planning to get married! *(Laughter)*.

"...bring somebody to your parents..."

(Healthy rel. with children
=) unburdened from guilt, shame & worry.)

DESCRIPTIVE LINGUISTIC

CONCEPTUAL

662 I: Ah, it's lovely. Oh, it's actually, it's, it's, excellent. And is there any final
663 points you think I should be aware of for this research?

664 B: I think just to know that it's not, it's not easy, it's not, and everybody deals
665 with this in their own way, but I think the common thing is just that not knowing
666 is a burden, it's so painful.

667 I: Yeah, yeah, yeah I've had, I've had people who've taken over three years
668 around this, so…you are absolutely right I think.

669 B: And I feel, if people decide not to test their children they're in denial. They
670 are in denial.

671 I: Do you, do you…

"..it's not, it's not easy.."

"..not knowing is a burden, it's so painful"

(reason to know other than not to know ↓ freeing/liberating.)

"if people decide not to test their children, they're in denial..."

[• Denial = not testing
• Testing = not being in denial]

Appendix K – Example of generating emergent themes and sub-themes

Emergent Themes	**Interview 1** (line number\page number	**Interview 2** (line number\page number)	**Interview 3** (line number\page number)	**Interview 4** (line number\page number)	**Interview 5** (line number\page number)	**Interview 6** (line number\page number

Acceptance\ Adjustment				487-490/48, 592-593/58, 627/61	143-145/13, 181-187/17, 202-204 & 206/19, 27-238/22 285-286/26, 336-339/31, 373-374/35, 399-400/38, 444-446/42, 451-456/43, 473-479/45, 538-540 & 547-549/51, 565-567/53, 584-594/55, 614-615/57, 632-638/59, 645-649/60, 664-666/62,	244-246/25,

Adherence\ Treatment Compliance	18/2	282/28, 286-288/28, 294-296/29,	54-55/6;	81-83/8, 108-109/11, 123-126/12, 241/24, 262-263/26 422-424/41, 652-654/64	547-549/51, 590-594/55,	92-94/10, 165-166 & 171-172/17,
Africa vs. UK Comparison Diagno-sis\Testing	10-12/1, 27-29/2 100-101/7	10-15/2, 19/2, 27-28/3 49/5	148-150/15, 198-199/19, 248-249/24, 267-268/26, 277-279/27, 386-388/38, 425-426/42	23-27/3, 40-43/4, 47-51/5, 54-55/5, 342/33, 355-356/34,	18-19/2, 273-275/25,	185-188/19,

Other Country\being diagnosed outside UK\not Africa						16-21/2, 65-66 & 68/7, 87-88/9, 100-102/10, 192-194/19, 199/20, 206-213/21,
Africa vs. UK Treatment	27-29/2, 115-118/8, 194-198/13	20/2 26/3 135/13	14-16/2, 177-178/17, 179-180/18, 251-253/24, 257-259/25, 311-312/30, 471-473/47, 548-550/54	109-113/11, 123-126/12, 128-129/13, 140-143/14, 241-244/24, 262-263/26, 419-421/41, 519-522/51	150-153/14, 312/29,	

Africa vs. UK attitudes towards HIV (more acceptance)	115-118/8, 161-162/11	221/22	176-178/17, 196/19, 343-346/34, 390-392/38, 428-431/42, 471-472/47, 509/50 548-550/54	46-47/5, 59-60/6, 110-112/11, 122-124/12, 131-132/13, 140-141/14, 308-312/30, 324-326/31, 389-390/38 396-398/38 454-455/44 478-479/47, 496-497/48, 505-507/49, 519-522/51	48-51/5, 273-275/25, 300-303/28, 307-308/28, 312 & 314-315/29	
Am I going 'mad'			98/10,			

Antenatal Opt-in vs. Opt-out					15&18/2, 374 & 376/35	
Being Normal (Concept) i.e. no HIV				254-258/25, 344-345/33, 454-455/44	59-61/6, 547-549/51,	
Blame for own HIV	89-91/6 100-105/7 106-107/7			125-127/12, 151-153/15,	141-142/13 277-278/26, 329-334/31, 376-379/35, 585-587/55	40-42/4, 188-189/19(?)

HIV Burden			564-565/56 596-597/59 603-604/60 627/62	31-32/3, 41-42/4, 84-87, 108/11, 123-124/12, 138/14, 138-141/14, 152-154/15, 156-157/15, 160-161/16, 165-167/16, 201-204/20, 56-258/25, 268-269/26, 271-272/26, 357-359/35, 396-398/38 414-416/40, 520-522/51, 542-543/53, 603-605/59, 609/60	59-61/6, 67-68/7, 73-74/7, 124-125/12, 141-144/13, 150-153/14, 210 & 216- 220/20, 232-233/22, 244-247/23 277-278/26 280-282/26, 314-315/29, 36-339/31, 344-345/32, 376-379/35, 409-410/39, 413-419/39, 452-456/43, 470-472/44, 473-479/45 & 483/45, 486-494/45 (other peo- ples bur- den), 501-505/47, 510-512/48, 52-526/49, 590-594/55, 596-599/56, 605-607/57	