The Effects of a Human Immunodeficiency Virus Diagnosis on the Identities of Black African Women

Elizabeth Ann Corker

A thesis submitted in partial fulfilment of the University of East London

requirements for the Professional Doctorate in Clinical Psychology

May 2019

ABSTRACT

Black African women make up a significant proportion of the people living with a human immunodeficiency virus (HIV) in the UK and yet they represent an underserved population in terms of research regarding their experiences. Little is known regarding if and how a HIV diagnosis impacts on the personal and social identities of Black African women and in particular, if this population experience HIV-related self-stigma. This gap may exist due to a lack of acknowledgement regarding how different aspects of identity related to Black African women living with HIV in the UK interact with public attitudes, along with the political, social and health systems within the UK.

Using a critical realist stance, this research was designed to address this knowledge gap and explore the experiences of a HIV diagnosis on the identities of Black African Women living with HIV in the UK. Photovoice, a participatory action research method was used to ensure collaboration between the researcher and participants, with a focus on social justice. Participants took photographs that they felt represented their identity, provided a description of their photographs and took part in a semi-structured interview using Photovoice techniques to explore the strengths and challenges within the sample's identity.

Five Black African women living with HIV were interviewed. Two women provided two photographs and one woman provided one photograph for use in the research. Thematic analysis was used to analyse the data. Two main themes were identified: 'retention of self' and 'prevalence of outdated information'. Participants described how holding onto personal values was important for them to retain control of their narrative, in spite of awareness of negative attitudes and social or structural barriers regarding their HIV status. None of the women internalised the negative stereotypes that they were aware of, regarding their HIV status.

Implications regarding future research, including further considerations of the impact of the intersectionalities of identity are considered, along with clinical and policy implications of the results of this study.

Table of Contents

List of Tables and Figures

ACKNOWLEDGEMENTS

1. INTRODUCTION

1.1. Overview

This chapter aims to review and assess gaps in the available literature and provide a context for the study. Relevant terminology is outlined and concepts explored. The chapter concludes with the rationale and research aims for the current study.

1.2. Human Immunodeficiency Virus in Context

Human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) remain a public health concern, despite a decrease in the rates of morbidity and mortality over the past decade (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2017). Historically, research regarding people living with HIV (PLHIV) tended to focus on men (Bova, 2000), and contemporary evidence suggests that HIV disproportionally effects women (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2017), particularly Black African women (UN Women, 2018). With some notable exceptions, providing important insights (Anderson & Doyal, 2004; Dibb & Kamalesh, 2012; The People Living With HIV, 2015), there has been a limited attempt to understand if and how aspects of identity are affected by Black African women living with HIV in the UK. This is concerning as any attempt to improve wellbeing or transmission rates may be undermined by a lack of understanding of how HIV status affects aspects of identity within this population.

In the UK, people from a Black African background account for 31% of those accessing HIV treatment, whilst making up 1.8% of the entire UK population and around 65% of this group is female (National AIDS Trust, 2018; Squire,

2013). One of the main problems relating to HIV is stigma, which has been described as the 'third phase' of the HIV pandemic (Mann, 1988; Mawar, Saha, Pandit, & Mahajan, 2005).

1.3. Relevant Terminology, Definitions and Concepts

Over time, terminology and definitions of social and diagnostic terms change to reflect the contemporary scientific and political landscape. Without an understanding of this landscape, research is of limited use. Therefore, it is important to outline the use of terminology and the main definitions within the context of this research, before engaging in a critical evaluation of the research. Relatedly, throughout, the term 'Black' will be used to describe people of the African diaspora (Tharps, 2014), whereas the term 'white' will also be used, without capitalisation as this term does not refer to an identifiable group of people (Perlman, 2015). It is also important to note that, the title of this thesis was chosen to incorporate how stigma impacts on identity. The word 'stigma' was not used in the title, or in any of the information sheets given to participants, in order to allow space for this experience to be defined by the participants themselves, rather than the researcher. Additionally, the title reflects the researcher's acknowledgement that stigma may not have been a relevant concept for the target population.

1.3.1. Human Immunodeficiency Virus

Human immunodeficiency virus (HIV) affects CD4 cells within the immune system, and affects the body's ability to resist and overcome infection or other diseases. The last stage of HIV is acquired immunodeficiency syndrome (AIDS) in which the immune system is so damaged that it is subject to increasing numbers of severe opportunistic infections (HIV.gov, 2017).

Worldwide, it is estimated that 36.9 million people were living with HIV at the end of 2017 and that 77.3 million people have been infected since the epidemic started, with the epidemic reaching its peak in 1996 (when 3.4 million people

were infected). As of 2017, 35.4 million people have died from AIDS-related diseases (UNAIDS, 2018a). Between 2010 and 2017, new HIV infections have decreased by 16% (UNAIDS, 2018a). The decline in deaths has largely been attributed to the development and accessibility of antiretroviral therapy (ART), and the decline in new HIV infections is seen to be the result of global HIV prevention and treatment programmes. However, the rate of new infections is still too high to meet the global target set in 2016 by the United Nations of fewer than 50,000 new infections per year by 2020 (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2017).

Within the UK, in 2017 it was estimated that: there were 101,600 PLHIV; one third of PLHIV accessing HIV specialist care were women; one third of of PLHIV accessing HIV specialist care were Black African and 98% of PLHIV were receiving treatment (National AIDS Trust, 2018). Additionally, almost 92% of PLHIV accessing HIV specialist care within the UK did so within England and 43% of these people accessed HIV care in London (National AIDS Trust, 2018). Although there were many public awareness campaigns related to HIV at the start of the epidemic, the numbers of these have decreased in recent years (National AIDS Trust, 2011), and there is evidence that knowledge within the public regarding HIV is low (National AIDS Trust, 2014a).

At the start of the HIV/AIDS epidemic, diagnosis was based on symptoms and presentations typically found in men, due to a belief that this was a mainly 'male' condition (Bova, 2000). The consequences of this were that many women were not meeting the AIDS diagnostic criteria (Selik, Buehler, Karon, Chamberland, & Berkelman, 1990) and were dying sooner (Rothenberg et al., 1987). By changing the AIDS definition in 1987, more women were able to enter clinical trials and AIDS related diseases specific to women were reflected within the diagnosis (Bova, 2000). However, the focus of contemporary research sometimes still suggests that HIV is a mainly male condition (Rodger et al. 2019). This discussion highlights how even seemingly ontologically static constructs are subject to social and political influences (Williams, 1999).

1.3.2. <u>Identity</u>

Identity can refer to a number of different aspects of a person, such as gender, class, ethnicity and sexuality (Frable, 1997), which interact and may be visible or invisible, voiced or unvoiced depending on context (Burnham, 2013; Burnham, 1992). Personal identity may refer to a person's beliefs, goals or values (Hitlin, 2003), whilst social identity may refer to a group that an individual either chooses to belong to, or has been classified into (Correll & Park, 2005; Tajfel & Turner, 1979).

Historically, the term 'values' has been defined as an individual's interests, duties or attractions (Williams, 1979). Due to the complexity of interplay between individual and social influences that both frame them and call on them for action (Schwartz, 1993), values have been regarded as difficult to capture and measure (Hitlin & Piliavin, 2004). Values are regarded as important in the study of identity and behaviour and they could link social positions and individual choices that reproduce features of social structures (Hitlin & Piliavin, 2004). Although values are thought to be the product of many interrelating social, historical and cultural factors (Hitlin & Piliavin, 2004), generally, differences have been found in relation to values between genders, with females tending to hold stronger values to do with compassion and the welfare of others, compared to males (Beutel & Mooney, 1995; Longest, Hitlin, & Vaisey, 2013).

Historically, it has also been suggested that Black communities place high value on cultural traditions and heritage (Porter & Washington, 1979), and it has been found that adopting a 'Western' name may be damaging for, whilst being able to speak English beneficial for, self-esteem in people who migrate to the US (Berry & Kim, 1988; Schnittker, 2002), suggesting that different aspects of assimilation have differing impacts on identity and wellbeing. More recently, in relation to women who migrate to Spain, it was found that inclusion in a social group, rather than a well-developed sense of ethnic identity was seen as important in terms of identity construction (Salgado & Silva, 2018), suggesting that social connections may be important in women that migrate.

Despite the vast amount of research regarding identity, its construction and components, it has been suggested that there is a dearth of research regarding how and if aspects of identity, change throughout the life course (Hitlin & Piliavin, 2004), for example, as a result of being diagnosed with a chronic health condition.

The groups that people belong to also form part of identity and maintaining a positive self-evaluation may be, in part, reliant on social comparisons (Festinger, 1954). It has been suggested that people learn about groups they are a part of through the actions of others, for example, it has been found that encountering discrimination can increase awareness of inequalities within Black communities (Worrell, Cross, & Vandiver, 2001), and among women (Downing & Roush, 1985). In a review of the literature, Correll and Park proposed a Model of Ingroup as a Social Resource (MISR) (Correll & Park, 2005) which describes ingroups as a way of validating positive self-evaluation through the individual identifying with a cohesive and valued group. The MISR also recognises that ingroups are not always chosen by the individual, and ingroup labels may be forced onto a person, for example, if they are given a diagnosis of an illness. According to the MISR, belonging to groups that are believed to have little value results in a less positive self-evaluation and potentially negative judgments from others, when negative attitudes or behaviours are associated with the ingroup.

1.3.3. <u>Stigma</u>

Goffman defined stigma as a social attribute that turns a person's identity from 'whole' to 'spoiled' (Goffman, 1963), thus highlighting the potential impact of experiencing stigma on identity. Stigma is a multifaceted concept, which can impact on various aspects of personal and social identity, as well as material resources (Deacon, 2005; Parker & Aggleton, 2003), see Table 1.1. for an overview of the facets of stigma currently defined in the literature. Due to the interrelated nature of the different facets of stigma, terms and definitions sometimes overlap, see Figure 1.1. for a visual representation of how stigma facets are connected.

Table 1.1. Definitions of Different Facets of Stigma.

Facet of stigma	Also referred to as	Definition	Reference
Anticipated	Internalised, perceived, self	"The stigma people expect from others should they be known to be HIV-positive"	(Deacon, 2005)
Self	Internalised, perceived, felt	"The acceptance among people living with HIV of negative beliefs and feelings associated with HIV about themselves"	(Stangl, Brady, & Fritz, 2012)
Perceived	Anticipated, public, social	"Regardless as to whether a person has objectively experienced HIV stigma, the perception of HIV stigma is what appears to be most strongly related to outcomes"	(Wagner et al., 2010)
Public	Experienced, felt, social	"Presence of experience of discriminatory behaviours, actions or attitudes from others"	(Lindayani, Ibrahim, Wang, & Ko, 2018)
Structural	Institutional	"Structural conditions that produce exclusion from social and economic life"	(Parker & Aggleton, 2003)
Courtesy	Relational	Negative attitudes held towards those who are in contact with people from a stigmatised group, such as family members or health care workers.	(Goffman, 1963)
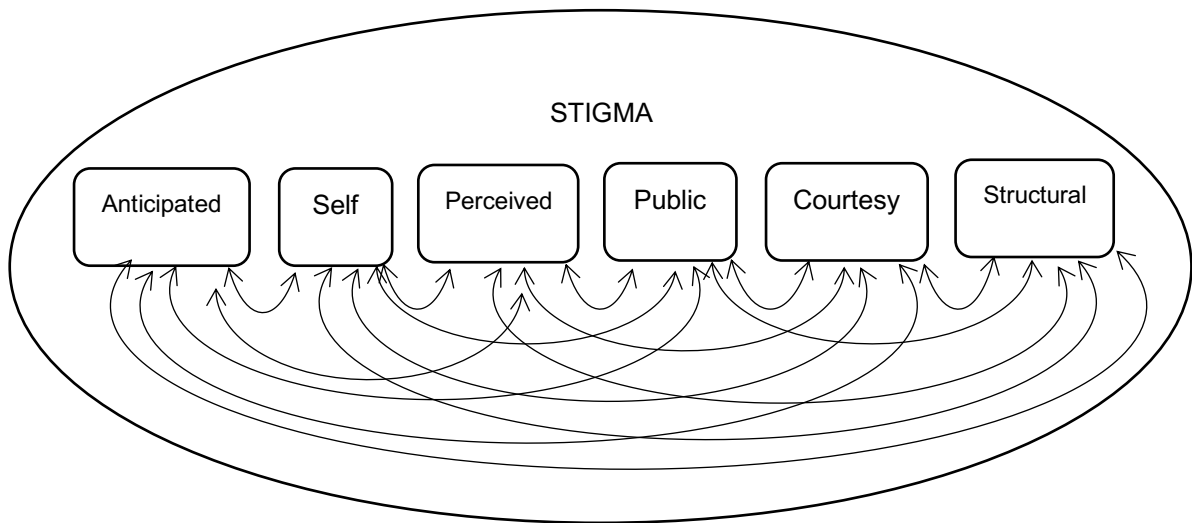
Figure 1.1. Visual Representation of how Stigma Facets are Connected

1.4. HIV and Stigma

Since the start of the epidemic, HIV has been portrayed as a stigmatising condition. Addressing stigma has been described as fundamental in the efforts to decrease the impact of HIV/AIDS internationally (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2015), and within the UK (Kirwan, Chau, Brown, Gill, & Delpech, 2016).

Historically, stigmatising attitudes and discriminatory behaviour has been attributed to ideas around incurability and fatality (Daniel & Parker, 1990). The development of ART means that many PLHIV now have a similar life expectancy to that of the general population (May et al. 2014). Medical advances have also decreased HIV transmission rates, for example, if the virus is undetectable within an individual, then it cannot be transmitted (British HIV Association, 2017), leading to the message, 'undetectable=untransmittable' (U=U) (Prevention Access Campaign, 2017). However, these advances have not seen an end to HIV-related stigma, as was expected by some (Chambers et al. 2015), suggesting that ideas around mortality and contagion were not the full explanation. Sontag has suggested that metaphors of punishment or plague are

related to the stigma of HIV (Sontag, 1991), and these may continue to have an effect on PLHIV as they may seek to reconcile the historical and contemporary images of HIV with their sense of identity, values and goals.

Empirically, stigma has been found to be prevalent throughout the lives of PLHIV (Campbell & Deacon, 2006; Herek, 1999). Stigmatising attitudes have been found within healthcare settings (Chambers et al., 2015), family and intimate relationships (Loutfy et al., 2012), daily and community living (Earnshaw, Bogart, Dovidio, & Williams, 2015), religious contexts (Otolok-Tanga, Atuyambe, Murphy, Ringheim, & Woldehanna, 2003) and impacts on overall quality of life (Lindayani et al., 2018). The consequences of stigmatising attitudes are far reaching, with avoidance of testing (Musheke, Merten, & Bond, 2016), seeking appropriate treatment and adherence to treatment (Mukolo, Torres, Bechtel, Sidat, & Vergara, 2013), as well as lack of disclosure of HIV status, being demonstrated (Arrey, Bilsen, Lacor, & Deschepper, 2015; Mill, Edwards, Jackson, MacLean, & Chaw-Kant, 2011). In turn these consequences may be seen by some as providing further justification for negative attitudes, as they impact on the rates of infection, thus making it harder for PLHIV to access timely and appropriate care. Additionally, the increased availability of ART has been referred to by Roura and colleagues as "scaling up stigma", in rural Tanzania, as attitudes blaming individuals counterbalanced what was viewed as positive normalisation of HIV that accompanied improved treatment availability (Roura et al., 2009).

Despite Goffman explicitly stating that stigma is socially based (Goffman, 1963), many have interpreted this work on an individual level. Using individually focussed definitions of stigma, researchers, clinicians and policy makers have proceeded to use cognitive notions, such as attribution theory (Mak et al., 2007; Weiner, 1993) and socio-cognitive theories to explore HIV-related stigma (Parker & Aggleton, 2003). This has also been the case of other conditions that are stigmatised in society, such as psychiatric diagnoses (Corrigan et al., 2000; Corrigan, Markowitz, & Watson, 2004).

Generally, socio-cognitive theories suggest that stigma is grounded in problems with knowledge (ignorance); problems with attitude (stigma) and problems with

behaviour (discrimination) (Henderson & Thornicroft, 2009; Thornicroft, 2006). It follows that by providing the correct information regarding means of infection transmission, at-risk population groups, or more recently, mortality rates (targeting ignorance), that attitudes (stigma) towards PLHIV will improve, as will behaviours (discrimination). This theory has influenced mass education campaigns, by various national (Centres for Disease Prevention and Control, 2018; HIV Prevention England, 2018) and international organisations (UNAIDS, 2018b), seeking to correct the 'ignorance' of the general population and PLHIV with regards to HIV. Disappointingly, despite a relative increase in the knowledge around HIV within the general population and PLHIV, levels of HIV knowledge within the general population remain low and there is little evidence that stigmatising attitudes have declined (National AIDS Trust, 2016; Stigma Index UK, 2016; UNAIDS, 2018b). This suggests that stigma is not an individualised socio-cognitive construct that can be modified by education alone.

Using a more social framework, Parker and Aggleton have argued that stigma towards PLHIV is based on, and strengthens and perpetuates, the social, material and political inequalities already experienced by the populations most effected by HIV (Parker & Aggleton, 2003). This argument may account for why HIV-related stigma is not experienced equally among the different populations that HIV effects. So-called 'layered stigmas' have been documented within the experiences of PLHIV (Reidpath & Chan, 2005), in which it has been found that those who already belong to minority, or stigmatised groups and have less access to resources and power, experience more HIV-related stigma, than those who belong to more traditionally powerful and resourceful groups (Grove, Kelly, & Liu, 1997; HIV Psychosocial Network, 2018). In particular, women and people from a non-white background have been found to experience more HIV-related stigma than their white, male peers (Loutfy et al., 2012) and poverty has been found to accompany more HIV-related stigma in highly affected communities (Duffy, 2005; HIV Psychosocial Network, 2018). Additionally, HIV-related stigma has been recorded as a mechanism of social and institutional control, for example, in a study conducted within the Canadian health system, participants reported disempowering practices related to HIV care that served to

control their behaviour (Mill et al., 2011). Additionally, Earnshaw and colleagues have proposed the Stigma and HIV Disparities Model, which suggests that structural and individual level stigmas that relate to population groups, particularly in relation to ethnicity, explain how disparities reinforce HIV-related stigma and differences in status, along with access to resources and social or political influence (Earnshaw et al., 2015). Similarly, Logie and colleagues have demonstrated links between HIV-related stigma, racist discrimination and housing insecurity (Logie, Jenkinson, Earnshaw, Tharao, & Loutfy, 2016), providing a concrete base from which to consider social level interventions. The socio-political frameworks for understanding HIV-related stigma provide researchers with more nuanced lenses through which to view and understand this experience, which has translated into suggestions for changes to UK public policy and laws that could help to reduce the structural inequalities that underlie stigma and discrimination (National AIDS Trust, 2016). However, these suggestions appear to have had little impact on the experiences of PLHIV (HIV Psychosocial Network, 2018).

1.4.1. <u>Self-Stigma</u>

Due to the focus on beliefs and feelings towards oneself, self, or internalised stigma (sometimes the spelling 'internalized' stigma is used, for consistency, any use of 'internalised' stigma throughout is taken to encompass both spellings) may be particularly important with regards to identity. HIV-related self-stigma is not always well-defined, sometimes referring to a fear of being stigmatised (Tshabalala & Visser, 2008), self-blame (National Network of Persons Living with HIV in Ghana, Ghana AIDS Commission, & UNAIDS, 2014), low self-esteem (GNP+ & NEPWHAN, 2011), or internalising negative HIV-related attitudes (Pantelic, Shenderovich, Cluver, & Boyes, 2015). Additionally, researchers will sometimes use a different stigma related term to describe the subjective experience of stigma, such as perceived, anticipated or felt stigma.

In 2012, a technical briefing from Strive (Stangl, Brady, & Fritz, 2012, 2018) gave guidance on the measurement of HIV-related stigma and discrimination.

This brief defines internalised stigma as, "the acceptance among people living with HIV of negative beliefs and feelings associated with HIV about themselves" (Stangl et al., 2012, 2018, pg 2). This suggests that self-stigma impacts on the identity of PLHIV through the acceptance that negative stereotypes regarding this population apply to the self. This echoes the definition of mental health related self-stigma, outlined by Corrigan and colleagues (Corrigan et al., 2006).

1.5. Women and HIV

According to the World Health Organisation, 51% of PLHIV are women. This figure has remained stable for some time, and contributed to Millennium Development Goal 5, the reduction of maternal mortality (World Health Organization, 2018). The response to women living with HIV (WLHIV) has been influenced by attitudes towards women and the roles women play in society (Amuyunzu-Nyamongo et al., 2007; Bova, 2000; Bunting, 1996; Grove et al., 1997; Mill, 2001). HIV was viewed as a male condition in the early stages of the epidemic, with women viewed as 'vessels' of infection; excluded from research and in many cases, denied treatment due to a lack of understanding of the development of HIV in women (Bova, 2000).

As epidemiological knowledge developed and women were included within the definition of HIV/AIDS, women accessing research and treatment faced further obstacles due to gender related attitudes found in the general public, within the context of marriage and reproduction, and from healthcare professionals (Bunting, 1996). In particular, attitudes towards women's potential roles as mothers have been examined. Although the importance of maternal health is not being debated, it is interesting to note that the route for recognition of HIV/AIDS status, research and treatment for women has been through this potential role, rather than research and treatment for its own sake. Additionally, it has been found that WLHIV are thought to be 'less fit' mothers than women with other long term health conditions (Lawson, Bayly, & Cey, 2013) and WLHIV who are intending to become mothers may be judged negatively by their physicians (Wagner et al., 2010).

Negative attitudes towards WLHIV are also related to the material resources and access to power that women have globally. Historical and contemporary oppression of women contributes to the transmission of HIV and inaccessibility of HIV treatment for many women (Bunting, 1996; Geary et al., 2014; Sontag, 1991), particularly those living in areas where women have less access to resources and power (Amuyunzu-Nyamongo et al., 2007; Sangaramoorthy, Jamison, & Dyer, 2017). Applying Connell's structural theory of gender and power (Connell, 1987), to the experiences of WLHIV in Nigeria, Mbonu and colleagues found differences in the ways that the general public and healthcare professionals, viewed and treated men and women living with HIV. Women's generally low status underlined more negative attitudes held towards them and manifested in power relations to do with accessing treatment, for example, healthcare professionals would routinely ask women to inform their partners of their HIV status, as it was assumed the partner would be paying for their treatment (Mbonu, Van Den Borne, & De Vries, 2010).

Studies have found, and global bodies have acknowledged links between WLHIV and violence (Cohen et al., 2000; Maman, Campbell, Sweat, & Gielen, 2000) and WLHIV are more likely to earn a living in ways that increase their chances of re-infection, such as sex work (Amuyunzu-Nyamongo et al., 2007), which may lead to women being unable to disclose their HIV status and seek appropriate care (Grove et al., 1997). As female gender and HIV status have been shown to be aspects of a person's life and identity that may be stigmatised, it would be expected that these socially defined attributes combine in ways that result in higher levels of stigma being experienced (Reidpath & Chan, 2005).

Studies have found that WLHIV experience high levels of stigma, across North America (Colbert et al., 2010; Sandelowski, Lambe, & Barroso, 2004; Vyavaharkar et al., 2010), Africa (Amuyunzu-Nyamongo et al., 2007; Mill, 2001) and Europe (Arrey et al., 2015), suggesting that stigma impacts on WLHIV across the globe.

1.6. Black African Women and HIV

Black African women are disproportionately affected by HIV (UN Women, 2018). Sexism and racism may impact on the prevention, diagnosis and treatment of HIV. For example, African women living in Canada are seven times more likely to be infected with HIV than white women living in the same area (Logie et al., 2016). In particular, health and access to healthcare may be affected due to institutional, cultural and interpersonal racism (Cobbinah & Lewis, 2018). These behaviours and attitudes impact on access to the material and educational resources required to know and understand health risks and how to mitigate them (Williams & Collins, 1995) and impacts on relationships with healthcare professionals (Cobbinah & Lewis, 2018). According to Hardeman and colleagues, a lack of explicit recognition of institutional racism in public health systems contributes to the material realities causing health inequalities and is also partly why these inequalities persist (Hardeman, Murphy, Karbeah, & Kozhimannil, 2018). Furthermore, intersections between ethnicity and gender mean that Black women are more vulnerable to the consequences of inequalities (Loutfy et al., 2015; Taylor, 1998).

The term prejudice is used more often in relation to racism than the term stigma, and the terms 'prejudice' and 'stigma' are sometimes confused as synonyms, giving the impression that they are the same concept. Phelan and colleagues thoroughly explored each term and the related concepts and concluded that, although they are quite similar in nature, and in consequence (that is, discrimination towards a person or group), 'prejudice' and 'stigma' do have slightly different purposes (Phelan, Link, & Dovidio, 2008). Prejudice, according to Phelan, exists to keep people down; in order that one group of people can justify enslaving another, they may refer to prejudicial attitudes to confirm their relatively superior position: this is what is commonly referred to as racism. Stigma, however, exists to keep people away, therefore stigmatising ideas regarding contagion or dangerousness may exist in order to keep people with conditions such as leprosy away from the general community (Phelan et al., 2008). Using this distinction, it is suggested that Black African WLHIV may experience overlaps between layered stigma and prejudice. Therefore, it is

20

important to note that stigma related experiences, for Black African women, may be related to prejudice or racism.

The negative experiences of HIV-related public stigma in Black African women have been recorded, and have been found to impact on diagnosis, treatment and prevention (Sangaramoorthy et al., 2017); access to adequate housing and social support (Logie et al., 2016) and rates of depression (Loutfy et al., 2012). Additionally, WLHIV who possess a form of 'symbolic capital', in terms of being white, were found to have experienced less public stigma and were still seen as a 'nice girl' in the eyes of the community (Grove et al., 1997), which serves to reinforce the negative stereotypes and metaphors that exist around Black WLHIV (Sontag, 1991). Additionally, it has been found that Black African WLHIV who appear to be able to resist stigma and its negative effects also deny that the stereotypes surrounding their population group are accurate (Buseh & Stevens, 2007). However, as the majority of the literature fails to examine the unique contributions of ethnicity or gender, along with failing to acknowledge or examine the impact of intersectionality more generally, including age, socioeconomic status and citizenship, to HIV-related stigma, it is hard to understand each factor separately. Although this may not be a problem, as intersections of identity cannot be separated out within a person's lived experience, it allows researchers and policy makers to neglect their impact, thus undermining the health needs of an already marginalised, and highly socially stigmatised population.

1.7. Literature Review

To understand how the impact of self-stigma on the identity of Black African WLHIV has been researched thus far, a literature review was conducted.

1.7.1. <u>Identifying Relevant Studies</u>

In order to identify relevant literature, the following search strategy was used. Electronic databases, Web of Science, PubMed, PsychInfo, CINAHL, Embase and the Cochrane database were searched in July 2018 for English language papers, from 1900 to 2018, using the following search terms, ["self-stigma" OR "internalised stigma" OR "internalized stigma"] AND "HIV" AND "women" AND "Black" AND "African". Additionally, relevant journals and the references of key papers were hand searched.

The inclusion criteria for the literature review were:

1. The focus or outcome of the article was self or internalised stigma;
2. The focus of the article was on adults (over 18 years old), as it is possible that self-stigma may differ between children and adults;
3. The focus of the article was on women;
4. The focus of the article was on HIV.

The exclusion criteria for the review were:

1. The focus or outcome of the article was not self or internalised stigma;
2. The focus of the article was children or adolescents under the age of 18;
3. The focus of the article was not on women;
4. The focus of the article was not on HIV.

The search did not exclude non-data articles, such as editorials or opinion pieces. It was not possible to include articles written in languages other than English, due to language and resource constraints.

The search yielded a total of 1510 articles. All articles underwent an initial title screening to ascertain relevance which resulted in retention of 62 articles. The abstracts of these articles were reviewed, resulting in 41 full texts that were selected for use in the review, see Figure 1.2. for a preferred reporting items for systematic reviews and meta-analyses (PRISMA) (Moher, Liberati, Tetzlaff, & Altman, 2009) flowchart of the articles selected for review.

Once the articles had been selected, a data chart template was developed to extract the relevant aspects of the articles. These aspects were: use of 'self' or

'internalised' stigma; definition of internalised or self-stigma and the relevant citation if applicable; type of article (qualitative, quantitative or non-data); country in which the work took place; sample; model of stigma used; any constructs measured; any measurements used; results of any measurements and conclusions drawn by the authors (see Appendix 1 for the data chart template).
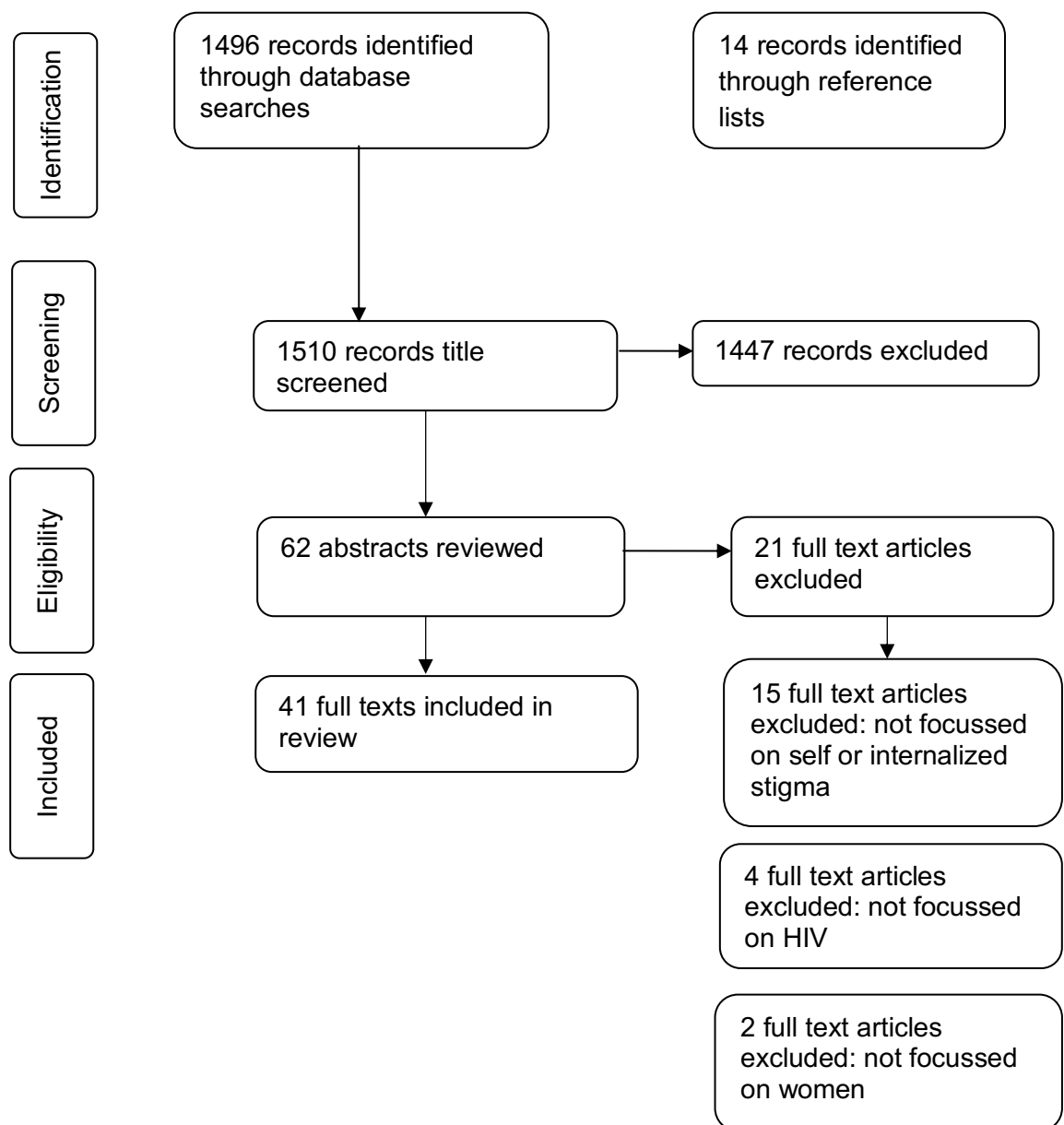
Figure 1.2. PRISMA Flow Chart of Articles Selected for Review

For an overview of the selected papers, see Appendix 2. Eighteen (44%) of the 41 studies reviewed presented quantitative data (Amuyunzu-Nyamongo et al., 2007; Colbert et al., 2010; Cuca, Onono, Bukusi, & Turan, 2012; Geary et al., 2014; Herek, Saha, & Burack, 2013; Lawson et al., 2013; Lee, Kochman, & Sikkema, 2002; Lindayani et al., 2018; Logie et al., 2016; Loutfy et al., 2012; Mak et al., 2007; Rao et al., 2012; Simbayi et al., 2007; The People Living With HIV, 2015; Tsai, 2015; Turan et al., 2016; Vyavaharkar et al., 2010; Wagner et al., 2010); four (10%) were reviews (Chambers et al., 2015; Herek, 1999; Otolok-Tanga et al., 2003; Sandelowski et al., 2004); 13 (32%) presented qualitative data (Anderson & Doyal, 2004; Arrey et al., 2015; De Wet & Wouters, 2016; Dibb & Kamalesh, 2012; Grove et al., 1997; Holzemer et al., 2007; Mbonu et al., 2010; Mill, 2001; Mill et al., 2011; Roura et al., 2009; Sangaramoorthy et al., 2017; Teti et al., 2010, 2012) and six (15%) were opinion papers containing no data (Bova, 2000; Bunting, 1996; Campbell & Deacon, 2006; Earnshaw et al., 2015; Parker & Aggleton, 2003; Stangl et al., 2012).

1.7.2. <u>Characteristics of Quantitative Articles</u>

Of the 18 articles that presented quantitative data, three did not provide a definition for self or internalised stigma (Colbert et al., 2010; Lawson et al., 2013; Wagner et al., 2010).

Eleven articles defined internalised stigma (Geary et al., 2014; Herek et al., 2013; Lee et al., 2002; Logie et al., 2016; Loutfy et al., 2012; Rao et al., 2012; Simbayi et al., 2007; The People Living With HIV, 2015; Tsai, 2015; Turan et al., 2016; Vyavaharkar et al., 2010), with two of these articles not providing a reference for their definition (Geary et al., 2014; Lee et al., 2002). Specific HIV-related internalised stigma references were provided by seven articles (Logie et al., 2016; Loutfy et al., 2012; Simbayi et al., 2007; The People Living With HIV, 2015; Turan et al., 2016; Vyavaharkar et al., 2010), whilst two articles (Rao et al., 2012; Tsai, 2015) provided a definition from mental health related literature.

Four articles defined self-stigma (Amuyunzu-Nyamongo et al., 2007; Cuca et al., 2012; Lindayani et al., 2018; Mak et al., 2007), of which: two articles did not provide a reference (Amuyunzu-Nyamongo et al., 2007; Cuca et al., 2012); one (Lindayani et al., 2018) provided a HIV specific definition, and one (Mak et al., 2007) provided a mental health specific definition.

1.7.3. Characteristics of Qualitative Articles

Of the 13 articles that presented qualitative data, six provided no definition for self or internalised stigma (Anderson & Doyal, 2004; Dibb & Kamalesh, 2012; Grove et al., 1997; Mbonu et al., 2010; Teti et al., 2010, 2012).

Four articles provided a definition for internalised stigma (De Wet & Wouters, 2016; Holzemer et al., 2007; Mill et al., 2011; Sangaramoorthy et al., 2017). Of these: one did not provide a reference for the definition used (Holzemer et al., 2007) and three articles referenced a HIV specific internalised stigma definition (De Wet & Wouters, 2016; Mill et al., 2011; Sangaramoorthy et al., 2017).

Two articles provided a definition for self-stigma (Arrey et al., 2015; Roura et al., 2009). Of these, one (Arrey et al., 2015) did not provide a reference and one (Roura et al., 2009) provided a specific HIV-related self-stigma reference.

1.7.4. Characteristics of Review Articles

Of the four review articles: one study did not provide a defintion of internalised or self- stigma (Otolok-Tanga et al., 2003) and three provided a defnition for internalised stigma (Chambers et al., 2015; Herek, 1999; Sandelowski et al., 2004). Two of these did not provide a reference (Chambers et al., 2015; Sandelowski et al., 2004) whilst the other provided a specific HIV-related internalised stigma reference for their definition (Herek, 1999).

1.7.5. Characteristics of Opinion Pieces

Of the six opinion pieces: three provided no definition for self or internalised stigma (Bova, 2000; Bunting, 1996; Parker & Aggleton, 2003); two provided a

definition for internalised stigma (Campbell & Deacon, 2006; Stangl et al., 2012) with no reference, whilst one provided a definition of self-stigma (Earnshaw et al., 2015), also with no reference.

It is interesting to note that none of the studies published after the technical guidance relating to the definition of HIV-related internalised stigma, used this as a definition (Stangl et al., 2012, 2018), whereas four out of the fourteen studies that provided a definition took this from literature relating to mental distress. This raises the question of why the same definition is not being used throughout the HIV-related stigma research, and raises concerns, as it is important for research to have clear and transparent definitions when describing and measuring concepts.

1.7.6. <u>Measures of HIV-Related Self or Internalised Stigma</u>

A number of studies measured internalised stigma using various tools. Six studies used scales previously validated with PLHIV. Four studies (Logie et al., 2016; Loutfy et al., 2012; Turan et al., 2016; Wagner et al., 2010) used a subscale of The HIV Stigma Scale ('negative self-image') (Berger, Ferrans, & Lashley, 2001), one (Geary et al., 2014) used five items from the Internalized AIDS Stigma Scale (Kalichman et al., 2009), one (Lee et al., 2002) used two items taken from the Functional Assessment of HIV infection (Peterman, Cella, Mo, & McCain, 1997) and one (The People Living With HIV, 2015) used a standardised questionnaire (The People Living With HIV, 2009). One study (Rao et al., 2012) used a tool devised for use with people with a chronic illness diagnosis (Rao et al., 2009), and adapted and validated it for use with African American PLHIV. One (Simbayi et al., 2007) study used seven items from the AIDS Related Stigma Scale (Kalichman et al., 2005) that were re-worded, with no psychometric validation presented. In order to measure HIV-related internalised stigma, one study (Tsai, 2015) used several items referring to public stigma (for example, ''would you buy fresh vegetables from a shopkeeper or vendor if you knew that this person had HIV?'') and took endorsement of these items to infer a level of internalised stigma among PLHIV. Finally, one

study (Vyavaharkar et al., 2010) reported the use of an 'internalized stigma scale', but did not provide a reference, or any description of the scale.

In relation to measuring self-stigma, one study (Cuca et al., 2012) used a subscale of a HIV stigma scale ('negative self-perception') (Holzemer et al., 2007); two studies (Herek et al., 2013; Simbayi et al., 2007) reworded items from established HIV/AIDS related stigma scales, however, these were not subjected to psychometric validation, and one study (Mak et al., 2007) developed a HIV-related self-stigma scale and subjected it to psychometric validation. One study (Lindayani et al., 2018) used a single item to measure self-stigma, with no psychometric data presented.

Overall, five standardised self or internalised stigma measures were used across the reviewed studies (Berger et al., 2001; Holzemer et al., 2007; Kalichman et al., 2005; Peterman et al., 1997; Rao et al., 2012), although they were not always validated for use within the context of the research presented.

Common themes across the measures were shame, self-blame, and secrecy suggesting that self-stigma is measured by how negative attitudes held by the general public are endorsed as applying to oneself, and not disclosing the diagnosis to others. However, due to the variability in the psychometric validation of the measures, it is difficult to know if the same construct is being assessed across studies, or how comparable the results are.

1.7.7. <u>Prevalence of HIV-Related Self-Stigma</u>

The literature suggests that self-stigma impacts on at least a fifth of WLHIV (Lee et al., 2002; Lindayani et al., 2018; Simbayi et al., 2007; Tsai, 2015), and within the UK, up to half of WLHIV reported self-stigma (The People Living With HIV, 2015). There is evidence that self-stigma is apparent during the time a person is first diagnosed and then declines (Lindayani et al., 2018). Lindayani and colleagues suggest that this is due to understanding more about the condition over time (Lindayani et al., 2018), although the results from this study conducted in Indonesia have not been replicated. Additionally, this study

employed a cross-sectional methodology and so with no prospective data, it is impossible to know the self-stigma trajectories for individuals.

It has been suggested that public stigma, whilst necessary, is not sufficient for the emergence of self-stigma, as they may be separate, albeit related concepts (Herek et al., 2013). In contrast, Simbayi and colleagues have suggested that the key to decreasing self-stigma is to reduce public stigma and discrimination (Simbayi et al., 2007).

1.7.8. HIV-Related Self-Stigma Theories

As with public stigma, cognitive and socio-cognitive theories have been used to explain the presence of self-stigma. Although a guiding theory is not explicit in many papers, cross sectional and self-report cognitive measures imply an individual based theory across the literature (Amuyunzu-Nyamongo et al., 2007; Bunting, 1996; Lawson et al., 2013; Lindayani et al., 2018; Otolok-Tanga et al., 2003; The People Living With HIV, 2015; Tsai, 2015). Attribution theory (Weiner, 1993) was used as the framework for one study, however, contrary to what would be expected if attribution theory were able to explain self-stigma, blame was not found to significantly correlate with self–stigma, high internal controllability was inversely correlated and responsibility was not correlated with self-stigma, leading the authors to conclude that attribution theory may be able to explain public stigma, however it is not useful in explaining self-stigma (Mak et al., 2007). This suggests that different (albeit related) processes may be underlying public and self-stigma.

The cognitive-relational theory of stress, appraisal and coping (Lazarus & Folkman, 1984), would suggest that as social support increases, stress (in this study HIV-related self-stigma) decreases. Vyavaharkar and colleagues were unable to find a direct link between HIV-related stress and self-stigma, however they did find that HIV-related self-stigma mediated sources of social support available and levels of depression in a sample of African American women (Vyavaharkar et al., 2010). Unfortunately, the measurement of self-stigma used in this study was not standardised, making replication of this result difficult.

Furthermore, further research would be required to focus on the mediation effects found, including longitudinal research, to validate these findings.

Extending the individual cognitive explanation for the experience of HIV-related self-stigma, Turan and colleagues used structural equation modelling techniques to demonstrate a sequential attribution model, to demonstrate how HIV-related self-stigma impacts on ART medication adherence. They found that low perceived social support, symptoms relating to low mood and loneliness, mediated the relationship between HIV-related self-stigma and medication adherence in women from a minority, or Black background (Turan et al., 2016). The results are used to suggest that interventions focussing on reducing self-stigma, low mood and loneliness will increase medication adherence, however, as there is no clear causal pathway in this correlational analysis, there is no way to know which way the direction of change is. Furthermore, reducing the impact of self-stigma to medication adherence further highlights how public health concerns regarding HIV transmission are turned into issues of individual responsibility for PLHIV. Placing this burden for change on the individual is unrealistic and ethically dubious as members of stigmatised groups may lack the access to power and resources required to change, due to their perceived devalued status (Campbell & Deacon, 2006).

The majority of work conducted regarding HIV-related self-stigma has focused on individual cognitions. However, there has been some work that uses social or political theories of self-stigma as a basis. One such study conducted in 12 countries in sub-Saharan Africa, found that levels of self-stigma were not related to the levels of general, public stigma found within a country, instead, self-stigma was found to be related to lower levels of income. The authors suggest that self-stigma therefore affects people with the least resources (Tsai, 2015), perhaps suggesting that self-stigma is not simply explained as the internalisation of widely known negative stereotypes.

These studies attempt to demonstrate how, despite HIV-related self-stigma impacting on an individual's identity and goals, the causes, potential interventions and mechanisms for change should not be grounded within the same individuals, as this responsibility may further exacerbate the differences in

power and resources (Campbell & Deacon, 2006; Parker & Aggleton, 2003). It is clear that further understanding of the context and process of HIV-related self-stigma is required (Holzemer et al., 2007). This is needed to ensure that interventions and clinical interactions with PLHIV are not contributing to increasing levels of self-stigma through misunderstandings of the mechanisms and pathways that contribute to this phenomena.

1.7.9. <u>Black African Women and HIV-Related Self-Stigma</u>

Only five studies were found that specifically focussed on HIV-related self-stigma in Black African WLHIV (Anderson & Doyal, 2004; Arrey et al., 2015; Cuca et al., 2012; Dibb & Kamalesh, 2012; The People Living With HIV, 2015). Cuca and colleagues found that 45.5% of 154 postpartum WLHIV in rural Kenya reported experiencing HIV-related self-stigma. However, as this study used a subscale designed to measure 'negative self-perception' (Holzemer et al., 2007), which the authors describe as measuring self-stigma, self-perception, social withdrawal and disclosure, it is difficult to establish what proportion of this relates specifically to self-stigma. Additionally, Cuca and colleagues focused on self-stigma in pregnant WLHIV and related this to receiving appropriate care and reducing maternal HIV transmission, perhaps unwittingly reinforcing a negative message that women are seen as a 'vessel' of disease in this part of Kenya. Despite these limitations, the authors conclude that HIV-related self-stigma is socially constructed and is related to a lack of empowerment for Black African WLHIV (Cuca et al., 2012).

Arrey and colleagues interviewed 28 WLHIV from 14 sub-Saharan African countries who were living in Belgium regarding decisions around disclosure of their HIV status. HIV-related self-stigma was suggested to be one factor that influenced this decision, described by the authors as "denial, secrecy, silence, shame and avoidance" (Arrey et al., 2015, pg 14). This study focusses more on finding reasons why individual WLHIV may have difficulties with disclosure, citing self-stigma as a factor, instead of examining self-stigma itself. Although the authors do acknowledge that the act of disclosure can leave some WLHIV vulnerable to social and physical threats, they also describe the tensions

inherent in disclosure decisions among WLHIV, with disclosure being seen as a positive action in terms of social support, and disease prevention, and judgements sometimes aimed at those who choose not to disclose (Arrey et al., 2015).

Anderson and Doyal conducted a qualitative analysis with 62 women from 11 African countries, living in London (Anderson & Doyal, 2004). Although this study does not state the proportion of participants who report experiencing HIV-related self-stigma, it suggests links between self-stigma and disclosure, with 16% of the participants not disclosing their status to anyone apart from healthcare professionals, and many of the participants expressing concerns regarding disclosing to family and friends who remained in Africa. Finally, another qualitative study (Dibb & Kamalesh, 2012), interviewed six WLHIV from Uganda, and six WLHIV from Zimbabwe, all of whom were currently living in London. Although this study did acknowledge that self-stigma may be a part of the participants' lives, the authors highlight some positive aspects of living with HIV that came from the data, such as positive behaviour changes, and changes in values and goals in the participants' lives, which were interpreted as 'positive growth' by the authors.

Studies that focussed on women found that, along with experiencing high levels of public stigma, WLHIV also report experiencing HIV-related self-stigma (Amuyunzu-Nyamongo et al., 2007; Rao et al., 2012; Turan et al., 2016). The levels of HIV-related self-stigma in WLHIV are usually found to be higher than men (Geary et al., 2014; Herek et al., 2013). In contrast, one study found positive aspects to living with HIV (Dibb & Kamalesh, 2012). To highlight the effects of intersectionality on HIV-related self-stigma and the relevance of the context of inequality, Herek and colleagues found that women and African American participants scored higher on self-stigma scales than male and white American counterparts and suggested that there is a need to understand stigma within the context of the objective reality of the inequalities of the groups that PLHIV belong to (Herek et al., 2013).

Overall, Black African WLHIV represent an underserved community in terms of research: in the UK in 2016 13,200 Black African women were living with HIV,

compared to 46,000 men who have sex with men (Brown et al., 2017), approximately 3.5 times more in the latter population. A Google Scholar search for "Black African women" AND "HIV" AND "stigma" resulted in 573 hits and "men who have sex with men" AND "HIV" AND "stigma" resulted in 33,000 hits, crudely suggesting approximately 58 times more research regarding the latter population (search conducted in March 2019).

1.8. Limitations of the Literature

Some of the limitations of the literature have been touched upon within the relevant sections. Cognitive theories suggest that the mechanisms of self and public stigma are the same, that is, lack of awareness around HIV, leading to misconceptions and endorsement of negative stereotypes resulting in negative attitudes turned towards the self. However, interventions to reduce public stigma using this theory as a basis, by increasing awareness through educational messages, or mass media campaigns have had only a limited impact on public attitudes and behaviour (National AIDS Trust, 2016; Sengupta, Banks, Jonas, Miles, & Smith, 2011; Stangl, Lloyd, Brady, Holland, & Baral, 2013). This suggests that although these interventions have a role in stigma reduction, they are not, in isolation sufficient to combat it, as has also been evidenced with stigma related to mental distress (Evans-Lacko, Corker, Williams, Henderson, & Thornicroft, 2014; National AIDS Trust, 2016), and interventions and changes need to take place across all ecological levels (Bronfenbrenner, 1993). For example, changes at policy and law making levels are needed to ensure that PLHIV are receiving access to the support they need and that stigmatising practices that reinforce negative messages are removed (National AIDS Trust, 2016), understanding needs on an individual level and ensuring that PLHIV have the opportunities to speak about their needs and for these needs to be used to inform policy and legislation.

Currently, public health concerns tend to be prominent in HIV-related stigma research, which may make sense from an epidemiological perspective, where

the aims are to reduce HIV infection rates. Additionally, although the public health messages of ending HIV-related stigma were nominally implemented to improve the quality of life of PLHIV (United Nations, 2017), the overall aim was to increase awareness of HIV and thereby reduce infection rates, rather than eliminating stigma purely to benefit PLHIV. This has led to a public health message of fear surrounding HIV, that, although may have resulted in better access to diagnosis and treatment, may have had a negative impact on the lives of PLHIV, due to the narrow focus of the messages. As Parker and Aggleton explain, due to the disempowered and stigmatised status of PLHIV, this population is not given a voice to amend these messages which then perpetuate the notions of fear (Parker & Aggleton, 2003).

The relative lack of representation from minority or marginalised groups, such as women and people from a Black African background, in HIV research is another limitation and may be due to the lack of acknowledgment of the influences of prejudice and racism in public health. This particular attitude mirrors that seen during the 1980s in the US when approximately 23,000 people died from AIDS before it was acknowledged by the federal government as a public health problem in 1987 (Gibson, 2015). It has been proposed that, because many of those who were affected were men who have sex with men, HIV was not seen as an important issue and was viewed as being controllable through "morality" and abstinence (Boyd, 1987). Furthermore, the majority of the work carried out in this area is done by people who are not part of the communities they are working with. Although this may be less of a problem if the work being done is led or guided by the relevant community and seeks to make their concerns and voices heard (Orr, Paul, & Paul, 2002), with some exceptions (National AIDS Trust, 2016; Teti et al., 2010, 2012; The People Living With HIV, 2015), this has not been found within this review. Although some of the research reviewed took place within African countries, the majority of this work was led by North American or European researchers, which may have led to 'Western' concepts being imposed without considering their validity in an African context and perpetuating Western domination and imperialism, whilst ignoring socially and culturally relevant interpretations and knowledge,

along with the impact of colonialism on people's lived experiences, which has been criticised as a feature of HIV-related research (Chambers et al., 2018).

In addition to these limitations, the available research relating to the experiences of HIV in Black African women living in the UK (The People Living With HIV, 2015) uses survey measures that may not allow for a full exploration of the potential impact on personal or social identity. Due to the social and health structures of the UK (such as the NHS, other health care providers and social support) and the multiple intersectionalities of identity that may become salient (or not) living in the UK, it may not be appropriate to generalise findings from studies of WLHIV living in other countries to this population.

It was not possible to engage in critical reflexive dialogue with the authors (or participants) of any of the work reviewed, and although critical reflection was a tool used throughout each stage of the review process, this was done in isolation, or with supervisors, which may result in the conclusions reflecting a worldview held by the author. Given the power of reviews in the hierarchy of evidence (Murad, Asi, Alsawas, & Alahdab, 2016), perhaps more focus could have been given to the critical reflection of available research, rather than using this reflection as a basis on which to rest more research.

1.9. Conclusions of the Review

Despite the limitations, some conclusions can be drawn from the literature. There is evidence within the literature that having a HIV diagnosis may have a negative impact on the lives of Black African women, although, with some exceptions, research conducted so far tends to have focussed on the public health consequences of this impact, such as disclosure and treatment adherence rather than how the impact affects aspects of identity. Furthermore, cognitive, individually based theories have not been useful for explaining HIV-related, self-stigma, with evidence suggesting that socio-political mechanisms may be relevant in explaining the disempowerment described by participants. Additionally, the experiences of the participants' may have been viewed through

lenses of the researchers' world views, that is, the data may have been interpreted through a different socio-political perspective than that which was experienced. This may have led to a non-intentional misrepresentation of participant's experiences. In order to guard against this, future research needs to adopt a more community based approach to allow the researchers to be guided by the participants and for researchers to facilitate the participants' voices to be heard.

1.10. Rationale for Current Study

This chapter has reviewed relevant literature to provide a summary of the research regarding HIV-related self-stigma in relation to the identities of Black African women and the gaps in the knowledge base. There is little evidence regarding HIV related-self-stigma and the impact this may have on Black African WLHIV. One of the reasons for this gap in the literature may be that researchers have not acknowledged the intersectionalties of Black African WLHIV in the UK, and how these may interact with public attitudes and the social, political and health systems within the UK.

Additionally, due to the variation in the use of psychometric validation procedures to strengthen the validity of self-stigma measures used within the reviewed research, it is possible that the concepts being measured reflect Westernised, potentially male-centric premises, which may not be suited to describe and explore the identities of Black African WLHIV. There is a need, therefore, to step back and attempt to understand the challenges and problems, along with the strengths of Black African WLHIV, through more collaborative methodologies that allow the women's voices to be heard directly. It is clear that Black African WLHIV are in possession of multiple publicly stigmatised identities, however, the impact of this is not clear and without this knowledge, there is little researchers, clinicians or policy makers can do to support this population.

1.11. Study Aims

From the review of the literature, the rationale of the study presented in this chapter, and a discussion with a representative from a charity that represents Black African WLHIV in London, the following aim has been developed for the current research:

- To explore the impact of public and self-stigma on identity among Black African women living with HIV.

More specifically, the research questions are:

1. What, if any, experiences of stigma from others are reported by a sample of Black African women living with HIV in the UK?
2. What, if any, experiences of self-stigma do a sample of Black African women living with HIV in the UK experience?
3. How do any stigma experiences impact on a sample of Black African women living with HIV in relation to their perceived identity as a Black African woman?

2. METHOD AND METHODOLOGY

2.1. Overview

This chapter provides a statement of the researcher's epistemological position, on which the research method, participatory action research (PAR) and methodology, Photovoice, were based. Details regarding the target population, the recruitment process and participant sample are then provided. The Photovoice and data collection procedure is presented, and finally, the analysis plan is displayed.

2.2. Epistemological Position

It is important to clarify the researcher's position in terms of epistemology, as this underpins the researcher's values, along with the aims and methodology of the research. The current research uses critical realism (Bhaskar, 1975) as a framework. Although Chapter One highlighted the social and political influences on the diagnosis of HIV, it needs to be held in mind that HIV is a chronic illness. Within critical realism, chronic illnesses are held to be biological realities, as suggesting otherwise downplays the social and economic consequences they have on the lives of those affected (Williams, 1999). Although critical realism proposes that observing the ontological reality of HIV is not possible, it suggests that it is prudent to examine the phenomena it produces and its effects.

2.3. Methodology and Method

2.3.1. <u>Considerations of Methodology</u>

Different approaches towards answering the research questions proposed in Section 1.11 were considered. In particular, a qualitative methodology may have been suitable. Qualitative methodology has been used in previous research with this population, and has been criticised for not including PLHIV in

the design of the research, or the interpretation (Chambers et al., 2018).
Therefore, to invite aspects of collaboration between the researcher and the
target population, participatory action research was considered to be an
appropriate methodology (Chevalier & Buckles, 2013). PAR has been
associated with research using a critical realist epistemological stance (Reza,
2007) and attempts to reduce unequal power distributions when working with
marginalised groups (Ponterotto, 2005).

2.3.2. Participatory Action Research

The PAR process has three core elements: collaboration between researchers
and participants at every stage, thereby creating a 'researcher/researcher'
relationship (Cassano & Dunlop, 2005; Chavez, Duran, Baker, Avila, &
Wallerstein, 2003; Evans-Agnew & Rosemberg, 2016); social justice and social
transformation (Sitter, 2017) and long-term engagement (Reza, 2007). The aim
of PAR is to be of benefit to marginalised populations by questioning the
ideologies, power and politics that underlie and uphold distress (McTaggart,
1991;Teti, Murray, & Binson, 2012).

Through the core elements, PAR acknowledges that the values and interests of
the researcher inform the research process, and holds that the position of the
researcher impacts on the work conducted, rather than suggesting that they are
an objective observer (McTaggart, 1991; Sitter, 2017), giving researchers the
opportunity to re-dress power imbalances created by the researcher/researched
dichotomy (Cassano & Dunlop, 2005).

2.3.3. Photovoice

Photovoice asks participants to take a number of photographs to communicate
their experience of the issue under research (Wang & Burris, 1994). Context
and elaboration of the photographs can be provided by way of group discussion
or semi-structured interviews. Photovoice is based on Freire's theory of critical
consciousness (Freire, 1974), feminist inquiry (Wang, 1999) and a community
approach to documentary photography (Wang & Burris, 1994). It allows
members of underserved communities the opportunity to capture and define the

strengths and challenges they face (Wang, 1999). Through engagement of critical dialogue and the dissemination of the community's ideas, Photovoice seeks to empower those who participate in projects (Teti et al., 2012). Photovoice was designed for use as, and is viewed as a PAR methodology (Wang, 1999), although it has been noted that the three core elements of PAR are sometimes missing from Photovoice projects (Sitter, 2017).

Photovoice was first used by Wang and Burris to study the reproductive health needs of rural Chinese women (Wang, Burris, & Ping, 1996). The term 'Photovoice' comes from combining 'photo' with "Voicing Our Individual and Collective Experience" (Wang & Burris, 1997). Within the current research, the definition of the term 'voice' is taken from an application of critical race theory and is taken to be a way of clarifying the reality of oppression within one's own story, which is described as an emancipatory act (Knaus, 2009). Photovoice has been used as a method to understand the health and healthcare contexts of diverse underserved populations, including: people with a learning disability (Overmars-Marx, Thomése, & Moonen, 2018; Tajuria, Read, & Priest, 2017); people with a physical disability (Dassah, Aldersey, & Norman, 2017); people who identify as lesbian, gay, bisexual, transsexual or queer (Holtby, Klein, Cook, & Travers, 2015; Zway & Boonzaier, 2015) and young people (Dakin, Parker, Amell, & Rogers, 2015; Van Der Wal, Grace, & Baird, 2017). Photovoice projects have also been used in the US to enable WLHIV to comment on the health system and wider socio-structural issues that affect them (Teti, Massie, Cheak-Zamora, & Binson, 2012; Teti et al., 2012). A scoping review of Photovoice projects conducted with PLHIV, that included 22 studies, concluded that it has a 'critical' role to play in defining and exploring health priorities within this population (Teti et al., 2012).

Photovoice can contribute to knowledge in at least three ways: describing phenomenological experiences (Plunkett, Leipert, & Ray, 2013); seeking and promoting social change (Catalani & Minkler, 2010), and using the photographs and stories to develop theory regarding the experiences of a community (Teti et al., 2012). The current research is attempting to describe experiences within a

community with an overall goal of social change. Therefore a Photovoice methodology was decided on, incorporating photographs, freewrites (one or two sentences produced by the participants' to describe the photographs) and semi-structured interviews to provide context and elaboration regarding the images.

2.4. Data Analysis

A number of analysis strategies may have been appropriate for use within this research, including interpretative phenomenological analysis (IPA) (Smith & Osborn, 2004) or grounded theory (Glaser & Strauss, 1967). IPA relies on language to adequately describe experiences (Willing, 2013), therefore as English was not the first language of the target population, there was a risk of details being lost in translation (Willing, 2007) and so IPA was deemed inappropriate. Although grounded theory can be an appropriate analysis method within a social constructionist or empiricist epistemology, it was decided against due to its relatively positivistic stance of 'uncovering' the truth (Willing, 2013), which may ignore the influence and biases of the researcher (Dey, 1999), thereby biasing the interpretations and conclusions.

Thematic analysis is used to identify, analyse and report patterns or themes within a given dataset (Braun & Clarke, 2006). As these themes can be used to analyse photographs (Gleeson, 2011; Willing, 2013) and the researcher's position can be explicitly acknowledged, thematic analysis was selected for use for this research.

Due to the range of uses and interpretations that thematic analysis can offer, explicitly stating the approach used to interpret a dataset is important, situating this within the epistemological framework of critical realism. A thematic analysis can identify themes inductively (focussing on the themes present within the data, with less concern regarding relevant theory or research questions), or theoretically (where analysis is driven by the research questions and relevant literature to build or refute theory). The level at which a theme is interpreted must also be considered (Boyatzis, 1998). A semantic method of interpretation

relies exclusively on the words used by the participant, and is, therefore a direct, mainly descriptive representation of what the participant has said. A latent method of interpretation takes into account the context of the interview such as the ideologies influencing it, or assumptions made within it (Willing, 2013). In order to answer the research questions, a theoretical thematic analysis was used, interpreting the themes on a latent level. Within the framework of critical realism, this allowed the researcher to explore the different experiences and social and material consequences of HIV within the participants' lives.

2.4.1. Data Sources

The current project produced three sets of data: the photographs taken by the participants; freewrites, and transcripts of the semi-structured interviews. Thematic analysis was used to analyse each transcript and the themes from this analysis were used as a frame to analyse the photographs and freewrites.

2.5. Selection of Sample and Participants

2.5.1. Target Population

The target population for the current research was Black African women, who have a diagnosis of HIV, living in the UK. In 2014, 25,660 Black African women living in the UK were known to be diagnosed with HIV (National AIDS Trust, 2014b). Due to resource constraints, the target population was narrowed down to women living in London. Approximately 58% of PLHIV from a Black African background who reside in the UK, live in London (National AIDS Trust, 2014b).

2.5.2. Sample

A HIV charity network in London was founded with the aim of pursuing the goals and interests of HIV Non-Government Organisations (NGOs) and HIV community members (HIV Psychosocial Network, 2018a). The sample for the current research was recruited from within the target population, via two charities that are part of this HIV charity network.

2.5.3. Inclusion and Exclusion Criteria

Inclusion Criteria

- Identifies as female;

- Diagnosis of HIV;

- 18 years old or over;

- Self-identifies as being from a Black African background;

- Has private access to a camera phone.

Exclusion Criteria

- Does not identify as female;

- No diagnosis of HIV;

- Under 18 years old;

- Does not identify as being from a Black African background;

- Does not have private access to a camera phone.

2.5.4. Building Relationships

Staff at two charities within the HIV charity network were interested in taking part in the current research. It was suggested that the women attending both charities would appreciate an invitation to participate in a Photovoice workshop in which group members would be encouraged to discuss their experiences alongside receiving information regarding the research. The workshop content is covered in Section 2.8.1.

2.5.5. Recruitment Process

As is also the case with qualitative research, participatory action research designs do not use formal power calculations. Regarding the use of semi-structured interviews, and thematic analysis, as three pieces of data per participant were being used, and the interviews would be in depth, it was possible that data saturation (the point at which no new information is being observed in the data collected) would be achieved by the sixth interview (Guest, 2006; Morse, 1995). Potential participants were invited to attend the workshops, through flyers and staff members talking about the project (see Appendix 3 for

project flyer). A total of 13 women attended the workshops. Alongside each workshop, there was an informal lunch and a chance to speak privately with attendees.

At the end of each workshop, and after any questions had been answered, Participant Information Sheets (PIS) were given to women who expressed an interest in the project, which was expected to yield at least eight consent forms (see Appendix 4 for PIS and Appendix 5 for consent forms). The researcher explained the information within the PIS, and was on hand to answer any questions. In order to give the women enough time to consider taking part in the project, the researcher returned one week later to speak to the women who wanted to take part in the project and collect consent forms.

A review of Photovoice methodology, assessing the quality of the participation (which refers to the collaboration between the participant and the researcher, a core participatory action research requirement), found a median of 13 participants (range, n= 4-122) over 37 studies and that there was no relationship between the N and the quality of participation (Catalani & Minkler, 2010). However, it is acknowledged that resource constraints may have impacted on the recruitment of this research and saturation of the data.

2.6. Photovoice Procedure and Interview Process

2.6.1. <u>Photovoice Workshop</u>
The workshops covered details of: development of the Photovoice theory and methodology; an example project (Teti et al., 2012); aims of the research and details of the proposed methodology; guidance on taking photos with a camera phone and the legal and ethical considerations that are important within Photovoice (Wang & Redwood-Jones, 2001), which are:

- Intrusion into private space;
- Disclosure of embarrassing facts about people;
- Images painting a false light;

- Safety of participants;
- Responsibility and authority of participants.

The legal and ethical considerations were discussed using examples of historical unethical practice (Wang & Redwood-Jones, 2001). There were opportunities for group discussion and asking questions built into the format of the workshop, (see Appendix 6 for the Photovoice workshop slides).

2.6.2. Photovoice Procedure

Once informed consent was obtained, participants were asked to take photographs on their camera phones that they felt represented their identity as a Black African WLHIV. A time-frame of four weeks was given for participants to take any number of photographs, and select two that they felt were the best representation of their identity. They were asked to send the photos to the researcher, along with a freewrite, a short description of why they had chosen each image to the researcher's password protected email address. The researcher then contacted the participant to arrange a semi-structured interview. All interviews took place within a private room in the charity building which the participant attended. The time and date of the interview was chosen by the participant. Participants gave consent for their photographs to be used in the research project. If a participant was unable to take photographs, but still wanted to take part in the research, a semi-structured interview was arranged with them. Each interview was recorded, with the participant's consent.

2.6.3. Interview Schedule

An interview schedule was designed by the researcher, to probe each participant regarding the same experiences (identity) whilst also allowing individual experiences to be discussed in an unrestricted manner. The interview schedule was based on a technique used in previous Photovoice projects (Holtby et al., 2015; Teti et al., 2012; Wallerstein & Bernstein, 1988; Wang & Burris, 1997; Wang & Redwood-Jones, 2001; Wang, Yi, Tao, & Carovano, 1998), known as 'SHOWeD'. The mnemonic 'SHOWeD' represents the following questions, used to generate discussion regarding photographs:

1. *What do you See here?* (invites description of the photograph)
2. *What's really Happening here?* (invites deeper description of what the photograph represents)
3. *How does this relate to Our lives?* (invites reflection on how the photograph relates to their community)
4. *Why does this problem or strength exist?* (invites reflection on causes of problems or strengths)
5. *What can we Do about it?* (invites reflection on change ideas)

It has been suggested that the use of discussion of the photographs using this technique helps the participant voice to gain power, through constructing and describing what is happening in the image (Evans-Agnew & Rosemberg, 2016). If any participant who took part did not take photographs, two of the questions in the SHOWeD technique were modified, so as to discuss their experiences in a comparable style:

1. *What do you see in your identity?*
2. *What is happening currently with your identity?*

The remainder of the questions were used in the same way.

In addition to using the SHOWeD technique, participants were also asked the following questions:

1. *Has HIV changed how you feel about yourself?*
2. *Has HIV changed your relationships with others?*

These questions were added to ensure that there was an opportunity to discuss issues around personal identity (goals, values and beliefs) (Hitlin, 2003) and the participants' social identity (inclusion in valued groups) (Correll & Park, 2005). Participants were also asked several questions regarding demographic and clinical information, to understand more about the structure of the sample, and

the transferability of themes observed to the target population. The participants' HIV diagnosis was ascertained from their use of the charity services; both charities require proof of a HIV diagnosis before they offer access to services. The demographic and clinical questions were:

1. Age;
2. Nationality and first language;
3. Length of time living in UK;
4. Occupation category;
5. Age when HIV diagnosis first received;
6. Marital status, number of children and living arrangements;
7. Currently accessing NHS services in relation to HIV diagnosis?

For the full interview schedule, see Appendix 7.

2.7. Participants

A total of five semi-structured interviews were completed. Using the number of women who attended the Photovoice workshops to represent potential participants (n=13), this gave a response rate of 38%. Three participants gave consent for photographs they had taken to be used as part of the analysis and research. Two participants provided two photographs and two freewrites, whereas one participant provided one photograph and one freewrite. This gave a total of five interview transcripts, five photographs and five freewrites. The average length of the semi-structured interviews was 54 minutes (range: 45 to 58 minutes) and totalled four and a half hours. The participants who gave consent for their photographs to be used in the written stages of the research stated that they did not want the photographs to be shown publicly, including within the charities. Participants were aware of, and consented to, their images being used as part of this research, including being available through the University's repository. Additionally, personal or locality identifiers were disguised by partially blurring the image.

2.7.1. <u>Demographic Characteristics of the Sample</u>

Demographic characteristics of the sample were collected in order to add context to the data sources. Additionally, these data gave a small insight into the transferability of the sample of the target population. Some of the demographic characteristics of the sample are presented in Table 2.1. Additionally, each participant recorded their nationality as a different African country to each other; English was not the first language for any participant; all participants were in receipt of specialist HIV treatment; one participant was in paid employment; one participant volunteered as a peer mentor for WLHIV; three of the participants had children; two participants used a 'Western' name; one participant was married and lived with her husband and two children; two participants lived with their children and two lived alone.

Table 2.1. Characteristics of the Sample

Characteristic	Total Sample (N=5)
Age (years)	
Range	38-58
Mean	49.6
Time in UK (years)	
Range	12-26
Mean	19
Years since diagnosis	
Range	7-18
Mean	13.2

2.8. Ethical Considerations

One of the main ethical issues was the potential for participants to become distressed during the interview which explored their experiences of identity and their diagnosis of HIV. A distress protocol was written by the researcher and included in the application for ethical approval (see Appendix 8). Ethical approval was given by the UEL School of Psychology Research Ethics Committee on 12th March 2018 (see Appendix 8 for the ethics application form and Appendix 9 for the notice of ethics review decision).

2.8.1. Consent and Withdrawal

Examples of questions in the interview schedule were included in the PIS given to potential participants, to ensure that informed consent was obtained and that everyone in the study was fully aware of the subject matter to be covered. Participants were informed at the initial contact (at the workshop), in the PIS and reminded during both the phone call to arrange the interview, and the interview itself that participation was voluntary and could be withdrawn at any time until the researcher entered the write-up stage of the project.

2.8.2. Confidentiality and Anonymity

Confidentiality of the participants' personal details was maintained. Consent forms containing personal details were kept in a locked filing cabinet to which only the researcher had access. Personal details were removed from research data and replaced with a unique ID number. The research data was stored on a restricted access drive, in an encrypted file.

2.8.3. Ethical Considerations Regarding Photovoice

In addition to the ethical considerations of the research in general and the semi-structured interviews, it was also necessary to consider the ethics of the use of the Photovoice method (Teti et al., 2012; Wang & Redwood-Jones, 2001). There are potential hazards and risks of injury to the participants when collecting photographs. Guidance on how to minimise risks was given in the Photovoice workshops, including guidance on taking photographs of other people: participants were required to obtain a permission and release form from any person they photographed (Blackman & Fairley, 2007) (see Appendix 5 for the consent and release form).

2.9. Data Processing and Transcription

All interviews were transcribed verbatim by the researcher. To minimize data reduction, transcriptions were completed as soon as possible after each interview was conducted (Braun & Clarke, 2006). As thematic analysis was used, it was felt that a full conversation analysis notation system (Jefferson,

1984; Silverman, 1993) was not required. Although this may have meant that some of the interactional data was lost, this was felt to be appropriate for the purposes of this research and the sample. An abbreviated version of transcribing (Poland, 2001) as outlined in Table 2.2 was used to capture detail within the interviews. Interview transcripts were imported into the qualitative analysis software programme, NVivo (version 12). Memos were created relating to each piece of datum that recorded reflections of the researcher and the context of the interview (see Appendix 10 for an extract).

Table 2.2. Notations used in Transcripts

Notation	Meaning
(…)	Pause, length of pause denoted by number of dots, for example a 3 second pause is denoted by 3 dots.
(Laughing)/(coughing)	Laughing or coughing during speech.
(-)	Point of interruption in speech.
(Overlapping)	Used with (-) to indicate overlapping speech.
[ ]	Word substitution to preserve anonymity.
xxxx xxxx [?]	Words that cannot be deciphered, and guess of word used when not clear.

2.10. Approach to Analysis

All data sources were analysed using thematic analysis. Thematic analysis was used in this study to ensure that the main themes in the transcripts were captured. The interview transcripts were analysed first and used as a framework to analyse the photographs and the freewrites from the perspective of the narrative of each participant. As the interviews used the SHOWeD technique (see section 2.6.3), this verbal data was related to the visual data, and so the analysis of the photographs was based on the narrative of each participant, along with the researcher's knowledge regarding theories of self-stigma. This is in line with the research aims of this project, and previous Photovoice research (Hannay, Dudley, Milan, & Leibovitz, 2013; Hunt, Braathen, Swartz, Carew, & Rohleder, 2018; Teti et al., 2012). Additionally, due to the interrelated nature of each participant's data sources, they exist together and can only be interpreted through relating them to each other (Gleeson, 2011).

2.10.1. <u>Analysis Plan</u>

Upon completion of the transcriptions, the six stages of thematic analysis methodology were followed (Aronson, 1994; Braun & Clarke, 2006):

- Stage one involved becoming immersed in the data, through a process of familiarisation. This happened through repeated, close readings of each transcript.

- Stage two was generating initial codes. Initial codes were taken from the interview data to represent features that were interesting to the researcher. Each transcript was systematically worked through and care was taken to ensure that full attention was given to each transcript and experiences that were repeated between and within transcriptions were coded. As many codes as needed were recorded along with the surrounding text, to ensure that the context was not lost. Codes were not mutually exclusive; one section of data could be coded multiple times, if relevant to different codes. A total of 26 codes were generated. These are displayed, along with descriptive information and an example from a transcript, in Appendix 11. Examples of coded data extracts are provided in Appendix 12.

- Stage three was searching for themes. During this stage, codes from stage two were organised into preliminary themes by searching the list of codes for similar features, so they could be combined and potential relationships between themes identified.

- Stage four was reviewing the themes. This stage refines the themes from stage three by collapsing themes together, or disregarding them if the data is not sufficient, or deemed redundant. For this stage, the data extracted from each transcript was reviewed with relation to the relevant theme and if necessary, moved to more appropriate themes or disregarded as unnecessary. The next part of this stage reviewed the

validity of the themes in relation to the complete dataset. To achieve this, the complete dataset was re-read and examined in relation to each theme. The preliminary themes are displayed in Appendix 13.

- Stage five was defining and naming themes. This happened by examining the data collected for each theme and giving the theme an appropriate name, from the data. Data was re-organised to form a cohesive and consistent account, and narrative added to explain the themes. The development of the themes is presented in Appendix 14. The final thematic map is displayed in Chapter Four. These themes were then used to analyse the photographs and the freewrites.

- Stage six was producing the report. This is the write-up of the entire thematic analysis process and is presented in Chapter Four of this thesis.

2.11. Quality Checks

2.11.1. Validity

The assertion that Photovoice is a valid PAR technique (Wang & Burris, 1997), has been challenged by some, who claim that Photovoice positions the researcher above the participants (Sitter, 2017), resulting in a loss of the participants' voice, and thus their power (Evans-Agnew & Rosemberg, 2016). To ensure that the participants' voice was not lost within the current project, aspects of PAR methodology were drawn on, as described below.

Firstly, the Photovoice methodology was chosen as an inclusive way of creating a narrative. Photography has been used across many cultures to provide a narrative and it may not require a common spoken language to understand the meanings. Participants did not need to rely on extensive vocabularies to be able to produce their narrative, which was important, as English was not the first language for any of the participants. It was also important to allow the participants to contextualise their photographs, in order to take control of the

meaning for them, as the same photograph could be viewed with several lenses and interpretations (Spence, 1988). Throughout history, photographs taken of people have been used in exploitative ways (Gross, Katz, & Ruby, 1988; Wang & Redwood-Jones, 2001) and so care was taken to ensure that the photographs being used were within ethical boundaries (see Section 2.8.1). Moreover, it was made clear to participants that their involvement in the project was not dependent on them taking photographs.

Next, the research questions were reached through collaboration with a representative of one of the charities involved in the study. Alongside their role within the charity, this person is also a Black African WLHIV and so had an insight into the strengths and challenges of this community. Of course, this person's interpretation of those strengths and challenges may not reflect the community as a whole, and ideally, meeting/s between the charities, including representation from people who attend them would have been arranged, however, it was not possible to schedule such meeting/s, due to demands on the time for the charities. Therefore, the interviews were designed so that participants could speak to any issue they felt was important and were not guided to speak about any specific issue, particularly, participants were not asked about experiences regarding any form of stigma, allowing them to refer to, and define any stigma related experiences themselves. In addition, a 'member-checking' meeting (Barusch, Gringeri, & George, 2011) was held at one of the charities involved in the research, giving participants and members of the community an opportunity to clarify or elaborate on any of the themes, which was fed into the final analysis.

A validity concern regarding participatory action research generally, is time. It has been argued that projects using participatory action research commonly do not allow for the time needed in order to foster real engagement within the communities the projects aim to serve (Pratt, 2007; Sitter, 2017). This is of particular concern with the current project, given the time constraints imposed by the nature of producing a third year research project on a Professional Doctorate course. Conducting rigorous research within the confines of a student

project has been discussed (Yu, Abdullah, & Saat, 2014), and although it is acknowledged that some elements of the research may suffer, such as sampling up until data saturation, as long as the research is designed to be realistically completed within the time-frame, and care is taken to ensure that the data collected and analysed is treated respectfully, then time constraints are not a validity concern. Therefore, time constraints were made clear to all of the stakeholders within this project, including the participants and the analysis plan was designed and followed carefully, to ensure respectful treatment of the data.

2.11.2. <u>Reflexivity</u>

A key aspect of participatory action research is awareness of the researcher of the influence they have in shaping the research question, interview and data (McTaggart, 1991; Sitter, 2017), known as reflexivity (Sultana, 2007). Reflexivity can be broken down into personal and epistemological.

Personal reflexivity relates to how the researcher's own values, beliefs, knowledge structures and autobiographical history affects their research. Therefore in the current research, personal reflections were recorded at the start and end of each interview. Alongside logistical notes referring to where the interview was conducted, the researcher made notes regarding their views about how the participant came across in the interview, or any concerns about rapport style, which were discussed in supervision.

Epistemological reflexivity regards the intrinsic limitations on the data collection, imposed by the research questions and specific questions in the interview schedule. Again, for the current research, the researcher recorded concerns regarding the questions and the type of information being elicited (or not) from them at the end of the interviews and this was discussed in supervision.

It is also important to consider reciprocity within this project, given that the interviews consisted of a one-to-one conversation. The concept of reciprocity has been described as a process of negotiation with regards to meaning and power (Lather, 1986). A level of interpretation is needed on the part of the

54

interviewer, for them to understand and make sense of the experiences that the interviewee chooses to reveal. The researcher remained vigilant regarding problems concerning reciprocity by being mindful of instances of misunderstandings during the interviews. Any misunderstandings were dealt with by a process of reflexivity and altering the wording or style of questions where appropriate, or asking for further clarification when necessary. Nevertheless, the concept of reciprocity in a semi-structured interview, or indeed in a participatory action research project, may seem counterintuitive, as the aim is for the interviewer to elicit information from the interviewee, whilst the aim for a participatory action research project is to empower participants. So how can the process of a semi-structured interview empower a participant? Firstly, the interview itself may be seen as a means for empowerment as the interviewee puts across their thoughts and feelings regarding an experience, thus allowing them to take control of the narrative and their role within it. Secondly, as was discussed during the Photovoice workshops, the purpose of the research as a whole was to empower the community groups to which the participants belong, by understanding more fully their experiences, how these can be improved and ideas regarding how to make these improvements.

2.11.3. Rigour

It is important that all research has aspects of rigour that are appropriate to the design and epistemology of the work (Spencer & Ritchie, 2012). In regards to the current research, transparency and safety of participants were considered in regards to rigour, along with validity and reflexivity. Transparency was achieved through continuity of communication with the participants and charities regarding the research aims, through the Photovoice workshops, PIS and consent forms, and individual communication with participants. Safety of the participants was considered throughout the data collection process through the Photovoice workshop, the distress protocol, and the shared decision making regarding levels of dissemination.

2.11.4. <u>Researcher Position</u>

As themes are not simply waiting to be found within the data, analysis inevitably is influenced by the researcher and their position. In addition to keeping memos and notes referring to values and beliefs within the analysis, it is also important for the researcher to be explicit about their position regarding the research (Madill, Jordan, & Shirley, 2000; Willing, 2013). I am interested in social justice and gender equality, and using research to inform social attitudes and policy to this end. I believe this political position comes from my background as a white working-class woman. I am aware that my understanding of PLHIV has been influenced by political and sociocultural contexts reported through mainstream media throughout my life. However, this understanding consisted mainly of the experiences of men who have sex with men. My interest in gender equality led me to want to understand more about women's experiences with HIV. Additionally, my understanding of women from a Black African background has also been influenced by the media, and the interpretations of British political relationships with different African countries. Therefore, although I do not identify with the same intersectionalities as the participants in this research, I am motivated politically to understand their experiences as part of a more general outlook regarding the treatment of women globally. I would position myself as an ally to this population (Burwell-Chen, 2015).

3. RESULTS

3.1. Overview

This Chapter presents the results from the thematic analysis of the semi-structured interviews, photographs and freewrites. Presentation of the qualitative data is provided with use of quotes for illustrative purposes. Presentation and analysis of the visual data is also provided.

3.2. Analysis of Themes

The thematic analysis followed the outline described in Section 2.12.1, and represented in Figure 3.1. Two main themes and six subthemes were yielded from the data. See Figure 3.2 for the final thematic map.
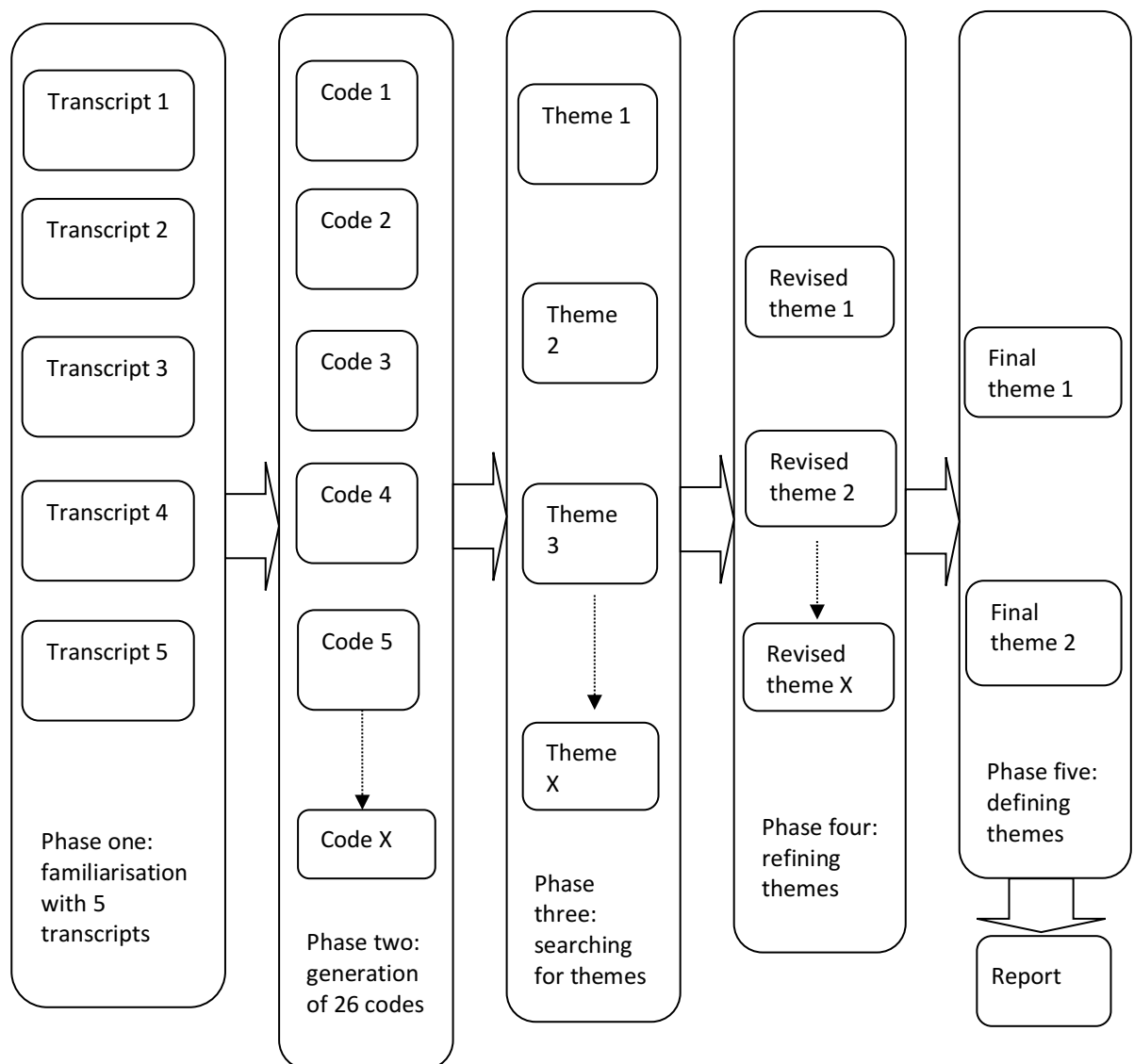
Figure 3.1. Journey of Qualitative Data

```
┌─────────────────────┐        ┌─────────────────────┐
│ Theme one: Retention │        │ Theme two: Prevalence│
│ of self              │        │ of outdated information│
│                      │        │                      │
│ "I'm still in there" │        │ "Remaining with the old│
│                      │        │ information"         │
└─────────────────────┘        └─────────────────────┘

┌─────────────────────┐
│ Sub-theme one: Values│
│                      │
│ "Everyone should be  │
│ treated with respect and│
│ equality"            │        ┌─────────────────────┐
└─────────────────────┘        │ Sub-theme one: Public│
                                │ stigma               │
                                │                      │
┌─────────────────────┐        │ "They are not well   │
│ Sub-theme two: Support│       │ educated, enlightened│
│                      │        │ about HIV, so there's that│
│ "Doctors are so caring as│    │ stigma around, someone│
│ well, they are supportive"│   │ has HIV"             │
└─────────────────────┘        └─────────────────────┘

┌─────────────────────┐
│ Sub-theme three:    │
│ Comparisons         │
│                      │
│ "I would rather be HIV│       ┌─────────────────────┐
│ positive than being │        │ Sub-theme two:       │
│ diagnosed with either│       │ Systems              │
│ diabetes or cancer" │        │                      │
└─────────────────────┘        │ "So how does the     │
                                │ economy stand, when the│
┌─────────────────────┐        │ citizens are dying every│
│ Sub-theme four:     │        │ day"                 │
│ Impact of diagnosis │        └─────────────────────┘
│                      │
│ "I didn't have hope  │
│ thinking that I would│
│ survive"             │
└─────────────────────┘
```

Figure 3.2. Final Thematic Map

1.11.1.   Theme One: "I'm still in there" (P3)

The first theme consisted of four subthemes. Overall, this theme was concerned
with the preservation of the participants' identity, and a desire to communicate
that living with HIV is not their dominant narrative. Sub-theme one, 'values'

demonstrated this by expressing commitment to values held prior to receiving the HIV diagnosis:

"it doesn't remove anything that is from you" P1;

"from when I was a kid, I have like, ten pounds, I like to share, with everyone [...] I need to be kind to everyone" P2;

"if I can manage to help I will, you know, do my best, you know go the extra mile, erm [..] not thinking about myself" P4.

These quotes further illustrate how the values held by most of the participants were connected to sub theme-two, 'support', through responsibilities they felt for helping, caring, supporting or educating others. This was shown throughout various aspects of the participants' private, family lives:

"I need to be kind to everyone and that's what I teach my children" P2;

"my daughter, she have er, twins, children, so nobody to look after them, because all them live in different towns, so she is alone at home, she call me, she cry, she cries so I say ok, I will, I will come and help" P5.

This responsibility was also felt in relation to wider society:

"you have to tell them that now it's U=U [..] you can move forward and make sure that the people are learning" P1;

"I don't want to see someone, you know suffering or struggling" P4.

One participant however, rejected the notion of caring for others, and had made a decision to focus on their own health and wellbeing:

> "I'm just working towards my goals, just focussing on myself and what I want to do" P3;

> "just focus on me, don't focus on other people, focus on what I need to do" P3.

This participant framed this rejection of others as a mechanism to achieve their goal of returning to paid work.

Participants experienced changes with their established roles and identities. One of these was accepting care and support from others, a role they were mainly used to performing for others. All of the participants expressed gratitude for the care they had received from their support systems:

> "there are people out there who are very very kind like this, doing things, helping people" P1;

> "if I was down, I would just, you know phone them and then we will talk and sometimes they would phone me from back home to find out how I am" P4.

More formal treatment from healthcare professionals was also acknowledged:

> "my doctors talk to me nice, they encourage me, they give me support [.] they give me hope" P2;

> "The NHS saved me and then gave me some time, gave me some direction, help me to get where I want to get" Pt3.

Participants seemed able to integrate the acceptance of care within their narrative as this fitted in with their values of caring and helping, albeit with a reversal of expected roles.

In sub-theme three, 'comparisons', all participants also compared the HIV treatment they were receiving in the UK to the treatment they could expect in their home countries. Participants felt that receiving appropriate treatment helped them to have the time and resources to retain their sense of self. Although all the participants came from a different country, they all emphasised how much better they believe the situation is for WLHIV in the UK:

> "it's not as easy as here, over there it's not erm, as cheap as it is here, you have to pay some of the money, and erm, the government is doing something about it but it is not enough but not like here where it is given top most priority" P2;

> "when I go back home I see some people, they have it, a lot of them die" P5.

Additionally, three of the participants either compared their diagnosis in a favourable way to people with other chronic health problems such as cancer or diabetes, or equated these diagnoses to HIV, in line with the message 'a disease like any other' (Odlind, 2018);

> "sometimes people think that it's a shame to have HIV but it's not a shame, it is like every other dis, diabetes" P1;

> "I would rather be HIV positive than being diagnosed with either diabetes or cancer and I think now, if I am diagnosed with cancer, I will be more worried than HIV" P2.

One participant however, rejected the notion that HIV is a 'disease like any other', and suggested that people with other health diagnoses are more favourably treated:

> "when you look at people who have cancer or people who have other disabilities, they are treated completely different, you know. If I had cancer, just cancer […] it would be completely different, cause I've got this other status, it's another, that status, it's, it's [..] it messes up everything" P3.

Sub-theme four, the 'impact' of the HIV diagnosis was felt for each participant in relation to their ideas and expectations of HIV, and how they thought this would interrupt, or end, their lives:

> "being positive, actually, at first, when I was first diagnosed, I thought it [..] that it was end of my life" P1;

> "I thought, oh my end has come" P2;

> "I was ah, you know thinking that at first it is a death sentence, that well I will be dying soon, so you know I didn't have hope thinking that I would survive" P4.

The contrast between how participants first responded to their diagnosis, and their attitudes towards living with HIV after a period of adjustment represent a journey; one which has not ended, as participants still acknowledged that HIV has an impact on their day-to-day lives:

> "I've got medication to take at ten times a day, it, you know and it's always at the back of your mind" P3;

> "sometimes I get upset, I sit and cry and cry" P5.

However, most participants described reacting to the initial impact of their diagnosis, through a determination to achieve their goals, and live according to their values, despite their HIV status:

> "I have been a fighter for many, for HIV now, for me I call myself an activist, I'm an activist, I no longer call myself a victim" P1;

> "it's not like you can't live if you have HIV, you can have a good life, you can live longer than you think" P2.

Throughout, none of the participants consistently used the term 'HIV' in relation to themselves or their HIV status, some used the word 'positive' to describe their diagnosis:

> "when you are positive, sometimes people don't know to say we are positive" P1;

> "maybe it's part of the [..] the other, illness" P3.

This may be a reflection of the difference between the expectations of what would happen when the HIV diagnosis was received, that is, that they would die, and the reality of living with HIV, that is, that they are alive. It appears that the idea of HIV that has been, and is still reinforced as a "death sentence" (P4), is separated off from the reality of living with HIV, and therefore, the experience is described using alternative words.

Overall, theme one describes how participants struggled, and mainly were able, to remain connected to their personal values and goals when they were first diagnosed, and of how they have fought to ensure that they are not defined by their diagnosis or the narratives other people may have for them. As all of the participants have been living with HIV for a number of years (mean = 13 years, see Table 2.1), they have all had some time to adjust to the demands of living with a chronic illness. All of the participants express a clear gratitude to the

support of the health services that they receive in the UK, which is viewed in contrast to their perceptions of healthcare provision in their home countries.

1.11.2.   Theme Two: "remaining with the old information" (P1)

The second theme consisted of two subthemes. Overall, this theme represented the participants' perceptions of how other people, and wider systems view them and their HIV status. All of the participants expressed frustration at the outdated information they saw in media coverage of, or in public health educational material relating to, HIV:

> "at that time people were dying they used to show us people who were dying here, everything [..] but, what they have failed to do now, they didn't come back, after the U=U everything, they failed to come back […] to say publicly, U=U it's not the message it's not out there, so people are remaining with the old information" P1;

> "they are not well educated, enlightened about HIV" P2;

> "you can't catch it from just having a cup of tea you have to, somebody have to bleed or through sex or things like that [..] so it was good to have such an education, and people need to have more education about that," P3.

There was also an awareness of the stereotypes regarding WLHIV, captured in sub-theme one, 'public stigma', that are perpetuated within societies, particularly, according to the participants, within the Black African community:

> "she felt ashamed that she is not married and she has HIV [..] automatically, the pointers will indicate that sleeping around" P2;

"the community just think that you've, you are like that, you know, you are a loose, that's what made you get that you know illness, compared to men, men you know because of the culture they say that men can do as many wives, as many women as they want, so it's not that bad for men to, you know, be criticised compared to women [..] especially if you are not married, I've experienced that at home as well, so in the Black community" P4.

Although the participants did not endorse these stereotypes, either in relation to themselves or to other WLHIV, they understood these stereotypes to be very powerful, and noticed how people in their community would speak about those with their diagnosis:

"it's just the stigma, yeah, and sometimes people think that it's a shame to have HIV" P1;

"stigmatisation plays a major role in my country, and these talking about you, gossiping" P2;

"you are HIV positive, it means you are going to infect everyone [.] so people start running from you" P2;

"you go in their house, people treat you different, I've seen all this in my African community, like, I, one of my aunties friends [..] I was doing her hair and she said stop doing her hair because she's got this and this and I'm like, yeah, I'm one of them, but you don't know that" P3;

"there are some who, look down on people with HIV, even here, especially the Black community, they look down on you, you know talk bad about you" P4;

"if I say to anybody, the people going to stare at me, going to look at me different, don't come near me all that I don't know" P5.

The awareness of the negative stereotypes and what participants described as "gossiping" within their communities, led all of the participants' to express feelings of shame with regards to their diagnosis, and to implement strategies around who they could and could not disclose their HIV status to:

"you can't go up to a church and go oh I'm positive, in church, even when I am talking about HIV, yeah [..] it's not that I go everybody tell me I am positive" P1;

"they kind of isolate people and that's the reason why the stigmatisation plays a major role in my country, and these talking about you, gossiping, as we speak now […] not every member of my family knows my status, because it is still there" P2;

"even if now things are different I'm not gonna say anything to anyone to be honest, yeah, I've gone through too much, I don't want to, like, I just don't want to have to worry about what people are talking about, out there, I don't want to be facing that" P3;

"even at one of these groups I saw someone I know, she saw me and she say oh what are you doing here, I said I come here to do the volunteer and that's it [..] otherwise she run tell people, she say oh, do you know what they are doing here, I say yes, I know, you want to come, I say yes" P5.

All participants spoke about how they are selective in disclosing their HIV status. All participants had disclosed their HIV status within healthcare contexts and they all also had experience of people dying because they 'lived in denial', which referred to people not disclosing, or seeking treatment for their HIV

diagnosis. According to the participants, these decisions were based on people being afraid of the attitudes of other people:

"he passed away because he lived in denial, he didn't want nobody to know [..] not even his wife" P2;

"a lot of them, they just die in silence, because they are afraid to come out" P4.

Two participants also expressed doubt, or doubt from others as to their own HIV status. These doubts appeared to stem from ideas around what living with HIV is like, based on perhaps outdated information:

"sometime I don't personally think I have any disease because I am doing very well, my medication, very good, I am undetectable" P2;

"I've told my children, they say no, I don't believe you so [….] a sister and brother, I told them, they don't believe it [….] I know me, sometimes I don't believe it" P5.

Sub-theme two, 'systems', describes how interactions with systems and structures also reflected frustrations. Participants suggested that governments, in the UK and in the African countries that were the participants' home countries, were not trained using the most up to date information regarding HIV treatment, in contrast to UK healthcare professionals. Additionally, participants suggested that the benefits and housing systems are not set up to suit their needs:

"I lost my accommodation, everything, the rent, the home office, you're not allowed to work" P1;

"my medical records is already telling you what I am, why do I have to fill in so many forms to actually prove that? My doctor's already proved

what's going on in my life [..] that's enough, that's already enough itself, then to be able to have to also prove to other people, you know" P3;

"you find a medical person back home, you tell them you are HIV, you see the eyes, the reaction, alright, they are also scared because they are not trained" P2.

Overall, theme two demonstrates how the participants interact with larger social systems, and society's perceptions of WLHIV. Generally, the participants present themselves as relatively powerless, having to provide information in what seem like out-dated systems so that they can receive the support they need. Additionally, they are fully aware of the stigmatising attitudes held by some sections of society towards WLHIV, which impact on how they express their belonging to religious or community groups. Participants felt that these attitudes stemmed from outdated knowledge regarding living with HIV and its treatment.

3.3. Member-Checking and Final Review of Themes

As part of the analysis, two 'member-checking' (Barusch et al., 2011) meetings were held, one with women who attended services provided by charities involved in the research and one with staff from the charities. The first of these meetings consisted of six women, two who had taken part in the research, two who had attended a Photovoice workshop and had not taken part, and two women who were new to the research. The staff meeting consisted of two male, and one female staff members, who were all familiar with the research. The initial themes, arrived at during phase three of the TA were presented to both groups (see Table 3.1). Generally, both groups agreed that the themes matched their experiences, or their experiences of working with this sample. More emphasis was placed on the differences between the experiences of Black African WLHIV and the men living with HIV who also attended services run by the charities. In the women's group, the process of the menopause was highlighted as something unique to their experience, along with child care

responsibilities. Interestingly, one woman spoke about how the levels of stigma that she had witnessed in her home country (South Africa) were lower than in the UK, in contrast to the experiences of other African countries spoken about by the participants. The staff members also commented that they noticed that the impact of 'gossip' within Black African communities appeared to be prominent in the women's experiences and connected to their decisions regarding disclosure of their HIV status. Additionally, the staff group commented that they felt there is an urgent need for a government funded mass education campaign to correct outdated information within the general public.

Table 3.1. Description of Initial Themes

Preliminary theme	Codes within theme	Description of theme
Maintenance of identity	Description of diagnosis; support or supporting people; having children; activist; perception of self; helping others; religion; importance of education; distress accompanying diagnosis.	How values are maintained or emerge in relation to a HIV diagnosis.
Comparisons	Differences between UK and African countries; 'disease like any other'.	How the experience of a HIV diagnosis is understood through comparisons between countries and/or other illnesses
Stigma	Perceptions of others; gossiping; outdated messages; denial; exclusion; shame.	Awareness of the levels of knowledge, attitudes and behaviours regarding HIV in the general public, and effects of these.
Systems	Battles; treatment or medication; lack of voice or power; services- health, benefits, money; political problems or government priorities; disclosure; survival; strength.	How micro, meso and macro-level systems exert control

Following the member checking meetings, the initial themes were revised to reflect the feedback. In particular, the experience of stigma appeared to be related more to participants' relationships with systems and other people, rather than impacting directly on their identity. Therefore, two themes were created to

capture the impact of HIV on the personal and social identities of the participants (theme one), and their experiences of other people and systems, which appeared to be governed by the prevalence of outdated information related to HIV (theme two).

3.4. Thematic Analysis of Photographs and Freewrites

Once the thematic analysis of the interview transcripts was completed, the researcher became familiar with each photograph and freewrite by viewing or reading them several times. The themes from the thematic analysis of the interviews were used to analyse the images and freewrites in relation to each participant's narrative.

1.11.3.　　　　Photograph One: Phonebox

Freewrite: "people can still come and use the phone, even though we have the HIV diagnosis, it doesn't make us not useful to society" P1.

In 'phonebox', the telephone is a symbol of helping and caring, two important values for the participant. The impact of the HIV diagnosis on identity is shown by the dirty appearance and lack of maintenance of the phonebox, which may represent the perception of others, and the neglect of WLHIV within political systems. Both themes are present within this photograph. Theme one is present through illustrating values that are important to the participant, and the demonstration that the impact of the diagnosis does not detract from them. Theme two is present through the representation of neglect, demonstrating how the participant feels that PLHIV are treated by society.
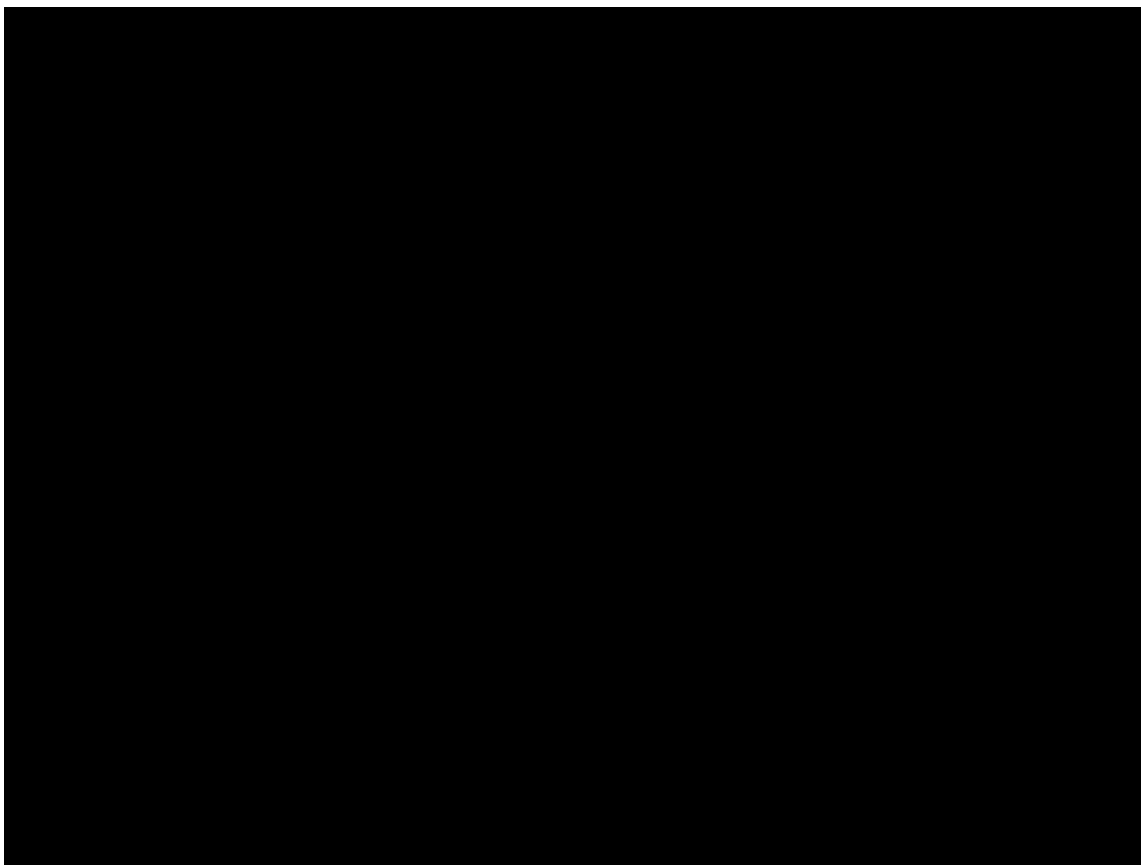
1.11.4. <u>Photograph Two: Look Both Ways</u>

Freewrite: "these are the two ways, it's either HIV positive or HIV negative. So you have to look both ways" P1.

'Look both ways' shows a road sign, warning pedestrians of two way traffic. The sign itself could be a symbol of the social systems and the general public's

need to be aware of the existence of WLHIV, or a symbol of their need to be reminded to acknowledge the contribution of people with HIV to society. Additionally, as the sign is on a road, this could represent the journey of the participant and of society with regards to living with HIV. There is also the threat of danger within this photograph, if the warning is not heeded, which could further represent the damage caused by systems or society not heeding the opinions or experiences of WLHIV. The impact of HIV on society as a whole is represented by the freewrite, which reminds us that everyone has a HIV status, be that positive or negative.

The first theme is present within this photograph in that the journey of the participant is shown. The second theme is also present with the sense of threat, or the degree of urgency conveyed, which may be an example of the need to update the information people have regarding HIV and its treatment.
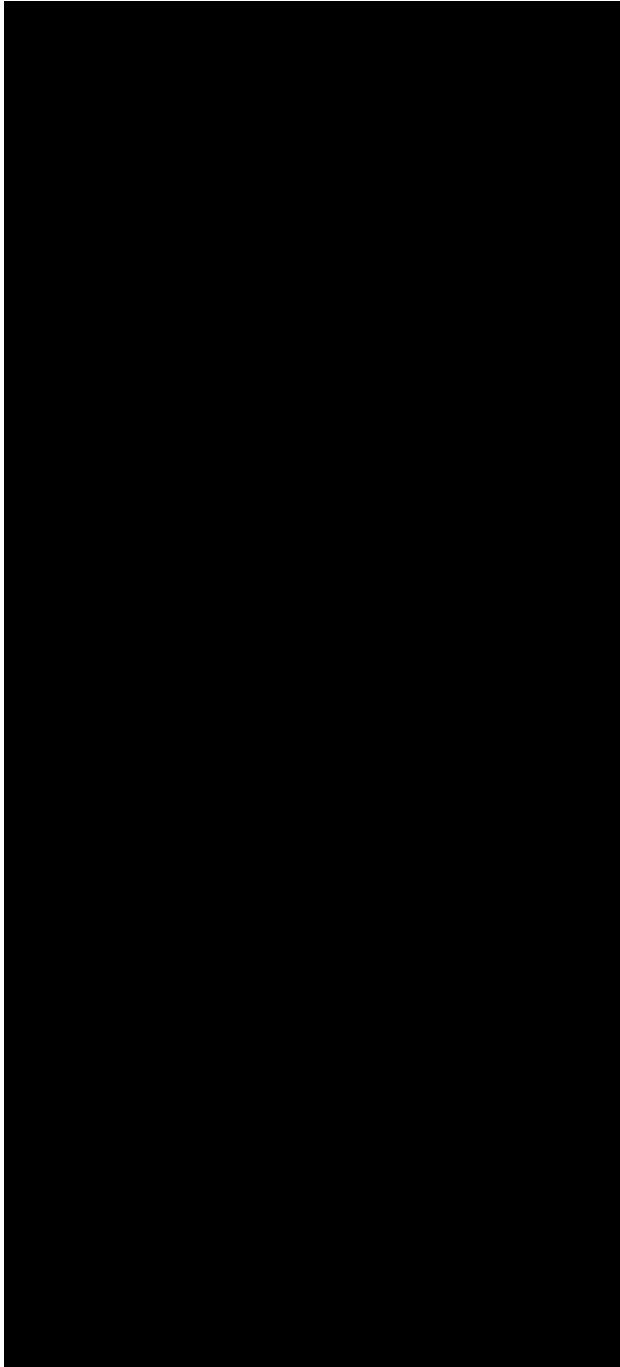
1.11.5.   Photograph Three: Mask

Freewrite: "this is a mask which I wear all the time in order to hide what's behind me" P3.

'Mask' shows what the participant describes as a traditional African mask. The mask may be a visual representation of the effects of public stigma, using a strong and traditional image as protection. The mask may also represent a

choice in regards to disclosing one's HIV status, however, the freewrite describes the mask as an object to 'hide' behind, which might suggest a lack of power, or lack of motivation to fight. Therefore, the second theme is most present in this photograph.
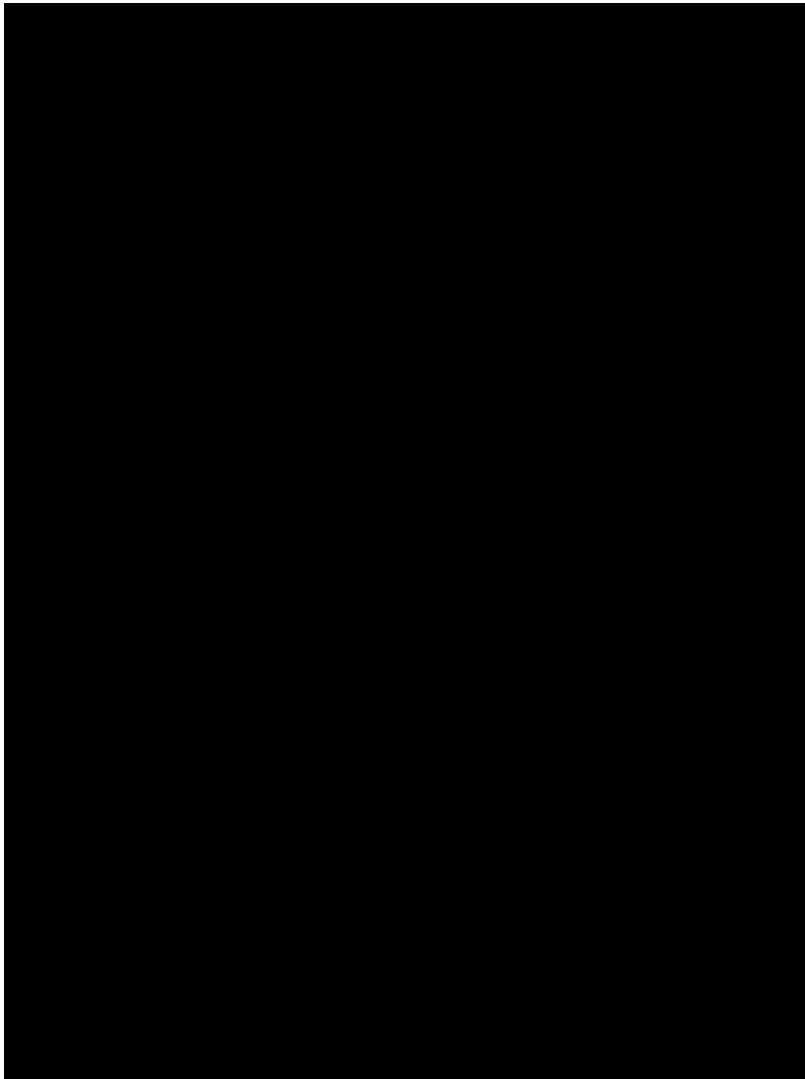
1.11.6.   <u>Photograph Four: Make Frida Proud</u>

Freewrite: "this image is very very special to my recovery, Frida Kahlo's books saved me, gave me strength, courage, my inspiration" P3.

'Make Frida proud' is an image of a Frida Kahlo exhibition poster. Kahlo here represents the participant's value of creativity and how one can contribute to society through art, even in times of adversity. The first theme is most present within this image and freewrite, as the participant is crediting the inspiration

offered by Kahlo and their shared values as 'saving' them. The image of Kahlo provides a reminder to the participant of the power one can have over their identity and the narrative of their identity, even as a woman dealing with chronic health issues.

1.11.7.   <u>Photograph Five: Blessed</u>

Freewrite: "I feel like I'm blessed with big big flower. God brought me here, to have a good life" P5.

'Blessed' is an image of several different plants, displayed together. The flower is 'good' which is the way the participant wants to live their life. Additionally, amongst all of the different plants within the photograph, the participant has chosen to present themselves through one flower, perhaps symbolising a favourable comparison between their life and other lives represented by the other plants. Theme one is apparent within this photograph as the participant's values and their desire to symbolise their journey are clear. The photograph is rather blurry, which may represent uncertainty, perhaps in the assertions that are made in the freewrite, and perhaps the participant struggles to fight for the power needed to control the narrative of their identity.

Four of the photographs and freewrites appear to have relevance to theme one. In 'phonebox', the photograph and the freewrite describe the telephone as a symbol of the participant being able to support others and the importance held of this value. In 'look both ways' the journey of the participant is represented. In 'make Frida proud', the image of Kahlo may represent the participant's values of creativity and how one can contribute to society through art, even in times of adversity, whilst the freewrite connects the image to the values held by the participant. Finally, in 'blessed', the flowers and plants represent the different ways the participant' s life could be, and the chosen flower symbolises a favourable life. Additionally, the photograph is blurry, which may represent that it is not always easy to hold onto values in times of adversity.

Three of the photographs and freewrites appear to reflect theme two. Firstly, in 'phonebox' the obvious lack of maintenance, shown by the dirt and the beer can, may symbolise how WLHIV feel about the support they receive from wider systems, perhaps particularly in their home countries. In 'look both ways' there is a latent threat of danger, which may represent how, by society not keeping up to date with relevant information, damage can be caused by systems or society to WLHIV. Perhaps the most striking image of how outdated messages affect WLHIV is 'mask': this is a very clear symbol and freewrite of hiding away and being aware of a lack of voice within systems.

The act of taking photographs, or deciding not to take photographs, may itself represent a way of retaining control over one's narrative. For the two participants who did not want to take photographs, this may represent feelings that images could not convey their identity, and an unwillingness to narrate their experiences through the lens of the researcher. For the participants who did provide photographs, they were able to provide images of their own choosing, with their own interpretation, which may have been at odds with some of their experiences with systems and structures in their lives. In 'phonebox', the participant's attitude that the phonebox is still vital to society, despite its disrepair and abuse it may have received, represents the participant's commitment to her values through a symbol of facilitating communication and support within a neglected community. The freewrite also demonstrates that the participant gives value to the WLHIV community as a whole, emphasising the contributions made to society. In 'look both ways' the sense of threat, or the degree of urgency conveyed may be an example of the importance of keeping control of one's narrative, in that the participant is emphasising that not acknowledging the WLHIV community could be bad for the whole of society. In the photograph and freewrite for 'mask', the participant has symbolised their identity through being able to choose to 'hide'. Here, the information regarding their HIV status is within their power to conceal or reveal as they decide fit, instead, they are choosing to display their heritage and creativity. Conversely, 'mask' may also represent not feeling able to control one's narrative, as the participant may feel that they are required to disclose their diagnosis in order to receive the support they need. In 'make Frida proud' the participant is showing the power of creativity inspired through adversity. In the freewite, the participant demonstrates their feelings of alignment with the life and work of Frida Kahlo, stating that this gives them strength. Finally, 'blessed' may be seen as an attempt to reframe the participant's experience as suffering from a chronic illness, to that of someone who is blessed, thus taking control of their narrative. However, even as the freewrite asserts the belief that the participant is intended to have a 'good life', the blurry nature of the photograph suggests some uncertainty.

Theme one is more apparent than theme two within the photographs and freewrites, perhaps due to the instructions given to the participants to capture their own identity, rather than how others, or society views them.

4. DISCUSSION

4.1. Overview

This chapter considers the findings of this exploratory study in the context of the initial aims and existing literature. A critical review of the research is presented, including consideration of both strengths and limitations. Next, a reflective account of the research process is given. The researcher's critical realist epistemological stance is reflected on throughout. Finally, implications of the research are suggested in terms of clinical practice, research and policy.

4.2. Situating the Research

Chapter One revealed a gap in the literature regarding the impact of HIV-related self-stigma on Black African WLHIV. It is important that clinicians, researchers and policy makers understand the strengths and difficulties within this population in order to design interventions, treatments and policies to support them. Therefore the aim of this study was to explore the impact of public and self-stigma on identity among Black African women living in London. Once the thematic analysis was completed for each data source, it was possible to answer the specific research questions posed in Section 1.11.

4.2.1. What. if any, experiences of stigma from others are reported by a sample of Black African women living with HIV in the UK?

It is clear from the codes and themes developed in this analysis that the sample of Black African women who participated in this research felt like they experienced stigmatising attitudes from others. All participants were aware of general negative attitudes towards P/WLHIV, such as a fear of contamination. They were also aware of, and had witnessed discriminatory behaviours from, their families and communities towards P/WLHIV. The participants spoke about

being exposed to these negative messages prior to receiving their diagnosis, and as such, it is possible that these messages and stereotypes provided the blueprint for what they expected their lives to be like after they received their diagnosis.

Specifically, regarding HIV-related stigma, all participants felt that outdated messages about HIV are still dominant, that they seem to underlie the public's negative attitudes towards PLHIV, and expressed frustration towards this situation. In contrast, participants generally expressed very positive attitudes towards the NHS and UK healthcare professionals, who they perceived to have up-to-date information regarding HIV treatment and transmission. This also contrasted with healthcare professional attitudes witnessed in the different African countries that the participants were from, and evidenced in the literature (Chambers et al., 2015). Furthermore, this is in contrast to some unhelpful behaviours that have been evidenced by some UK healthcare professionals, such as not listening to people with regards to medication or impact of symptoms, in relation to other stigmatising illness labels such as rheumatoid arthritis (Corker, 2015) and psychiatric diagnoses (Corker et al., 2013; Wahl & Aroesty-Cohen, 2010). However, during the member-checking process, one woman spoke about a nurse refusing to treat her, demonstrating stigmatising attitudes and discrimination towards her HIV status, within the UK from an NHS trained nurse. Although this was presented as an isolated example, and of course there was no way to check if the nurse in question had received up-to - date training regarding HIV, it serves to highlight how different experiences can be, between people and contexts, even when focussing on one diagnosis. Additionally, this suggests that negative attitudes can still exist within a context where education regarding HIV is mainly up-to-date, such as the NHS.

Stigmatising attitudes towards PLHIV were also reported within participants families, both in their home countries, in line with the literature (Loutfy et al., 2012) and in the case of one participant, in the UK. Again, in line with evidence in the literature, it was acknowledged by participants that these negative attitudes impact on community living within the UK (Earnshaw et al., 2015) and

impact particularly in religious settings (Otolok-Tanga et al., 2003). Negative attitudes that were perceived to exist in society towards PLHIV, as well as witnessing negative attitudes towards PLHIV, within the Black African community, influenced strategies regarding disclosure among the participants, in line with theories regarding anticipated stigma (Deacon, 2005), and found in practice by previous research (Arrey et al., 2015).

Three participants spoke about the importance of their role of being mothers, and in contrast to some literature (Lawson et al., 2013; Wagner et al., 2010), they had not experienced any judgement or negative attitudes towards them, even when their children had been born after their diagnosis. However, one participant spoke about her HIV status being the reason that she had not fulfilled a desired role to be a mother, which was a source of sorrow, and a grief was described for a family life and support system that has not been available.

All participants acknowledged different and worse attitudes and behaviours towards WLHIV compared to men, as described in previous literature (Bova, 2000; Downing & Roush, 1985; Sontag, 1991). These consisted of attitudes towards means of contracting HIV, along with attitudes related to contagion. These attitudes were usually communicated through 'gossip', which has been suggested to be a mode of transportation regarding allocation of blame for the HIV epidemic (Stadler, 2003). There was an understanding within this group of participants that gossip regarding HIV was specific to Black African communities and was particularly common amongst Black African women.

4.2.2.   What, if any, experiences of self-stigma do a sample of Black African women living with HIV in the UK experience towards themselves?

With regards to HIV-related self-stigma, there was limited support for the definitions presented in Chapter One of this thesis. Overall, there was no indication of internalising negative HIV attitudes (Pantelic et al., 2015; Stangl et al., 2012), or self-blame (National Network of Persons Living with HIV in Ghana et al., 2014). Furthermore, four of the participants expressed that they felt a responsibility to educate people regarding their experiences with HIV and share

more up-to-date public health messages such as U=U, which suggested a willingness to speak about living with HIV. However, in contrast to this, and in line with the theorised outcomes of experiencing self-stigma, all participants reported some secrecy and disclosure strategies regarding their HIV status (Anderson & Doyal, 2004; Arrey et al., 2015), particularly concerning family in the different African countries participants came from, which has been found in previous research with Black African WLHIV, living in the UK (Anderson & Doyal, 2004). In particular, this provides partial support for the 'negative self-perception' subscale of the HIV-stigma scale (Holzemer et al., 2007), due to the emphasis on disclosure. However, given that decisions regarding disclosure were framed as a response to the attitudes of other people, without internalising these negative attitudes, it becomes difficult to suggest that these decisions were part of experiencing HIV-related self-stigma, rather than anticipated stigma. Additionally, in line with some research (Lindayani et al., 2018), all participants reported experiencing negative feelings towards themselves and their HIV status at the time of their diagnosis, before any personal experience with public stigma. Of course, people will be aware of the negative stereotypes and attitudes regarding P/WLHIV prior to receiving a HIV diagnosis and personal experience of these attitudes (that is, experience of discrimination due to HIV status) would not be necessary to internalise negative attitudes, however, as there was no evidence within the transcripts that the participants believed that the negative stereotypes that they were aware of applied to themselves, there was little evidence of internalising these stigmatising attitudes at the time of the research (although some feelings of shame and distress were described at the time of diagnosis). Instead, the majority of participants reported positive attitudes and beliefs about themselves, in line with some research (Dibb & Kamalesh, 2012). Indeed, it could be that the renewed sense of connection with values, goals and beliefs that participants reported subsequent to their diagnosis, provided resilience against internalising these negative stereotypes, which would provide support for the concept of internalised stigma, without supporting the presence of it within this sample.

All the participants rejected the idea that the negative stereotypes described them, dismissing any potential personal impacts; they also denied that the stereotypes were accurate for any WLHIV, supporting literature suggesting that the denial of stereotypes links to the ability to resist the impact of stigma (Buseh & Stevens, 2007). This does not mean that having a HIV diagnosis has no impact on the participant's identity, however, this impact may be more in line with the personal narratives of the participants' lives, rather than internalising negative stereotypes. For example, one participant felt that her HIV diagnosis had interfered with several goals in her life, along with making it hard to maintain behaviour in line with her values. This participant described distress in regards to her diagnosis, however this distress did not seem to stem from accepting that negative stereotypes were applicable to herself, rather, that her sense of identity and narrative had been disrupted through barriers relating to her diagnosis that were stopping her from fulfilling her life goals, for example, to do with work. Indeed, this participant felt strongly that structures and systems set up within institutions in the UK were the cause of her frustrations, and attempts within theory to redirect the causes of this frustration internally may be reinforcing negative attitudes towards this community (Parker & Aggleton, 2003). This provides some support for the finding that work status and income were related to levels of self-stigma, rather than levels of public stigma in general (Tsai, 2015).

4.2.3. <u>How Do Any Stigma Experiences Impact on a Sample of Black African Women Living with HIV in Relation to their Perceived Identity as Black African Women?</u>

The stigma experiences relayed by this group of participants were expressed in relation to what they have witnessed in their home countries. The participants were all born in different African countries, and despite living in the UK for a number of years (mean = 19 years), they all had friends or family connections in these African countries. The stigma that the participants had either experienced personally, or witnessed in relation to HIV in general, impacted on their identity as Black African women in the following ways. Firstly, all of the participants indicated that they were unable to disclose their HIV status to most people in

their communities. This was because of the stigmatising attitudes they perceived to be common within these communities. Some of the participants stated that these attitudes also exist within the Black African communities living in London, and this impacted on decisions to disclose their status in the UK. Some of these attitudes specifically related to the perceived values and responsibilities that women have in Black African communities, and the participants felt that these attitudes, along with the perceived roles of women, were outdated. All of the participants expressed their concern about how stigmatising attitudes towards HIV in African countries were being expressed through discriminatory health policies and government priorities. The participants all stated that the medical support they receive in the UK is favourable in comparison to what they would expect to receive in their home countries. Therefore, there was a sense that the stigma experiences the participants had, impacted on their identity as Black African women by placing them outside of the communities in their home countries and sometimes, within the UK.

All participants identified as female. Although discussions regarding personally-held values were not explicitly framed within a gender context, there were some striking examples of gender related values such as caring and compassion for others (Beutel & Mooney, 1995; Longest et al., 2013), which appeared to impact on behaviours such as raising children, helping others and wanting to educate (Schwartz, 1993). The sense of responsibility present within theme one, which, although not explicitly spoken about in terms of gender, may be underpinned by messages in society that care-giving is, or should be, an important role for women. The efforts to ensure the maintenance, or even the effort to explicitly reject the value of, care-giving in relation to living with HIV, reflects the importance of this in the participants' identities. Additionally, receiving care, or support from others, including the healthcare service, is not taken for granted and is viewed as a privilege in comparison to the experience of people in the participants' home countries.

Caring and educating are also linked because of an expressed need to hold onto values related to fulfilling responsibilities. The descriptions of caring for, and educating others may be examples of how such tasks have been assigned to women without explicit acknowledgement, representing a burden of responsibility, outlined by feminist theorists (Friedan, 1963), that may be specific to the WLHIV experience, in contrast to men who are living with HIV. Understanding experiences from a critical realist stance, it is suggested that accepting or rejecting these sometimes implicit responsibilities will impact on the social and economic consequences for WLHIV (Williams, 1999).

All participants identified as Black African, and all had links to Black African communities within London. Connection with the participants' home countries, through family and friends was seen as important, alongside inclusion in community groups, that were not necessarily Black African (Salgado & Silva, 2018). In support of some previous work, the ability to speak English was viewed as essential (Schnittker, 2002) and in contrast to other work, at least two participants' had adopted a 'Western' name to help them integrate within London (Berry & Kim, 1988).

Another important aspect of identity for four of the participants was religion. Two participants identified as Christian, whilst two identified as Muslim. These participants described their religion in positive terms in relation to their identities, tying them in with other positively regarded values and expressing that finding strength through their faith was significant in the early stages of their diagnosis, as it helped them to make sense of the news. Despite the positive ways in which relationships with faith were expressed, none of the participants had disclosed their HIV status to the people within their local religious communities, due to beliefs around gossiping and general negative stereotypes held regarding WLHIV: this is significant for at least two reasons. Firstly, it represents a dichotomy between the positive impact that religion had on personal and social identity and the anticipated negative reaction from an important system within the participants' global identity. This may show that personal beliefs regarding religion are upheld in spite of the opinions of people within that

religion, and that personally identifying as a Christian or Muslim may be more important than being identified as part of a local religious group. Secondly, given the expressions of strength participants described from their religious beliefs and how this had helped them, participants may be missing out on potentially rich sources of social support by not disclosing to these groups. This suggests that the risks of disclosing outweighs the benefits for these participants; indeed, religious communities were described as having very stigmatising views towards WLHIV and the presence of anticipated stigma was suggested.

Therefore, several identities, both personal and social were expressed within the themes found in the analysis (for example, 'mother', 'positive', 'activist', 'fighter'), and these appeared to interact for the majority of the participants (Frable, 1997) to form a global identity. Overall, participants expressed satisfaction with their lives, however, one participant felt that their 'positive' status was holding back important aspects of their identity and was dissatisfied with this. Additionally, the ideas of traditional gender roles and negative attitudes held within society towards Black African identities may be playing more subtle roles that were not picked up on during the interviews or the thematic analysis with regards to ideas that may be upholding sexist and racist notions which may, in turn be compounded by a HIV diagnosis (McTaggart, 1991; Parker & Aggleton, 2003; Teti et al., 2012).

All five participants expressed that their personal values had not changed because of their HIV status, suggesting that life events did not detract from personal values, a question posed in previous research (Hitlin & Piliavin, 2004). Indeed, participants spoke about feeling more connected to their values as a way of structuring their lives than before their diagnosis. This could be interpreted as positive adjustment to their HIV status as found in previous research (Dibb & Kamalesh, 2012).

Four participants spoke about having to re-examine material goals in life, which included giving up work or education. This loss was a source of distress for the

participants and may be an example of how HIV reinforces sexist or racist notions (Parker & Aggleton, 2003) by placing Black African WLHIV in positions where they are unable to work.

Most participants made a number of comparisons regarding their identity as Black African WLHIV in London. Firstly, there was an acknowledgement of different and better treatment and better attitudes in general towards Black African WLHIV in the UK compared to being a Black African WLHIV in the African countries that the participants came from. This may have been expected, due to the literature that suggests negative attitudes are still prevalent regarding WLHIV in several African countries (Colbert et al., 2010; Sandelowski et al., 2004; Vyavaharkar et al., 2010). Additionally, most participants endorsed the message that HIV is a, 'disease like any other' (Odlind, 2018), commenting on advances made in the treatment of HIV such as ART. These attitudes are in contrast with what has been termed the 'new denial' regarding HIV (Ryan, 2015) in that, by equating the experience of PLHIV with other chronic illnesses, there is a denial of HIV-related stigma and discrimination, and its social and material consequences. Indeed, although participants appeared to find comfort in these messages, they were also aware of the unique positioning of a HIV diagnosis and the related negative attitudes within the general public and wider institutions, which may have reinforced participants' beliefs that education and accurate information regarding HIV is required to eliminate HIV-related stigma.

Limited support was found with regards to the Model of Ingroup as Social Resource (Correll & Park, 2005) within the current research. Participants valued the support offered to them through their integration with the charities. This was based on a shared idea that their identification as Black African WLHIV was cohesive and contained value. Group membership therefore, may have offered acceptance and some sense of positive self-evaluation. However, it is important to note that participants struggled to identify their ingroup through using the term 'HIV', perhaps reflecting that this label, which was not chosen by them, represents more negative attitudes and judgements, with which they do not

associate. Alternatively, the connecting factor of the ingroup and attached resourcefulness may not be viewed as the shared diagnosis between the participants. Instead, the shared experience of being a Black African woman living in London may be more salient and contain more useful resources. Additionally, it may be expected that people who attend services provided by a charity that exists to serve the needs of PLHIV would feel a sense of belonging; this positive self-evaluation may not be the case however, for PLHIV who do not have access to these services.

From a critical realist position, the descriptions that participants gave of the changing nature of experience, between individuals and cultures or societies, along with changes in the definition of HIV over time, reflects the human and social influences on the biological reality of a chronic illness (Williams, 1999). Furthermore, the interaction between the biological and social influences on the body and illness might reflect the micro and macro system influences on participants' lives. It is suggested that the personal and social identity of the participants has been and is continually influenced by the biological realities of, and personal and social responses to, living with HIV. The journey that the participants describe suggests that their sense of personal self as a Black African WLHIV may have excluded them from some of the social identities they held before receiving their diagnoses, which may have been valued ingroups (Correll & Park, 2005). However, their new ingroup, which was seemingly socially isolated at first, may have become more valued with the acceptance of support and recognition of their personal values from within the charities' services. In line with the stress, appraisal and coping theory (Lazarus & Folkman, 1984), and previous research (Vyavaharkar et al., 2010) participants who described access to social support tended to have positive attitudes towards themselves and their support system. A dynamic interplay between personal and social identity is presented here, as a strong sense of personal identity may be needed to underpin the social identity of living with HIV and the support offered from the social identity may provide validation for the personal identity. The retention of personal identity whilst facing adversity regarding the biological, psychological, social and material consequences of ill health has

been described as support for understanding illness and disability from a critical realist stance, rather than the more deterministic framework of positivism or, social models of disability, which may not allow for the interactions and influence of personal identities on illness experiences (Williams, 1996).

Individual differences between participants' identities that were discussed in the interviews also warrant reflection from a critical realist perspective. Of particular significance to the current sample was gender and ethnicity. Participants were aware of differences in their experiences of living with HIV compared to men, and of the negative attitudes regarding WLHIV within the Black African community. Previous literature may have failed to fully take into account the intersections of identity, including age, gender, social class and ethnicity, all of which are relevant when considering how social systems and biological factors relating to different people's bodies experience illness and disability (Williams, 1999). Unfortunately, this study was unable to fully isolate, or disentangle how, different aspects of self may be influencing identity in Black African WLHIV. However, this lack of evidence is not evidence that identity intersections are irrelevant in the experience of HIV, rather, that their complex interrelations were beyond the scope of this research. This further highlights the need to understand the meaning of chronic illness in terms of personal and social identity, not just the consequences, in order to understand how attitudes and behaviour may change in light of a diagnosis, which is one area where previous research has failed to give a full insight into living with HIV. Furthermore, although within the UK, the majority of HIV infections have occurred within the men who have sex with men population (Brown et al., 2017), within most African countries, most HIV infections occur within the heterosexual, and mainly female population (UN Women, 2018), suggesting that gender may impact on the experience of living with HIV in different ways between countries which needs to be acknowledged within research, clinical practice and policies.

4.3. Critical Review

The following sections discuss the use of the different elements of participatory action research and quality checks regarding validity, reflexivity, the role of the researcher, and rigor as outlined in Section 2.13.

4.3.1. Use of Participatory Action Research

One of the strengths of this project was the consideration and use of the core elements of participatory action research (see Section 2.4). Specifically, although collaboration between researchers and participants was not steering the research process as a whole, (Cassano & Dunlop, 2005; Chavez et al., 2003; Evans-Agnew & Rosemberg, 2016) members of the target population were consulted at each stage of the research: in the design stage, through consultation regarding formation of the research questions; during data collection by facilitation of different ways of participation; during data analysis through use of member checking (Barusch et al., 2011), using the feedback to refine the results and consulting participants regarding dissemination of results (McTaggart, 1991). Crucially, participants concerns were acknowledged regarding the photographs (Gross et al., 1988; Wang & Redwood-Jones, 2001) meaning that they were not displayed during the member-checking groups.

Recommendations from the voluntary and community sector in the UK, regarding recruiting 'hard to reach' populations, which include PLHIV and people from a Black or ethnic minority background (Flanagan & Hancock, 2010), into research, suggest that empowering involvement, attitudes of the researcher and flexibility are important (Flanagan & Hancock, 2010). The use of participatory action research and Photovoice and the attempts at relationship building went someway to meeting these suggestions.

Photovoice may offer an alternative 'way-in' with research regarding identity and stigma, contrasting with survey methods, or more traditional qualitative interview

techniques, in that, the researcher is not providing a definitional framework on which participants are expected to frame their experiences. Instead, participants are given a concept and asked to define it for themselves, perhaps giving a more accurate account of their experiences. Chapter One of this thesis found evidence suggesting that self-stigma is defined and measured by how negative attitudes held by the general public are endorsed as applying to oneself, and not disclosing the diagnosis to others and this definition persists, despite variability in the validity of the measures used. In the current research, the experience of a HIV diagnosis on identity did not necessarily match the definitions found through quantitative and qualitative methods, given in Chapter One, highlighting how there is not a clear definition of self-stigma in regards to a HIV diagnosis.

Despite some strengths, there were some potential concerns regarding the methodology of this piece of work, relating to its claims to be a participatory action research project (Wang & Burris, 1997), and claims that participatory action research empowers participants (Campbell, 2002). During the Photovoice workshops, the most common questions regarding the study concerned maintaining confidentiality and a worry that providing photographs may compromise anonymity and accidently reveal a person's HIV status. Although efforts were made to reassure potential participants that anonymity would be maintained, along with providing examples of previous Photovoice projects to demonstrate how photographs did not need to reveal identifying features, well over half of the women who attended the workshops decided not to participate, and two participants felt unable to provide photographs. This suggests that, although participatory action research methods in general and Photovoice in particular are designed to enhance collaboration and break down barriers between researchers and participants (Chavez et al., 2003; Ponterotto, 2005), perhaps this study was not received in this way by potential participants, possibly even being viewed as intrusive, raising questions regarding its claims to be a participatory action research piece of work. However, although it is acknowledged that the values and interests of the researcher informed the research process, and that the position of the researcher impacted on the

research conducted (McTaggart, 1991; Sitter, 2017), the structure of the interviews allowed participants to narrate their own experiences, which provided an opportunity to re-dress power imbalances created by the researcher/researched dichotomy (Cassano & Dunlop, 2005; Evans-Agnew & Rosemberg, 2016). Furthermore, photographs are viewed as an aid to communication (Spence, 1988) and may have allowed participants an opportunity to express beliefs and feelings beyond what can be captured with speech. This may have been particularly relevant for this group of participants, as English was not the first language for any of the sample, which meant that the photographs acted as a way to guard against experiences being 'lost in translation'. Additionally, ideas regarding social justice and social transformation (Sitter, 2017) were formulated by the participants and, although it is beyond the scope of the current project to implement these ideas, they may inform future research and policy development in this area (see Section 4.5). Although long-term engagement (Reza, 2007) is again beyond the scope of this project (see Section 2.3.2), the data collection and analysis were done respectfully and the time frame was made clear to the participants and relevant stakeholders. Finally, with regards to addressing power imbalances, it needs to be acknowledged that the researcher still held a position of a relatively non-disclosing and answer-seeking interviewer. Additionally, there are limitations with regards to how photographs can express further beliefs and feelings as the participants did not comment on the researcher's analysis.

As participants did not want to display their photographs to other people, critical dialogue regarding the strengths and challenges they represented between participants, viewed as a core element of Photovoice (Sitter, 2017), did not happen. However, through the semi-structured interviews, participants were able to engage in dialogue with the researcher, and the overall structure of the research allowed participants to define the strengths and challenges faced by WLHIV (Wang, 1999), which were discussed in the member-checking group. Comments made in the member-checking group discussion suggest that this was an empowering experience for some participants, as seen in previous research (Teti et al., 2012). The current research therefore perhaps achieved its

goal to describe some experiences within this community, and provided some ideas relating to social change.

It is notable that, despite care taken to ensure that the ethical nature of participants taking photographs of other people was covered in the Photovoice workshops, and acknowledgement from the participants of the importance of supportive people, no participants chose to take a photograph of themselves, or of someone that they knew. This may have been because the emphasis on consent and release forms within the Photovoice workshops may have been off-putting for participants, who decided to take photographs using alternative, non-human subjects, or not to take part at all. Alternatively, participants may have felt that their identities were best captured through photographs containing non-human subjects. Additionally, the analysis of the photographs was completed by the researcher, and was not subject to a member-checking process with the participants. Therefore, there is a risk that the analysis of photographs is subject to the researcher's biases and opinions, for example, with photograph five, 'blessed', the blurry image may just be the result of an unsteady hand.

4.3.2. Quality Checks: Validity

Due to the constraints on resources for this research, only one researcher reviewed the literature and performed the thematic analysis on the data sources. This could have introduced bias into both aspects, in that it is possible that studies were only included in the review if they contained evidence that, and the analysis only focussed on aspects that, the researcher expected or wanted to find (Dey, 1999). Efforts were made to ensure that conscious biases were kept out of the research. Firstly, multiple databases were searched for relevant papers using terms that were agreed on with the thesis supervisor. The research questions, along with the Photovoice methodology and workshops were produced in collaboration with a representative from the target population. The thematic analysis involved triangulation (Moran-Ellis, 2006; Willing, 2013), using the three data-sources and a negative case analysis (Barusch et al., 2011), comparing instances where opposing views were expressed. Member-checking was also utilised (Barusch et al., 2011), with responses from these

meetings fed back into the final themes, capturing details felt to be important by the target population. Unfortunately, the member-checking stage did not involve the person involved with formulating the research questions, as they had left the charity. While these processes do not eliminate the possibility of the presence of bias, they do go some way to ensure that the conclusions made are valid within the context of the research and the sample.

The concept of reciprocity was highlighted as important in Section 2.13.2 (Lather, 1986) in relation to this research. The researcher made concerted efforts to ensure that the experiences being described were understood and analysed in line with the participants' narrative, and interpretations made were subject to triangulation and member-checking processes. As the thematic analysis found evidence that was not in line with the current literature, this may be seen as an example of the researcher ensuring that the meaning and power of experiences described were not interpreted as simply confirmation of existing theories.

4.3.3. Quality Checks: Reflexivity and Role of the Researcher

The participatory action research approach, critical realist stance and latent level of analysis used in this piece of work allowed the researcher to interpret the data, going beyond the data in order to generate themes. It is therefore inevitable that the position of the researcher will impact on the data collected and the interpretation.

As stated in Section 2.13.4, my interest in this area stems from personal values held relating to social justice and gender equality. I had no previous experience of working with this population. Although I intentionally positioned myself as an ally by attending meetings, groups and lunches held by the charities and engaging in relationship building, I was conscious of my position being interpreted as a 'researcher' rather than as a 'collaborator' and I was keen to avoid any perpetuation of 'Westernised' dominance over participants' experiences (Chambers et al., 2018; Orr et al., 2002). Pre-clinical training, I had several years' experience as a researcher and it is possible that I slipped into

this familiar role, despite approaching this project very differently to previous work done. Additionally, I did not share many lived experiences with this population, and my initial questions to them may therefore have seemed clumsy or 'obvious', see Appendix 15 for an example of a 'learning by doing' reflective cycle (Gibbs, 1988) using personal reflexivity, which was used in discussion with my thesis supervisor. Finally, as my motivations for this project were explicitly political, in that I am interested in social change, this may have given an impression of access to power and privilege that were not shared within the population. Potential consequences of this positioning include potential participants deciding not to take part in the project, participants deciding not to expose their lives too much by not providing photographs and/or not speaking of their experiences fully during the interviews. These concerns were raised during the member-checking process, by asking if there were any blocks to participating that had not been addressed by the workshop, or by the researcher. Two members of the group who had attended the Photovoice workshop and decided not to take part said that their decision was made due to other priorities taking up their time. It may have been difficult for group members to criticise the approach taken by the researcher in regards to recruitment, in this forum of an open group at which the researcher was present. In the future, it may be more appropriate for feedback to be left with staff members of the charities or organisations involved with the research, see Appendix 16 for an example of a 'learning by doing' reflective cycle (Gibbs, 1988) using epistemological reflexivity.

4.3.4. Quality Checks: Rigour

Rigour may have different meanings across research using different methodologies and from different epistemological stances (Spencer & Ritchie, 2012). In terms of the current research, along with validity and reflexivity, rigour could refer to the transparency of the research, and considerations of safe conduct. Transparency in the research and analysis methods was achieved by outlining the research and aims in the Photovoice workshop, and providing PIS, consent forms and contact details of the researcher for the potential participants. Additionally, each stage of the analysis has been documented, and

Appendices 10-14 display the process. The safety of participants was of paramount importance throughout the research process. The Photovoice workshop provided details of how to stay safe when taking photographs, including the importance of consent when taking photographs of other people (see Appendix 6). Additionally, a distress protocol was designed (see Appendix 8) and shared with the charities involved in the research to ensure participants' safety during the interviews.

4.4. Research Limitations

4.4.1. <u>Limitations of the Literature Review</u>

There were a number of limitations of the literature review, presented in Chapter One, that need to be acknowledged. Due to the nature of the topic, the number of studies available and the type of data available, a scoping-type review of the literature was thought to be the most appropriate method of review. Systematic reviews and meta-analysis of data are thought to be the gold standard of evidence (Murad et al., 2016) and not using these methodologies may be seen as a limitation, especially because the decision was made not to review the quality of the studies found. However, it was decided that a systematic review and review of the quality of the studies would not be appropriate for this study, as the aim of the chapter was to provide a background and rationale for the research by assessing 'the lay of the land' around HIV-related self-stigma in Black African women (Colquhoun et al., 2014). Furthermore, it has been questioned whether positivistic, 'objective' methods of synthesising knowledge is the most appropriate way to understand complex psychological and social phenomena (Chambers et al., 2018).

Some factors within the literature search strategy may have hindered efforts to achieve the aim of the review. Time and resource limitations only allowed the ability to review literature written in English, which may have impacted on conclusions made regarding where research was being conducted and the nature of the literature itself (Chambers et al., 2018). However, some of the

research (n= 13) reviewed was conducted in non-English speaking countries. Although this may be viewed as an advantage for this review, there are problems to consider, such as whether this research was also disseminated in the dominant language of the country the work was conducted in. None of the reviewed papers specify if this happened and so the ethical questions of whether the results were fed back to the participants involved, or if and how the host communities were able to use the data collected remains unanswered (McLeod, 2007). Next, only two terms, 'internalised' (or 'internalized') and 'self-stigma' were used to search for papers. Although this decision was made in order to find an accurate overview of how these terms are used within the literature, it may have missed papers using different terms to describe this experience (see Section 1.3.3.) Again, although this decision was made for pragmatic reasons, it may have resulted in missing research that gave a more nuanced, perhaps even less 'Western-centric' perspective. Finally, due to the title of the research, it could also be argued that a more in-depth literature review could have been conducted regarding the concept of identity in Black African WLHIV. However, the decision to not include the term 'stigma' within the title of the project was intended to ensure that none of the promotional material relating to recruitment contained words that might lead participants into framing experiences within this construct and also to ensure that participants who did not feel that the construct of stigma applied to them (for instance, if they had not had any experience with stigma or discrimination) did not feel excluded from the research. This allowed participants to define their own experiences of how a HIV diagnosis had impacted on their identity, in line with the underlying aims of participatory action research (McTaggart, 1991), potentially allowing concerns and voices to be heard that have not been represented previously (Orr et al., 2002). Additionally, as stigma relates to ideas around a 'spoiled identity' (Goffman, 1963), it was felt that the constructs were linked to an extent that referring to both in the title may be redundant.

4.4.2. <u>Study Limitations</u>

Along with acknowledgements regarding the quality of the research presented, there are also a number of limitations within the study design that require reflection.

Perhaps the main limitation to this study was the relatively low sample size. Despite establishing communication with several charities across London, the total sample size was five participants representing four and a half hours of interview data and five photographs and freewrites. Although it was found that none of the participants had experienced an internalisation of the HIV-related stereotypes or beliefs that exist within society, as described by the literature, this may have been because the sample was not large enough to capture this experience, as self-stigmatising attitudes have been found in around a fifth of the lives of WLHIV (Lee, Kochman, & Sikkema, 2002; Lindayani, Ibrahim, Wang, & Ko, 2018; Simbayi et al., 2007; The People Living With HIV, 2015; Tsai, 2015). However, as the participants also failed to endorse the legitimacy of the negative stereotypes, it seems more likely that the process of internalising stigmatising attitudes was not being experienced by the sample, again supporting research suggesting that resisting the internalisation of stereotypes lessens the impact of stigma on the identities of Black African WLHIV (Buseh & Stevens, 2007).

With regards to the thematic analysis, the sample size raises questions regarding data saturation. It has been suggested that the minimum amount of interviews needed to achieve data saturation is six (Guest, 2006). However, during the coding stage of the thematic analysis it was noted that no new codes were used for the last interview to be analysed, suggesting that the low number of participants may not present a significant limitation to any conclusions drawn within the context of the sample. Additionally, the interviews represented a range of experiences from which similarities and contrasts could be found. However, it is acknowledged that a larger sample would have provided more validation for conclusions made regarding the current research.

The decision to recruit the study sample from within the charities connected to the HIV charity network meant that only women who had been in contact with NHS services were invited to participate and share their experiences. This was due to the charities' membership requirement that people need to provide medical evidence of their HIV status to access their services. This means that WLHIV, who are not accessing NHS services, did not have an opportunity to share their experiences regarding identity and stigma within this research. These experiences may have been very different to those women who are in contact with NHS services, particularly regarding the positive attitudes towards the NHS and healthcare professionals. Indeed, the literature suggests that experiences with stigma may impact on decisions to be tested for HIV and/or to access treatment services (Logie et al., 2016; Mbonu et al., 2010) and that institutional racism impacts on utilization of health services more generally (Cobbinah & Lewis, 2018). However, within the UK during 2017, it was estimated that 92% of PLHIV were aware of their HIV status, and that 98% of PLHIV who were aware of their status were receiving specialised HIV treatment (National AIDS Trust, 2018), suggesting that, regardless of the valence of the experience, the vast majority of PLHIV in the UK are accessing specialised services within the NHS. Additionally, it is possible that WLHIV who have engaged in charity support services may be more accepting and open regarding their HIV status than those who may be accessing NHS services, but do not access further support.

This research was conducted, in part, to address inequality within the literature regarding the experiences of WLHIV compared to the experiences of men who are living with HIV. Indeed, it has been estimated that there are twice as many Black African WLHIV than there are Black African men living with HIV in the UK (National AIDS Trust, 2014b). However, in doing so, this research has not attempted to account for the experiences of a large proportion of PLHIV (Brown et al., 2017). It is important that experiences of the different groups of PLHIV are explored and recorded to give nuanced and appropriate recommendations for treatment; historically by focussing on the male experience of living with HIV, women's health and lives were put at risk (Bova, 2000), therefore it is important

to state that the implications of this research are relevant only to the target population, and possibly only to the sample recruited. Further research is warranted to explore the differences and similarities between different groups of PLHIV, taking into account intersectionalities of identity (Burnham, 1992; Burnham, Alvis Palma, & Whitehouse, 2008) and inequalities faced by each group to ensure that services are offering appropriate treatment, and to further understand structural inequalities that may mean particular groups of people remain more likely to acquire a positive HIV status (Hatzenbuehler, Phelan, & Link, 2013; HIV Psychosocial Network, 2018; Parker & Aggleton, 2003). It is also important to acknowledge that the five women who made up the sample for this research may not represent the target population as a whole. This was highlighted in the member-checking group when different experiences regarding experiences with UK healthcare professionals were discussed. Additionally, in regards to the representativeness of this sample to the target population, although the average age of the participants' falls within the range at which the majority of Black African PLHIV are accessing treatment in the UK (National AIDS Trust, 2018) and the majority of the sample were unemployed, which has been documented in this population (National AIDS Trust, 2014b), the differences in individual and group level circumstances and experiences may outweigh any similarities both between the sample and the target population, and even between participants within the sample.

4.5. Implications and Recommendations

4.5.1. Clinical Implications

Some relevant clinical implications arise from this research. Overall, participants were happy with the way they had been treated by the NHS and healthcare professionals. No overt instances of stigma or discrimination were recorded by the participants in relation to their treatment in the UK, although this was questioned as a universal experience in the member-checking process. This was in contrast to what participants had witnessed in their different home countries. UK healthcare professionals were viewed as empathetic, sensitive

and well-informed regarding HIV and its treatment and participants viewed healthcare professionals as important allies.

The behaviour of healthcare professionals, along with the availability of HIV support services may have been important factors in developing resistance against the internalisation of negative stereotypes. Use of the 'understanding and challenging HIV stigma: toolkit for action', (Kidd & Clay, 2003) developed for use in hospitals in Africa, and used, with positive outcomes in both attitudes and behaviours in several countries (Oanh, Ashburn, Pulerwitz, Ogden, & Nyblade, 2008; Pulerwitz, Michaelis, Weiss, Brown, & Mahendra, 2010) has been recommended for use by the National AIDS Trust (National AIDS Trust, 2016). Given the mainly positive representation of healthcare professionals in this research, it may be helpful therefore, for clinicians to disseminate their knowledge and experience of working with Black African WLHIV to other sectors such as social care and social security by developing similar toolkits, designed to improve attitudes and behaviours and reduce structural elements of stigma that may exist within social institutions. Additionally, clinicians' knowledge and experience could be utilised to help design future public health education messages. In particular, in line with recommendations from the National Aids Trust, psychologists and other clinicians may be able to collaborate with Black African WLHIV to communicate the need for public health messages to go beyond the traditional scope of prevention, and include messages of how living with HIV may impact on a person's life, but should not exclude them from employment, community or family life (National AIDS Trust, 2018). Finally, positive relationships between healthcare professionals and PLHIV may improve engagement with treatment and services, thereby decreasing infection rates.

4.5.2. Research Implications

This was an exploratory study that was based on individual level experiences. Due to the nature of the HIV epidemic, the majority of research in this area has been conducted on a public health level, aimed at understanding the cognitions and behaviours that are associated with HIV. Research now needs to focus on

bringing these strands of exploration together, to understand how social, cultural and political contexts impact on individual experiences and wellbeing, and also how these experiences and contexts contribute to public health outcomes related to prevention and treatment, to foster social change, that is not viewed as the responsibility of PLHIV.

This research has led to a number of questions that require exploration. Firstly, how do the experiences described within this research compare to other groups of PLHIV? It is important to note similarities and differences within experiences so that interventions and treatments are not tailored to only benefit specific groups of people. It would be useful for researchers to compare the experience of stigma and discrimination across groups of people with different physical and psychiatric diagnoses labels, to understand any underlying attitudes or beliefs that could be related to why some populations within society remain more at risk of being diagnosed with chronic illnesses than others (Hatzenbuehler et al., 2013). This may help to uncover inequalities and structural violence being upheld within laws, policies or institutions (Lee, 2016). Next, it would be useful for research to identify the positive messages and/or training received by healthcare professionals and for these to be translated for use in other important contexts such as social care, social security and religious institutions. Research could also focus on if and how messages and training could be disseminated beyond the UK in an attempt to decrease the stigma and discrimination perceived to be prevalent. It would also be useful to perform audits within UK social care and social security institutions to uncover data relating to how information is shared across institutions and if this can be done more efficiently.

Although gender was discussed in relation to individual differences within the participants' interviews, the member-checking process raised the issue of how the menopause can impact on living with HIV, in terms of physical symptoms and societal responses. The menopause experience may bring together several different aspects of identity such as age, gender, ethnicity and social class (Kojic, Wang, & Cu-Uvin, 2007) and further investigations into this experience is

warranted, to further understand interactions between the intersectionalities of identity.

Research could determine the feasibility, practicality and effectiveness of the suggestions from participants that social change could be achieved both in their home countries and in the UK, through improving access to treatment and public education campaigns, both aimed at reducing levels of public stigma. These suggestions are in line with socio-cognitive theories of stigma reduction (National AIDS Trust, 2016), although they are in contrast with some evidence suggesting that increasing access to treatment may increase some aspects of public stigma (Roura et al., 2009). Additionally, participants also expressed a felt lack of power to influence social change because of their HIV status, along with other socially relevant identities such as gender and ethnicity, which together may be perpetuating existing negative attitudes (Parker & Aggleton, 2003) through layered stigmas (Reidpath & Chan, 2005), resulting in less access to power and more insecurities (Earnshaw et al., 2015; Grove et al., 1997; HIV Psychosocial Network, 2018; Logie et al., 2016). These feelings may have been underlying participants' desire for government run education campaigns, as government is seen to have a legitimate, high powered status within the UK, along with access to resources.

Further research that does not rely on a cognitive theory that seeks to confirm or deny stereotypes, using more collaborative, and narrative techniques could be utilised to design interventions for the reduction of HIV-related public stigma, perhaps taking into account the social contact hypothesis (Corrigan & Penn, 1999).

Finally, as participants were describing differences in their experiences between the time of their diagnosis and the time of the interview, it would be useful to conduct a study either tracking or comparing participants' experiences throughout the course of their illness.

4.5.3. Policy Implications

There are potential policy implications arising from this work. Following improvements in the diagnosis and treatment of HIV and in line with recommendations from the National AIDS Trust (National AIDS Trust, 2016), and conclusions from the HIV Psychosocial Network (HIV Psychosocial Network, 2018), interventions intended to reduce HIV-related stigma and discrimination should be designed, delivered and evaluated in collaboration with Black African WLHIV, along with other groups of PLHIV. Additionally, the UK government and the Equality and Human Rights Commission should increase awareness of the Equality Act 2010 and what this means for employers, and public bodies in relation to Black African WLHIV. The government should also review the impact of laws and policies on people at increased risk of HIV, including Black African communities and take steps to reduce structural inequalities experienced within this group.

From a critical realist stance, policy needs to reflect that living with HIV is both a biological and social reality, and that these realities influence each other dynamically, within relevant political contexts of, for example, austerity, or even U=U. The absence of a disability as defined by the Work Capability Assessment (Centre for Health and Disability Assessments, 2019), or having a viral load which is undetectable is not the absence of an illness itself, the real physical body which is affected with real biological illness, or the real pain that has real consequences (Williams, 1999). Additionally, the findings related to frustration with social systems, benefits and employment within this study are in line with conclusions made by the HIV Psychosocial Network, regarding the impact of the period of 'austerity' in UK public spending from 2008. They suggest that overall funding cuts in medical and social care budgets, along with a lack of understanding regarding intersectional issues affecting PLHIV have contributed to a more 'hostile' overall environment due, in part, to problems of unemployment and with benefits or social support (HIV Psychosocial Network, 2018). Developing policies within the integrated care systems and partnerships frameworks (Ham, 2018) may be important for realising a collaborative health and social system, which may be better positioned to understand and provide

for, the needs of Black African WLHIV. This is also in line with recommendations made by the HIV Psychosocial Network (HIV Psychosocial Network, 2018).

4.6. Conclusion

Despite some limitations and quality concerns, this piece of research can conclude the following.

Having a HIV diagnosis may impact on the identity of Black African WLHIV by increasing connections to their values, beliefs and goals. Social or structural barriers imposed due to a HIV diagnosis may impact on behaving in line with these values which may perpetuate discriminatory social and economic structures and exclude Black African WLHIV from several areas of life such as work, community, family and religious settings.

There is awareness of the negative beliefs and attitudes regarding Black African WLHIV that exist within society, which, although not seen as legitimate nor endorsed, may be a reason for not fully connecting with the idea of 'living with HIV' as a valued, resourceful ingroup. The outdated beliefs held by society may impact on PLHIV as they seek to reconcile these historical images and messages with their own experiences. The support received though the healthcare and charity services in the UK are viewed as instrumental in this process.

This research begins to demonstrate how identity can interact with an illness diagnosis. This highlights that clinical practice, research, interventions and policy aimed at increasing well-being or levels of treatment uptake need to be sensitive to the needs of people who may hold different beliefs and values, whilst acknowledging that existing structures may be harmful for those who are are most at risk from developing chronic illnesses.

5. REFERENCES

Amuyunzu-Nyamongo, M., Okeng'o, L., Wagura, A., & Mwenzwa, E. (2007). Putting on a brave face: The experiences of women living with HIV and AIDS in informal settlements of Nairobi, Kenya. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, *19*(1), 25–34.

Anderson, J., & Doyal, L. (2004). Women from Africa living with HIV in London: a descriptive study. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, *16*(1), 95–105.

Aronson, J. (1994). A pragmatic view of thematic analysis. *The Qualitative Report*, *2*, 3.

Arrey, A., Bilsen, J., Lacor, P., & Deschepper, R. (2015). "It's my secret": fear of disclosure among sub-Saharan African migrant women living with HIV/AIDS in Belgium. *PLoS ONE*, *10*(3), 1–22.

Barusch, A., Gringeri, C., & George, M. (2011). Rigor in qualitative social work research: a review of strategies used in published articles. *Social Work Research*, *35*, 11–19.

Berger, B., Ferrans, C., & Lashley, R. (2001). Measuring stigma in people with HIV: psychometric assessment of the HIV stigma scale. *Research in Nursing & Health*, *24*(6), 518–529.

Berry, J., & Kim, U. (1988). Acculturation and mental health. In P. Dasen, J. Berry, & N. Sartorius (Eds.), *Health and cross-cultural psychology* (pp. 207–236). Newbury Park: CA: SAGE.

Beutel, A., & Mooney, M. (1995). Gender and values. *American Sociological Review*, *60*(3), 436–448.

Bhaskar, R. (1975). *A realist theory of science*. London: Verso.

Blackman, A., & Fairley, T. (2007). The PhotoVoice manual: a guide to designing and running participatory photography projects. London: The PhotoVoice Network.

Bova, C. (2000). Women with HIV infection: the three waves of scientific inquiry. *Journal of the Association of Nurses in AIDS Care*, *11*(5), 19–28.

Boyatzis, R., E. (1998). *Transforming qualitative information: thematic analysis and code development*. Thousand Oaks, CA: Sage.

Boyd, G. M. (1987). Reagan urges abstinence for young to avoid AIDS.
Retrieved July 6, 2018, from:
https://www.nytimes.com/1987/04/02/us/reagan-urges-abstinence-for-
young-to-avoid-aids.html

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology.
Qualitative Research in Psychology, 37–41.

British HIV Association. (2017). BHIVA endorses "Undetectable equals
Untransmittable" (U=U) consensus statement. Retrieved December 19,
2018, from https://www.bhiva.org/BHIVA-endorses-U-U-consensus-
statement

Bronfenbrenner, U. (1993). Ecological models of human development. In M.
Gauvain & M. Cole (Eds.), *International encyclopedia of education* (2nd
ed., pp. 37–43). New York: Freeman.

Brown, A., Kirwan, P., Chau, C., Khawam, J., Gill, O., & Delpech, V. (2017).
*Towards elimination of HIV transmission, AIDS and HIV-related deaths in
the UK*. London.

Bunting, S. M. (1996). Sources of stigma associated with women with HIV.
Advances in Nursing Science, *19*(2), 64–73.

Burnham, J. (2013). Developments in Social GGRRAAACCEEESSS: visible-
invisible, voiced-unvoiced. In Krause (Ed.), *Cultural reflexivity*. London:
Karnac.

Burnham, J. (1992). Approach-method-technique: making distinctions and
creating connections. *Human Systems: The Journal of Systemic
Consultation & Management*, *3*(1), 3–26.

Burnham, John, Alvis Palma, D., & Whitehouse, L. (2008). Learning as a
context for differences and differences as a context for learning. *Journal of
Family Therapy*, *30*(4), 529–542.

Burwell-Chen, A. (2015). *How to be a good ally: a guide to dismantling
colorblidness, white normativity and everyday racism without erasing
oppressed voices* (Masters dissertation). Portland State University,
Portland, US.

Buseh, A. G., & Stevens, P. E. (2007). Constrained but not determined by
stigma: resistance by African American women living with HIV. *Women &*

Health, *44*(3), 1–18.

Campbell, C., & Deacon, H. (2006). Unravelling the contexts of stigma: from internalisation to resistance to change. *Journal of Community & Applied Social Psychology*, *16*(6), 411–417.

Campbell, J. (2002). A critical appraisal of participatory methods in development research. *International Journal of Social Research Methodology*, *5*(1), 19–29.

Cassano, D. R., & Dunlop, J. M. (2005). Participatory action research with south Asian immigrant women: a Canadian example. *Critical Social Work*, *6*(1), 56–66.

Catalani, C., & Minkler, M. (2010). Photovoice: a review of the literature in health and public health. *Health Education and Behavior*, *37*(3), 424–451.

Centre for Health and Disability Assessments. (2019). Work capability assessment handbook: for healthcare professionals. London: UK.GOV.

Centres for Disease Prevention and Control. (2018). Let's Stop HIV Together. Retrieved September 26, 2018, from https://www.cdc.gov/actagainstaids/campaigns/lsht/index.html

Chambers, L. A., Jackson, R., Worthington, C., Wilson, C. L., Tharao, W., Greenspan, N. R., Masching, R., Pierre-Pierre, V., Mbulaheni, T., Amirault, M., & Brownlee, P. (2018). Decolonizing scoping review methodologies for literature with, for, and by indigenous peoples and the african diaspora: dialoguing with the tensions. *Qualitative Health Research*, *28*(2), 175–188.

Chambers, L. A., Rueda, S., Baker, D. N., Wilson, M. G., Deutsch, R., Raeifar, E., Rourke, S., Adam, B., Bacon, J., Cairney, J., Husbands, W., Jackson, R., Jolly, R., Li, A., Logie, C., Noh, S., Millson, P., Strike, C., Tharao, W.,& Travers, R. (2015). Stigma, HIV and health: A qualitative synthesis. *BMC Public Health*, *15*(1), 1–17.

Chavez, V., Duran, B., Baker, Q., Avila, M., & Wallerstein, N. (2003). The dance of race and privilege in community based participatory research. In M. Minkler & N. Wallerstein (Eds.), *Community –based participatory research for health* (pp. 81–97). San Francisco: John Wiley & Sons.

Chevalier, J., & Buckles, D. (2013). *Participatory action research: theory and methods for engaged inquiry*. London and New York: Routledge.

Cobbinah, S. S., & Lewis, J. (2018). Racism & health: A public health perspective on racial discrimination. *Journal of Evaluation in Clinical Practice*, *24*(5), 995–998.

Cohen, M., Deamant, C., Barkan, S., Richardson, J., Young, M., Holman, S., Anastos, K., Cohen, J., & Melnick, S. (2000). Domestic violence and childhood sexual abuse in HIV-infected women and women at risk for HIV. *American Journal of Public Health*, *90*(4), 560–565.

Colbert, A., Kim, K., Sereika, S., & Erlen, J. (2010). An examination of the relationships among gender, health status, social support, and HIV-related stigma. *Janac-Journal of the Association of Nurses in Aids Care*, *21*(4), 302–313.

Colquhoun, H. L., Levac, D., O'Brien, K. K., Straus, S., Tricco, A. C., Perrier, L., Kastner, M., & Moher, D. (2014). Scoping reviews: time for clarity in definition, methods, and reporting. *Journal of Clinical Epidemiology*, *67*(12), 1291–1294.

Connell, R. W. (1987). *Gender and power, society, the person and sexual politics*. UK: Blackwell Publishing.

Corker, E. (2015). *The effects of self stigma on self-esteem and empowerment in people with a psychiatric diagnosis or rheumatoid arthritis* (Unpublished doctroal thesis) Insitiute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK.

Corker, E., Hamilton, S., Henderson, C., Weeks, C., Pinfold, V., Rose, D., Williams, P., Flach, C., Lewis-Holmes, E., & Thornicroft, G. (2013). Experiences of discrimination among people using mental health services in England 2008-2011. *The British Journal of Psychiatry. S55*, S58-63.

Correll, J., & Park, B. (2005). A model of the ingroup as a social resource. *Personality and Social Psychology Review*, *9*(4), 341–359.

Corrigan, P W., River, L. P., Lundin, R. K., Wasowski, K. U., Campion, J., Mathisen, J., Goldstein, H., Gagnon, M., & Kubiak, M. (2000). Stigmatizing attributions about mental illness. *Journal of Community Psychology*, *28*(1), 91–102.

Corrigan, P W, & Penn, D. L. (1999). Lessons from social psychology on discrediting psychiatric stigma. *The American Psychologist*, *54*, 765–776.

Corrigan, Patrick W, Markowitz, F. E., & Watson, A. C. (2004). Structural levels of mental illness stigma and discrimination. *Schizophrenia Bulletin*, *30*(3), 481–491.

Corrigan, Patrick W, Watson, A. C., & Barr, L. (2006). The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology*, *25*(8), 875–884.

Cuca, Y. P., Onono, M., Bukusi, E., & Turan, J. M. (2012). Factors associated with pregnant women's anticipations and experiences of HIV-related stigma in rural Kenya. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, *24*(9), 1173–1180.

Dakin, E. K., Parker, S. N., Amell, J. W., & Rogers, B. S. (2015). Seeing with our own eyes: youth in Mathare, Kenya use photovoice to examine individual and community strengths. *Qualitative Social Work*, *14*(2), 170–192.

Daniel, H., & Parker, R. (1990). Brazil: The goal of solidarity. In *The 3rd epidemic: repercussions of the fear of AIDS* (pp. 154–160). London: Panos Institute.

Dassah, E., Aldersey, H. M., & Norman, K. E. (2017). Photovoice and persons with physical disabilities: a scoping review of the literature. *Qualitative Health Research*, *27*(9), 1412–1422.

De Wet, K., & Wouters, E. (2016). Identity and the body: narrative accounts of two HIV-positive women with lipodystrophy in post-apartheid South Africa. *Social Theory and Health*, *14*(3), 351–371.

Deacon, H. (2005). *Understanding HIV/AIDS stigma: a theoretical and methodological analysis*. Cape Town: Human Sciences Research Council.

Dey, I. (1999). *Grounding grounded theory:guidlines for qualitative inquiry*. London: Academic Press.

Dibb, B., & Kamalesh, T. (2012). Exploring positive adjustment in HIV positive African women living in the UK. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, *24*(2), 143–148.

Downing, N. E., & Roush, K. L. (1985). From passive acceptance to active commitment a model of feminist identity development for women. *Counseling Psychologist*, *13*(4), 695–709.

Duffy, L. (2005). Suffering, shame, and silence: the stigma of HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, *16*(1), 13–20.

Earnshaw, V., Bogart, L. M., Dovidio, J. F., & Williams, D. R. (2015). Stigma and racial/ethnic HIV disparities: moving toward resilience. *Stigma and Health*, *1*(1), 60–74.

Evans-Agnew, R., & Rosemberg, M. (2016). Questioning photovoice research: whose voice? *Qualitative Health Research*, *26*(8), 1019–1030.

Evans-Lacko, S., Corker, E., Williams, P., Henderson, C., & Thornicroft, G. (2014). Effect of the time to change anti-stigma campaign on trends in mental-illness-related public stigma among the english population in 2003-13: An analysis of survey data. *The Lancet Psychiatry*, *1*(2).

Festinger, L. (1954). A Theory of social comparison processes. *Human Relations*, *7*(2), 117–140.

Flanagan, S. M., & Hancock, B. (2010). 'Reaching the hard to reach'- lessons learned from the VCS (voluntary and community Sector.) A qualitative study. *BMC Health Services Research*, *10*(92), 1–9.

Frable, D. (1997). Gender, racial, ethnic, sexual, and class identities. *Annual Review of Psychology*, *48*(1), 139–162.

Freire, P. (1974). *Education for Critical Consciousness*. New York: Seabury Press.

Friedan, B. (1963). *The feminine mystique*. New York: W.W. Norton & Company.

Geary, C., Parker, W., Rogers, S., Haney, E., Njihia, C., Haile, A., & Walakira, E. (2014). Gender differences in HIV disclosure, stigma, and perceptions of health. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, *26*(11), 1419–1425.

Gibbs, G. (1988). *Learning by doing: a guide to teaching and learning methods. Oxford Brookes University*. Oxford: Further Education Unit.

Gibson, C. (2015). A disturbing new glimpse at the Reagan administration's indifference to AIDS. Retrieved July 5, 2018, from https://www.washingtonpost.com/news/arts-and-entertainment/wp/2015/12/01/a-disturbing-new-glimpse-at-the-reagan-administrations-indifference-to-

aids/?noredirect=on&utm_term=.76ad46dd2622

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.

Gleeson, K. (2011). Polytextual thematic analysis for visual data: pinning down the analytic. In P. Reavey (Ed.), *Visual methods in psychology: using and interpreting images in qualitative research* (pp. 314–329). East Sussex, UK: Psychology Press.

GNP+, & NEPWHAN. (2011). *The people living with HIV stigma index Nigeria Country Assessment*. Amsterdam.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New Jersey: Prentice Hall.

Gross, L., Katz, J. S., & Ruby, J. (Eds.). (1988). *Image ethics*. New York: Oxford University Press.

Grove, K. A., Kelly, D. P., & Liu, J. (1997). "But nice girls don't get It" women, symbolic capital and social construction of AIDS. *Journal of Contemporary Ethnography*, *26*(3), 317–337.

Guest, G. (2006). How many interviews are enough?: an experiment with data saturation and variability. *Field Methods*, *18*(1), 59–82.

Ham, C. (2018). *Making sense of integrated care systems, integrated care partnerships and accountable care organisations in the NHS in England*. London.

Hannay, J., Dudley, R., Milan, S., & Leibovitz, P. K. (2013). Combining photovoice and focus groups: engaging Latina teens in Community Assessment. *American Journal of Preventative Medicine*, *44*(3), S215–S224.

Hardeman, R. R., Murphy, K. A., Karbeah, J., & Kozhimannil, K. B. (2018). Naming Institutionalized Racism in the Public Health Literature: A Systematic Literature Review. *Public Health Reports*, *133*(3), 240–249.

Hatzenbuehler, M. L., Phelan, J. C., & Link, B. G. (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health*, *103*(5), 813–821.

Henderson, C., & Thornicroft, G. (2009). Stigma and discrimination in mental illness: Time to Change. *The Lancet*, *373*, 1928.

Herek, G. M. (1999). AIDS and stigma. *American Behavioral Scientist*, *42*(7), 1106–1116.

Herek, G. M., Saha, S., & Burack, J. (2013). Stigma and psychological distress in people with HIV/AIDS. *Basic and Applied Social Psychology*, *35*(1), 41–54.

Hitlin, S. (2003). Values as the core of personal identity: drawing links between two theories of self. *Social Psychology Quarterly*, *66*(2), 118–137.

Hitlin, S., & Piliavin, J. A. (2004). Values: reviving a dormant concept. *Annual Review of Sociology*, *30*(1), 359–393.

HIV.gov. (2017). What are HIV and AIDS? Retrieved September 25, 2018, from https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/what-are-hiv-and-aids

HIV Prevention England. (2018). It starts with me. Retrieved September 26, 2018, from https://www.startswithme.org.uk/

HIV Psychosocial Network (2018a). HIV Psychosocial Network UK. Retrieved Febuary 2 2018, from https://hivpsychosocialnetworkuk.tumblr.com/

HIV Psychosocial Network. (2018). *Ten years after: an 'austerity audit'of services and living conditions for people living with HIV in the UK, a decade after the financial crisis.* London.

Holtby, A., Klein, K., Cook, K., & Travers, R. (2015). To be seen or not to be seen: Photovoice, queer and trans youth, and the dilemma of representation. *Action Research*, *13*(4), 317–335.

Holzemer, W. L., Uys, L. R., Chirwa, M. L., Greeff, M., Makoae, L. N., Kohi, T. W., Stewart, A., Mullan, J., Phetlhu, R., Wantland, D., & Durrheim, K. (2007). Validation of the HIV/AIDS stigma instrument-PLWA (HASI-p). *Aids Care-Psychological and Socio-Medical Aspects of Aids/Hiv*, *19*(8), 1002–1012.

Holzemer, W., Uys, L., Makoae, L., Stewart, A., Phetlhu, R., Dlamini, P., Greeff, M., Kohi, T., Chirwa, M., Cuca, Y., & Naidoo, J. (2007). A conceptual model of HIV/AIDS stigma from five African countries. Retrieved from

Hunt, X., Braathen, S. H., Swartz, L., Carew, M. T., & Rohleder, P. (2018). Intimacy, intercourse and adjustments: experiences of sexual life of a group of people with physical disabilities in south africa. *Journal of Health*

Psychology, *23*(2), 289–305.

Jefferson, G. (1984). *Caricature versus detail: on capturing the particulars of pronunciation in transcripts of conversational data* (Tilberg Papers on Language and Literature No. 31).

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2015). *On the Fast-Track to end AIDS 2016-2021 Stratergy*.

Joint United Nations Programme on HIV/AIDS (UNAIDS). (2017). *UNAIDS Data 2017*.

Kalichman, S., Simbayi, L., Cloete, A., Mthembu, P., Mkhonta, R., & Ginindza, T. (2009). Measuring AIDS stigmas in people living with HIV/AIDS: the internalized AIDS-related stigma scale. *AIDS Care*, *21*(1), 87–93.

Kalichman, S., Simbayi, L., Jooste, S., Toeft, Y., Cain, D., & Cherry, C. (2005). Development of a brief scale to measure AIDS-related stigmas in South Africa. *Aids and Behavior*, *9*(2), 135–143.

Kidd, R., & Clay, S. (2003). *Understanding and challenging HIV stigma: toolkit for action*. Washington, DC.

Kirwan, P., Chau, C., Brown, A., Gill, O., & Delpech, V. (2016). *HIV in the UK - 2016 report*. *Public Health England*. Retrieved from www.gov.uk/phe%0Awww.gov.uk/phe

Knaus, C. B. (2009). Shut up and listen: applied critical race theory in the classroom. *Race Ethnicity and Education*, *12*(2), 133–154.

Kojic, E., Wang, C., & Cu-Uvin, S. (2007). HIV and menopause: a review. *Journal of Women's Health*, *16*(10), 1402–1411.

Lather, P. (1986). Research as praxis. *Harvard Educational Review*, *56*(3), 257–277.

Lawson, K. L., Bayly, M., & Cey, E. (2013). Judgements regarding the acceptability of childbearing and parental fitness made towards women living with HIV. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, *25*(6), 676–679.

Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal, and Coping. New York*.

Lee, B. X. (2016). Aggression and violent behavior causes and cures VII: structural violence. *Aggression and Violent Behavior*, *28*(2), 109–114.

Lee, R. S., Kochman, A., & Sikkema, K. J. (2002). Internalized stigma among

people living with HIV-AIDS. *AIDS and Behavior, 6*(4), 309–319.

Lindayani, L., Ibrahim, K., Wang, J., & Ko, N. (2018). Independent and synergistic effects of self- and public stigmas on quality of life of HIV-infected persons. *AIDS Care, 30*(6), 706–713.

Logie, C. H., Jenkinson, J. I. R., Earnshaw, V., Tharao, W., & Loutfy, M. R. (2016). A structural equation model of HIV-related stigma, racial discrimination, housing insecurity and wellbeing among African and Caribbean Black women living with HIV in Ontario, Canada. *PLoS ONE, 11*(9), 1–20.

Longest, K., Hitlin, S., & Vaisey, S. (2013). Position and disposition: the contextual development of human values. *Social Forces, 91*(4), 1499–1528.

Loutfy, M., Logie, C., Zhang, Y., Blitz, S. L., Margolese, S., Tharao, W., Rourke, S., Rueda, S., & Raboud, J. (2012). Gender and ethnicity differences in HIV-related stigma experienced by people living with HIV in Ontario, Canada. *PLoS ONE, 7*(12), 1–10.

Loutfy, M., Tharao, W., Logie, C., Aden, M. A., Chambers, L. A., Wu, W., Abdelmaseh, M., & Calzavara, L. (2015). Systematic review of stigma reducing interventions for African/Black diasporic women. *Journal of the International AIDS Society, 18*(1), 1–7.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology, 91*(1), 1–20.

Mak, W., Cheung, R., Law, R., Woo, J., Li, P., & Chung, R. (2007). Examining attribution model of self-stigma on social support and psychological well-being among people with HIV+/AIDS. *Social Science & Medicine, 64*(8), 1549–1559.

Maman, S., Campbell, J., Sweat, M., & Gielen, A. (2000). The intersections of HIV and violence: directions for future research and interventions. *Social Science and Medicine, 50*(4), 459–478.

Mann, J. M. (1988). Statement at an informal briefing on AIDS to the 42nd session of the United Nations general assembly. *Journal of the Royal Statistical Society Series A (Statistics in Society), 151*(1), 131–136.

Mawar, N., Saha, S., Pandit, A., & Mahajan, U. (2005). The third phase of HIV pandemic: social consequences of HIV/AIDS stigma & discrimination & future needs. *Indian Journal of Medical Research*, *122*(6), 471–484.

May, M., Gompels, M., Delpech, V., Porter, K., Orkin, C., Kegg, S., Hay, P., Johnson, M., Palfreeman, A., Gilson, R., Chadwick, D., Martin, F., Hill, T., Walsh, J., Post, F., Fisher, M., Ainsworth, J., Jose, S., Leen, C., Nelson, M., Anderson, J., & Sabin, C. (2014). Impact on life expectancy of HIV-1 positive individuals of CD4 R cell count and viral load response to antiretroviral therapy. *AIDS*, *28*(8), 1193–1202.

Mbonu, N., Van Den Borne, B., & De Vries, N. (2010). Gender-related power differences, beliefs and reactions towards people living with HIV/AIDS: An urban study in Nigeria. *BMC Public Health*, *10*(1), 1–10.

McLeod, N. (2007). *Cree narrative memory: from treaties to contemporary times*. Saskatoon: Purich Pub.

McTaggart, R. (1991). Principles for participtory action reasearch. *Adult Education Quarterly*, *41*(3), 168–187.

Mill, J. E. (2001). I'm not a "Basabasa" woman: an explanatory model of HIV illness in Ghanaian women. *Clinical Nursing Research*, *10*(3), 254–274.

Mill, J., Edwards, N., Jackson, R., MacLean, L., & Chaw-Kant, J. (2011). Stigmatization as a social control mechanism for persons living with HIV and AIDS. *Qualitative Health Research*, *20*(11), 1469–1483.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement (reprinted from annals of internal medicine). *PLoS Medicine*, *89*(9), 873–880.

Moran-Ellis, J. (2006). Triangulation and integration: processes, claims and implications. *Qualitative Research*.

Morse, J. M. (1995). The significance of saturation. *Qualitative Health Research*, *5*(2), 147–149.

Mukolo, A., Torres, I., Bechtel, R. M., Sidat, M., & Vergara, A. E. (2013). Consensus on context-specific strategies for reducing the stigma of human immunodeficiency virus/acquired immunodeficiency syndrome in Zambézia Province, Mozambique. *Sahara J: Journal of Social Aspects of HIV/AIDS*,

10(3–4), 119–130.

Murad, M., Asi, N., Alsawas, M., & Alahdab, F. (2016). New evidence pyramid. *Evidence Based Medicine*, *21*(4), 125–126.

Musheke, M., Merten, S., & Bond, V. (2016). Why do marital partners of people living with HIV not test for HIV? A qualitative study in Lusaka, Zambia. *BMC Public Health*, *16*(1), 1–13.

National AIDS Trust. (2011). *The need for public awareness and understanding of HIV*. London.

National AIDS Trust. (2014a). *HIV: public knowledge and attitudes 2014*. London.

National AIDS Trust. (2014b). *HIV and Black African communities in the UK: a policy report*. London.

National AIDS Trust. (2016). *Tackling HIV stigma: What works?* London.

National AIDS Trust. (2018). HIV in the UK Statistics. Retrieved August 6, 2018, from https://www.nat.org.uk/we-inform/HIV-statistics/UK-statistics

National Network of Persons Living with HIV in Ghana, Ghana AIDS Commission, & UNAIDS. (2014). *Persons living with HIV stigma index study: Ghana*.

Oanh, K., Ashburn, K., Pulerwitz, J., Ogden, J., & Nyblade, L. (2008). *Improving hospital-based quality of care in Vietnam by reducing HIV-related stigma and discrimination. Horizons final report*. Washington, DC.

Odlind, C. (2018). "HIV is an infectious disease like any other." Retrived 23/3/19 from URL: https://ki.se/en/research/hiv-is-an-infectious-disease-like-any-other

Orr, J., Paul, J. J., & Paul, S. (2002). Decolonizing Mi'kmaw education through cultural practical knowledge. *McGill Journal of Education*, *37*(3), 331–353.

Otolok-Tanga, E., Atuyambe, L., Murphy, C., Ringheim, K., & Woldehanna, S. (2003). Examining the actions of faith-based organizations and their influence on HIV / AIDS-related stigma : A case study of Uganda. *African Health Sciences*, *7*(1), 55–60.

Overmars-Marx, T., Thomése, F., & Moonen, X. (2018). Photovoice in research involving people with intellectual disabilities: A guided photovoice approach as an alternative. *Journal of Applied Research in Intellectual Disabilities*,

31(1), e92–e104.

Pantelic, M., Shenderovich, Y., Cluver, L., & Boyes, M. (2015). Predictors of internalised HIV-related stigma: a systematic review of studies in sub-Saharan Africa. *Health Psychology Review*, *9*(4), 469–490.

Parker, R., & Aggleton, P. (2003). HIV and AIDS-related Stigma and Discrimination: A Conceptual Framework and an Implication for Action. *Social Science & Medicine*, *57*(1), 13–24.

Perlman, M. (2015). Black and white: why capitalization matters. *Columbia Journalism Review.* Retrieved 11/11/2018 from URL: https://www.cjr.org/analysis/language_corner_1.php

Peterman, A., Cella, D., Mo, F., & McCain, N. (1997). Psychometric validation of the revised functional assessment of human immunodeficiency virus infection (FAHI) quality of life instrument. *Quality of Life Research*, *6*(6), 572–584.

Phelan, J. C., Link, B. G., & Dovidio, J. F. (2008). Stigma and prejudice: one animal or two? *Social Science and Medicine*, *67*, 358–367.

Plunkett, R., Leipert, B. D., & Ray, S. L. (2013). Unspoken phenomena: using the photovoice method to enrich phenomenological inquiry. *Nursing Inquiry*, *20*(2), 156–164.

Poland, B. (2001). Transcription quality. In J. Gubrium & J. Holstein (Eds.), *Hanbook of interview research* (pp. 628–649). London: Sage publications, Inc.

Ponterotto, J. G. (2005). Qualitative research in counseling psychology: a primer on research paradigms and philosophy of science. *Journal of Counseling Psychology*, *52*(2), 126–136.

Porter, J., & Washington, R. (1979). Black identity and self-esteem: a review of studies of black self-concept, 1968-1978. *Annual Review of Sociology*, *5*(1), 53–74.

Pratt, G. (2007). Working with migrant communities: collaborating with the Kalayaan Centre in Vancouver, Canada. In S. Kindon, R. Pain, & M. Kesby (Eds.), *Participatory action research approaches and methods: connecting people, participation and place*. London: Routledge.

Prevention Access Campaign. (2017). U=U Community Partners 2017.

Retrieved 29/7/18 URL: https://www.bhiva.org/BHIVA-endorses-U-U-consensus-statement

Pulerwitz, J., Michaelis, A., Weiss, E., Brown, L., & Mahendra, V. (2010). *A global HIV stigma reduction framework adapted and implemented in five settings in India*. ICWR and Strive.

Rao, D., Desmond, M., Andrasik, M., Rasberry, T., Lambert, N., Cohn, S. E., & Simoni, J. (2012). Feasibility, acceptability, and preliminary efficacy of the unity workshop: an internalized stigma reduction intervention for African American women living with HIV. *AIDS Patient Care and STDs*, *26*(10), 614–620.

Rao, H., Mahadevappa, H., Pillay, P., Sessay, M., Abraham, A., & Luty, J. (2009). A study of stigmatized attitudes towards people with mental health problems among health professionals. J*ournal of Psychiatric and Mental Health Nursing* 16(2), 279-284.

Reidpath, D. D., & Chan, K. Y. (2005). A method for the quantitative analysis of the layering of HIV-related stigma. *AIDS Care*. 17(4), 425-432

Reza, H. (2007). Participatory action research (PAR): revisiting the history, concept and ethics. *Action Research*, *4*(2), 27–34.

Rodger, A., Cambiano, V., Bruun, T., Vernazza, P., Collins, S., Degen, O., Corbelli, G., Estrada, V., Geretti, A., Beloukas, A., Raben, D., Coll, P., Antinori, A., Nwokolo, N., Rieger, A., Prins, J., Blaxhult, A., Weber, R., Van Eeden, A., Brockmeyer, N., Clarke, A., Romero Guerrero, J., Raffi, F., Bogner, J., Wandeler, Gerstoft, J., Gutiérrez, F., Brinkman, K., Kitchen, M., Ostergaard, L., Leon, A., Ristola, M., Jessen, H., Stellbrink, H., Phillips, A., & Lundgren, J. (2019). Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive partner taking suppressive antiretroviral therapy (PARTNER): final results of a multicentre, prospective, observational study. *The Lancet,* 6736(19), 30418-0.

Rothenberg, R., Woelfel, M., Stoneburner, R., Milberg, J., Parker, R., & Truman, B. (1987). Survival with the acquired immunodeficiency syndrome. Experience with 5833 cases in New York City. *The New England Journal of Medicine*. 317(21), 1297-302.

Roura, M., Urassa, M., Busza, J., Mbata, D., Wringe, A., & Zaba, B. (2009). Scaling up stigma? The effects of antiretroviral roll-out on stigma and HIV testing. Early evidence from rural Tanzania. *Sexually Transmitted Infections*, *85*(4), 308–312.

Ryan, B. (2015). 'HIV is like diabetes'? Or so they say. Retrieved 24/3/19, from https://www.poz.com/article/hiv-like-diabetes-27956-9330

Salgado, L., & Silva, I. (2018). "I believe people need to know us in order to integrate us": immigrant women's cultural attitudes and needs. *International Migration & Integration*, *19*(2), 451–471.

Sandelowski, M., Lambe, C., & Barroso, J. (2004). Stigma in HIV-positive women. *Journal Of Nursing Scholarship*, *36*(2), 122–128.

Sangaramoorthy, T., Jamison, A., & Dyer, T. (2017). Intersectional stigma among midlife and older Black women living with HIV. *Culture, Health & Sexuality*, *19*(12), 1–15.

Schnittker, J. (2002). Acculturation in context: the self-esteem of chinese immigrants. *Social Psychology Quarterly*, *65*(1), 56–76.

Schwartz, B. (1993). On the creation and destruction of value. In M. Hechter, L. Nadel, & R. Michod (Eds.), *The origin of values* (pp. 153–185). New York: Walter de Gruyter, Inc.

Selik, R. M., Buehler, J. W., Karon, J. M., Chamberland, M. E., & Berkelman, R. L. (1990). Impact of the 1987 revision of the case definition of acquired immune deficiency syndrome in the United States. *Journal of Acquired Immune Deficiency Syndromes.* 3(1):73-82.

Sengupta, S., Banks, B., Jonas, D., Miles, M. S., & Smith, G. C. (2011). HIV interventions to reduce HIV/AIDS stigma: A systematic review. *AIDS and Behavior*, *15*(6), 1075–1087.

Silverman, D. (1993). *Interpreting qualitative data: methods for analysing talk, text and interaction*. London: Sage.

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

Sitter, K. C. (2017). Taking a closer look at photovoice as a participatory action

research method. *Journal of Progressive Human Services*, *28*(1), 36–48.

Smith, J. A., & Osborn, M. (2004). Interpretative phenomenological analysis. In *Doing social psychology research*. Leicester: The British Psychological Society and Blackwell Publishing Ltd.

Sontag, S. (1991). *Illness as metaphor and AIDS and its metaphors*. London: Penguin.

Spence, J. (1988). Working for the media, or making the media work for us. In *Putting myself in the picture: a political, personal and photographic autobiography* (pp. 106–115). Seattle: The Real Comet Press.

Spencer, L., & Ritchie, J. (2012). In pursuit of quality. In D. Harper & A. R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners* (pp. 227–242). West Sussex: John Wiley & Sons, Ltd.

Squire, C. (2013). *Living with HIV and ARVs three-letter lives*. Basingstoke and New York: Palgrave Macmillan.

Stadler, J. (2003). Rumor, gossip and blame: implications for HIV/AIDS prevention in Tte South African Lowveld. *AIDS Education and Prevention*, *15*(4), 357–368.

Stangl, A., Brady, L., & Fritz, K. (2012, updated 2018). *Measuring HIV stigma and discrimination*. Washington, DC.

Stangl, A. L., Lloyd, J. K., Brady, L. M., Holland, C. E., & Baral, S. (2013). A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: how far have we come? *Journal of the International AIDS Society*, *16*(3), 18734.

Stigma Index UK. (2016). *Stigma survey UK 2015*.

Sultana, F. (2007). Reflexivity, positionality and participatory ethics: negotiating fieldwork dilemmas in international research. *ACME: An International Journal for Critical Geographies*, *6*(3), 374–385.

Tajfel, H., & Turner, J. (1979). An integrative theory of intergroup conflict. *The social psychology of intergroup relations*.

Tajuria, G., Read, S., & Priest, H. M. (2017). Using Photovoice as a method to engage bereaved adults with intellectual disabilities in research: listening, learning and developing good practice principles. *Advances in Mental*

Health and Intellectual Disabilities, *11*(5–6), 196–206.

Taylor, J. Y. (1998). Womanism: a methodological framework for African American women. *Advances in Nursing Science*, *21*(1), 53–64.

Teti, M., Bowleg, L., & Lloyd, L. (2010). "Pain on top of pain, hurtness on top of hurtness": Social discrimination, psychological well-being, and sexual risk among women living with HIV/AIDS. *International Journal of Sexual Health*, *22*(4), 205–218.

Teti, M., Massie, J., Cheak-Zamora, N., & Binson, D. (2012). Photos to "show the world what we're going through": women use images to talk about living with HIV/AIDS. *Journal of Applied Arts & Health*, *3*(2), 163–182.

Teti, M., Murray, C., & Binson, D. (2012). Photovoice as a community-based participatory research method among women living with HIV/AIDS: ethical opportunities and challenges. *Journal of Empirical Research on Human Research Ethics*, *7*(4), 34–43.

Tharps, L. (2014). The case for Black with a capital B. Retrieved 11/11/18: https://www.nytimes.com/2014/11/19/opinion/the-case-for-black-with-a-capital-b.html

The People Living With HIV. (2009). *Give stigma the index finger*. London.

The People Living With HIV. (2015). *The people living with HIV stigma survey UK. Women*. London.

Thornicroft, G. (2006). *Shunned*. Oxford: Oxford University Press.

Tsai, A. C. (2015). Socioeconomic gradients in internalized stigma among 4,314 persons with HIV in sub-Saharan Africa. *AIDS and Behavior*, *19*(2), 270–282.

Tshabalala, J., & Visser, M. (2008). Developing a cognitive behavioural therapy model to assist women to deal with HIV and stigma. *Psychological Society of South Africa*, *41*(1), 17–28.

Turan, B., Smith, W., Cohen, M., Wilson, T., Adimora, A., Merenstein, D., Adedimeji, A., Wentz, E., Foster, A., Metsch, L., Tien, P., Weiser, S., & Turan, J. M. (2016). Mechanisms for the negative effects of internalized HIV-related stigma on antiretroviral therapy adherence in women: The mediating roles of social isolation and depression. *Journal of Acquired Immune Deficiency Syndromes*, *72*(2), 198–205.

UN Women. (2018). Facts and figures: HIV and AIDS. Retrieved 6/8/18, from http://www.unwomen.org/en/what-we-do/hiv-and-aids/facts-and-figures

UNAIDS. (2018a). 2017 Global HIV Statistics. Retrieved 5/7/18 from http://www.unaids.org/sites/default/files/media_asset/UNAIDS_FactSheet_ en.pdf

UNAIDS. (2018b). *Miles to go: closing gaps, breaking barriers, righting injustices*. Joint United Nations Programme on HIV/AIDS. Geneva, Swiitzerland.

United Nations. (2017). Millenium Development Goals and Beyond 2015. Retrieved October 12, 2017, from http://www.un.org/millenniumgoals/aids.shtml

Van Der Wal, J., Grace, R., & Baird, K. (2017). It takes more than "just scratching the surface": the perspectives of young people on living in a disadvantaged community. *Children Australia*, *42*(42), 256–267.

Vyavaharkar, M., Moneyham, L., Corwin, S., Saunders, R., Annang, L., & Tavakoli, A. (2010). Relationships between stigma, social support, and depression in HIV-infected African American women living in the rural southeastern United States. *Journal of the Association of Nurses in Aids Care.* 21(2) 144-152.

Wagner, A., Hart, T., Mohammed, S., Ivanova, E., Wong, J., & Loutfy, M. (2010). Correlates of HIV stigma in HIV-positive women. *Archives of Women's Mental Health*, *13*(3), 207–214.

Wahl, O., & Aroesty-Cohen, E. (2010). Attitudes of mental health professionals about mental illness: a review of the recent literature. *Journal of Community Psychology*, *38*(1), 49–62.

Wallerstein, N., & Bernstein, E. (1988). Empowerment education: Freire's ideas adapted to health education. *Health Education Quartery*, *15*(4), 379–394.

Wang, C. (1999). Photovoice: a participatory action research stratergy applied to women's health. *Journal of Women's Health*, *8*(2), 185–192.

Wang, C., & Burris, M. (1997). Photovoice: concept, methodology and use for participatory needs assessmeant. *Health Education & Behaviour*, *24*(3), 369–387.

Wang, C., Burris, M. A., & Ping, X. Y. (1996). Chinese village women as visual

anthropologists: a participatory approach to reaching policymakers. *Social Science and Medicine*, *42*(10), 1391–1400.

Wang, C., & Redwood-Jones, Y. (2001). Photovoice ethics: perspectives from Flint Photovoice. *Health Education & Behaviour*, *28*(5), 560–572.

Wang, C., Yi, W. K., Tao, Z. W., & Carovano, K. (1998). Photovoice as a participatory health promotion strategy. *Health Promotion International*, *13*(1), 75–86.

Wang, Caroline, & Burris, M. A. (1994). Empowerment through photo novella: portraits of participation. *Health Education & Behavior*, *21*(2), 171–186.

Weiner, B. (1993). On sin versus sickness: A theory of perceived responsibility and social motivation. *American Psychologist*, *48*(9), 957–965.

Williams. (1996). The vicissitudes of embodiment across the chronic illness trajectory. *Body and Society*, *2*(2), 23–47.

Williams, D. R., & Collins, C. (1995). US socioeconomic and racial differences in health: patterns and explanations. *Annual Review of Sociology*, *21*(1), 349–386.

Williams, R. (1979). Change and stability in values and value systems: a sociological perspective. In *Understanding human values: individual and social* (pp. 15–46). New York: The Free Press.

Williams, S. (1999). Is anybody there? Critical realism, chronic illness and the disability debate. *Sociology of Health & Illness*, *21*(6), 797–819.

Willing, C. (2007). Reflections on the use of a phenomenological method. *Qualitative Research in Psychology*, *4*(3), 209–225.

Willing, C. (2013). *Introducing qualitative research in psychology*. Berkshire: Open University Press.

World Health Organization. (2018). Number of Women Living with HIV. Retrieved September 26, 2018, from http://www.who.int/gho/hiv/epidemic_status/cases_adults_women_children _text/en/

Worrell, F. C., Cross, W. E., & Vandiver, B. J. (2001). Nigrescence theory: current status and challenges for the future Frank. *Journal of Multicultural Counseling and Development*, *29*(2), 201–213.

Yu, H., Abdullah, A., & Saat, R. M. (2014). Overcoming time and ethical

constraints in the qualitative data collection process: A case of information literacy research. *Journal of Librarianship and Information Science*, *46*(3), 243–257.

Zway, M., & Boonzaier, F. (2015). "I believe that being a lesbian is not a curse"': young black lesbian women representing their identities through photovoice." *Agenda-Epowering Women For Gender Equity*, *29*(1), 96–107.

6. APPENDICES

Appendix 1. Data Extraction Chart Template

Paper ID	
Author	
Year	
Self / internalised stigma or identity	
Definition	
Reference for definition	
Type of article	
Country	
Type of population	
Model used (individual, relationship, social?)	
If applicable: constructs measured	
If applicable: measures used	
If applicable: results of measures	

Conclusions drawn

Appendix 2. Overview of Selected Papers

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
1	Wagner, Hart, Mohammed, Ivonova, Wong, Loutfy, 2010	Correlates of HIV stigma in HIV-positive women	Quantitative	Not stated	Not stated	NA	NA	Subscale of The HIV Stigma Scale ('negative self-image') (Berger, Ferrans, & Lashley, 2001)	Yes
3	Simbayi, Kalichman, Strebel, Cloete, Henda, Mqeketo, 2007	Internalized stigma, discrimination, and depression among men and women with HIV/AIDS in Cape Town, South Africa	Quantitative	Internalised	"Socially constructed views of AIDS can be assimilated and internalized by infected persons" page 1824	Not stated	NA	Internalized AIDS Stigma Scale (Kalichman et al., 2009)	No

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
4	Sandelowski, Lambe, Barroso, 2004	Stigma in HIV-Positive Women	Review	Internalised	"Internalization of negative cultural views" page 124	Not stated	NA	NA	NA
5	Aggleton and Parker 2003	HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action	Model/concept	Not stated	NA	NA	NA	NA	NA
6	Sangaramoorthy, Jamison and Dyer, 2017	Intersectional stigma among midlife and older Black women living with HIV	Qualitative	Internalised	"HIV-related stigma is also internalised by those with HIV as feelings of shame, guilt, anger, distress, and	Earnshaw 2013	HIV literature	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
					self hatred, and has been shown to negatively impact the way individuals approach their illness and the choices that they make about seeking treatment and care" page 3				
7	Logie, Jenkinson, Earnshaw, Tharar, Loutfy, 2016	A Structural Equation Model of HIV-Related Stigma, Racial Discrimination, Housing Insecurity and	Quantitative	Internalised	"Acceptance of negative views about PLWHIV may be associated with shame and	Earnshaw 2009; Earnshaw 2013	HIV literature	Subscale of The HIV Stigma Scale ('negative self-image') (Berger, Ferrans, & Lashley, 2001)	Yes

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
		Wellbeing among African and Caribbean Black Women Living with HIV in Ontario, Canada			depression" page 2				
8	Chambers, Rueda, Baker, Wilson, Deutsch, Raeifar, Rourke, 2015	Stigma, HIV and health: a qualitative synthesis	Review	Not stated	Not stated	NA	NA	NA	NA
12	Lawson, Bayly and Cey, 2013	Judgements regarding the acceptability of childbearing and parental fitness made towards	Quantitative	Not stated	NA	NA	NA	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
		women living with HIV							
17	Loutfy, Logie, Zhang, Blitz, Margolese, Tharao, Rourke, Rueda, Raboud, 2012	Gender and Ethnicity Differences in HIV-related Stigma Experienced by People Living with HIV in Ontario, Canada	Quantitative	Internalised	"Internalized stigma refers to an individual's acceptance of negative beliefs, views and feelings towards the stigmatized group they belong to and oneself"	Herek 2007, Mak 2007, Stweward 2008, Kalichiman 2009	HIV , mental health and sexuality literature	Subscale of The HIV Stigma Scale ('negative self-image') (Berger, Ferrans, & Lashley, 2001)	Yes
19	Mbonu, Van den Borne, De Vries, 2010	Gender-related power differences, beliefs and reactions towards	Qualitative	Not stated	NA	NA	NA	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
		people living with HIV/AIDS: an urban study in Nigeria							
20	Colbert, Kim, Sereika, Erlen, 2010	An examination of the relationships among gender, health status, social support, and HIV-related stigma.	Quantitative	Not stated	NA	NA	NA	Secondary analysis	NA
21	Teti, Bowleg, Lloyd, 2010	'Pain on Top of Pain, Hurtness on Top of Hurtness': Social Discrimination, Psychological	Qualitative	Not stated	NA	NA	NA	NA	

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
		Well-Being, and Sexual Risk Among Women Living With HIV/AIDS							
22	Mill, Edwards, Jackson, MacLean, Chaw-Kant, 2011	Stigmatization as a Social Control Mechanism for Persons Living with HIV and AIDS	Qualitative	Internalised	"The themes of shunning and labeling highlighted in the current study are comparable to some of the constructs identified by researchers for the measurement of stigma. An Internalized AIDS-Related Stigma Scale	Kalichman 2009	HIV literature	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
					developed by Kalichman and colleagues (2009) included items to measure the endorsement of social sanctions (e.g., restriction on freedom and isolation) toward persons living with HIV" page 1478				
24	de Wet, Wouters, 2016	Identity and the body: Narrative accounts of two HIV-	Qualitative	Internalised	Internalised, anticipated and felt stigma taken to be the same	South African National AIDS	HIV literature	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
		positive women with lipodystrophy in post-apartheid South Africa			thing, page 366 and 354	Council, 2015			
26	Earnshaw, Bogart, Dovidio, Williams, 2015	Stigma and Racial/Ethnic HIV Disparities: Moving Toward Resilience	Model/concept	Self	"Devaluing and discrediting oneself or on'es group based on one's stigma"	Not stated	NA	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
27	Turan, Smith, Cohen, Wilson, Adimora, Merenstein, Adedimeji, Wentz, Foster, Metsch, Tien, Weiser, Turan, 2016	Mechanisms for the Negative Effects of Internalized HIV-Related Stigma on Antiretroviral Therapy Adherence in Women: The Mediating Roles of Social Isolation and Depression	Quantitative	Internalised	"Acceptance of stigmatizing beliefs that are present in the community and feelings of shame and low self-worth as a consequence" pg 199	Lee 2002	HIV literature	Subscale of The HIV Stigma Scale ('negative self-image') (Berger, Ferrans, & Lashley, 2001)	Yes
29	Herek, Saha, Burack, 2013	Stigma and Psychological Distress in People With HIV/AIDS	Quantitative	Self	"Internalization of the stigma and acceptance of its validity" pg 42 and "self-stigma is a	Corrigan and Watson 2002	Mental heath literature	Re-phrasing of various scales	No

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
					domain specific form of low self esteem" pg 43				
30	Mak, Cheung, Law, Woo, Li, Chung, 2007	Examining attribution model of self-stigma on social support and psychological well-being among people with HIV+/AIDS	Quantitative	Self	"Self stigma occurs when members of a devalued group, being aware of the prejudice, stereotype and discrimination in society, endorse and internalize these beliefs, feelings and behaviors" pg 1550	Corrigan and Watson 2002	Mental heath literature	Self stigma scale developled	Yes

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
31	Lindayani, Ibrahim, Wang, Ko, 2018	Independent and synergistic effects of self- and public stigmas on quality of life of HIV-infected persons	Quantitative	Self	"self-stigma is defined as a presence of devaluing beliefs, behaviors or actions in which people with HIV may hold or engage" pg 707	Chambers 2015	HIV literature	Single item measure	No
33	Arrey, Bilsen, Lacor, Deschepper	"It's My Secret": Fear of Disclosure among Sub-Saharan African Migrant Women Living	Qualitative	Self	"Self stigma among sub Saharan African women encompasses denial, secrecy, silence, shame and	Not stated	NA	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
		with HIV/AIDS in Belgium			avoidance" pg 14				
34	Cuca, Onono, Bukusi, Turan 2012	Factors associated with pregnant women's anticipations and experiences of HIV-related stigma in rural Kenya	Quantitative	Self	"Negative self perception" page 4	Not stated	NA	Subscale of a HIV stigma scale ('negative self-perception') (Holzemer et al., 2007)	Yes
37	Roura, Urassa, Busza, Mbata, Wringe, Zaba, 2009	Scaling up stigma? The effects of antiretroviral rollout on stigma and HIV testing.	Qualitative	Self	"internalised feelings of shame or blame derived from accepting stigmatising	Deacon 2005	HIV literature	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
		Early evidence from rural Tanzania			judgements of one's identity" page 309				
38	Rao, Desmond, Andrasik, Rasberry, Lambert, Cohn, Simoni 2012	Feasibility, Acceptability, and Preliminary Efficacy of the Unity Workshop: An Internalized Stigma Reduction Intervention for African American Women Living with HIV	Quantitative	Internalised	"Once public stigmas are enacted (personally experienced), they can be internalized by the stigmatized individual if the individual endorses the public stigma" page 615	Corrigan and Watson 2002	Mental heath literature	Stigma Scale for Chronic Illness, (Rao et al 09) adapted and validated for African American's with HIV	Yes

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
39	Geary, Parker, Rogrers, Haney, Njihia, Haile, Walakira, 2014	Gender differences in HIV disclosure, stigma, and perceptions of health	Quantitative	Internalised	"Many women fear abandonment, DV and abuse. These fears often result in internalized stigma that can affect people behavior even in the absence of rejection or discrimination" page 1419	Not stated	NA	Internalized AIDS Stigma Scale (Kalichman et al., 2009)	No
40	Tsai, 2015	Socioeconomic gradients in internalized stigma among 4,314 persons with HIV in	Quantitative	Internalised	"Persons with HIV may come to accept these perceptions as valid and thereby	Link 1989	Mental heath literature	Questions used to measure public stigma, taken to imply internalized stigma in those	No

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
		sub-Saharan Africa			develop self defacing beliefs about themselves, a phenomenon commonly referred to as internalized stigma" page 270			people who have HIV	
41	Vyavaharkar, Moneyham, Corwin, Annang, Tavakoli, 2010	Relationships between stigma, social support, and depression in HIV-infected African American women living in the rural	Quantitative	Internalised	"Sometimes individuals who are stigmatized by others accept and internalize the lived experiences of stigma and discrimination	Morrison 2006	HIV literature	'Internalised stigma scale' no reference	No

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
		southeastern United States			over time, resulting in internalized stigma" pg 145				
43	Otolok-Tanga, Atuyambe, Murphy, Ringheim, Woldehanna, 2007	Examining the actions of faith-based organizations and their influence on HIV/AIDS-related stigma: A case study of Uganda	Review	Self	Not stated	NA	NA	NA	NA
44	Amuyunzu-Nyamongo, Lkeng'O,	Putting on a brave face: The experiences of womenlivin	Quantitative	Self	Not stated	NA	NA	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
	Wagura, Mwenzwa, 2007	g with HIV and AIDS in informal settlements of Nairobi, Kenya							
45	Bova, 2000	Women With HIV Infection: The Three Waves of Scientific Inquiry	Model/concept	Not stated	NA	NA	NA	NA	NA
46	Bunting 1996	Sources of stigma associated with women with HIV	Model/concept	Not stated	NA	NA	NA	NA	NA
47	Grove, Kelly, Liu, 1997	"BUT NICE GIRLS DON'T GET IT" Women,	Qualitative	Not stated	NA	NA	NA	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
		Symbolic Capital, and the Social Construction of AIDS							
48	Teti, Massie, Cheak-Zamora, Binson, 2012	Photos to 'show the world what we're going through': Women use images to talk about living with HIV/AIDS	Qualitative	Not stated	NA	NA	NA	NA	NA
49	Lee, Kochman, Sikkema	Internalized Stigma Among People Living with HIV AIDS	Quantitative	Internalised	"PWHA may be at risk for internalizing the stigma associated with their disease and	Not stated	NA	2 items from Functional Assessment of HIV infection for internalized stigma	Yes

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
					holding a negative view of HIV disease and of themselves as a result" pg 310				
52	Herek, 1999	AIDS and Stigma	Review	internalised	"Non-disclosure may also reflect an internalizing of societal stigma by PLWHIVs which may lead to loathing, self-blame, and self-destructive behviors" pg 1111	Herek 1990	HIV literature	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
53	Campbell and Deacon 2006	Unravelling the Contexts of Stigma: From Internalisation to Resistance to Change	Model/concept	Internalised	"Even when members of stigmatized groups are not exposed to overt and direct acts of discrimination, individuals who carry stigmatized markers may 'internalise' negative representations of their status. This may lead to loss of confidence and self-esteem,	Goffman 1963	No specific populatio n	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
					undermining the likelihood that they will challenge their devalued status" pg 413				
55	Holzemer, Makoae, Stewart, Phetlhu, Dlamini, Greeff, Kohi, Chirwa, Cuca, Naidoo, 2007	A conceptual model of HIV/AIDS stigma from five African countries	Qualitative	Internalised	"(emic view) Thoughts and behaviours stemming from the person's own negative perceptions about him or herself based on their HIV status" pg 548	Not stated	NA	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
56	Mill, 2001	I'm Not a "Basabasa" Woman: An Explanatory Model of HIV Illness in Ghanaian Women	Qualitative	Not stated	NA	NA	NA	NA	NA
57	Anderson, Doyal, 2004	Women from Africa living with HIV in London: a descriptive study	Qualitative	Not stated	NA	NA	NA	NA	NA
58	Dibb, Kamalesh 2012	Exploring positive adjustment in HIV positive women living in the UK	Qualitative	Not stated	NA	NA	NA	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
59	People living with HIV, 2015	HIV in the UK: Changes and Challenges; Actions and Answers The People Living With HIV Stigma Survey UK 2015, women	Quantitative	Internalised	"Acceptance of negative self-beliefs associated with being HIV positive" pg 2	Not stated	NA	Not stated	NA
60	Stangl, Brady, Fritz, 2012, 2018	Measuring HIV stigma and discrimination	Model/concept	Internalised	"Internalised stigma (the acceptance among people living with HIV of negative beliefs and feelings associated with HIV about	Not stated	NA	NA	NA

ID	Author and year	Paper title	Type of article	Self or internalised stigma	Definition	Reference for definition	Origin of definition	Measure	Validated
					themselves" pg 2				

Appendix 3. Project Flyer

Call for participants

My name is Elizabeth Corker and I am a Professional Doctorate student conducting research into the experiences of Black African women who have been given a diagnosis of HIV.

Living with a diagnosis of HIV can have profound implications on a person's life, including how they view themselves. I am looking to find out more about if and how Black African women's sense of self is effected by having a HIV diagnosis.

I will be asking participants to document their experiences through photography, using their camera phones.

> ◈ **If you identify as a Black African female with a HIV diagnosis and you have private access to a camera phone, I would like to invite you to participate!**

I will be at XXX on   DATE   to explain more about the project and run a workshop to help you get started with documentary photography. Please contact me if you would like to know more.

You can also just come along to the workshop if you are interested in hearing more! If you have any questions or concerns please email me at e.corker@uel.ac.uk.

THE EFFECTS OF A HIV DIAGNOSIS ON THE IDENTITY OF BLACK
AFRICAN WOMEN, AN EXPLOATORY STUDY

PARTICIPANT INVITATION LETTER

You are being invited to participate in a research study. Before you agree it is
important that you understand what your participation would involve. Please
take time to read the following information carefully.

Who am I?
I am a Professional Doctorate student in the School of Psychology at the
University of East London and am studying for a Professional Doctorate in
Clinical Psychology. As part of my studies I am conducting the research you are
being invited to participate in.

What is the research?
I am conducting research into the experiences of Black African women living
with a diagnosis of HIV. Living with a diagnosis of HIV can have profound
implications on a person's life, including how they view themselves. I am looking
to find out more about if and how Black African women's values, goals and
sense of self is effected by having a HIV diagnosis.
My research has been approved by the School of Psychology Research Ethics
Committee. This means that my research follows the standard of research
ethics set by the British Psychological Society.

Why have you been asked to participate?

You have been invited to participate in my research as someone who fits the kind of person I am looking for to help me explore my research topic. I am looking to involve women from a Black African background who have been given a diagnosis of HIV.

I emphasise that I am not looking for 'experts' on the topic I am studying. You will not be judged or personally analysed in any way and you will be treated with respect.

You are quite free to decide whether or not to participate and should not feel coerced.

What will your participation involve?
If you agree to participate you will be asked to use your camera phone to take photographs that you feel describe any change in your sense of self, due to HIV status. Specifically, you will be asked to:

- Attend a workshop at KwaAfrica to learn about how to take documentary style photographs, along with the ethical and legal considerations of taking these types of photographs;
- Take photographs over a four week period documenting your experiences;
- Select two photographs that you think best represent your experience and write a short statement describing why this is;
- Attend a one hour long informal interview at KwaAfrica with the researcher to talk about your photographs. Questions will include, 'what do you see here?', and 'why do you think this problem or strength exists?'. This interview will be audio recorded and transcribed by the researcher;
- Complete a short questionnaire asking you some demographic questions, such as your age, and when you received your HIV diagnosis;

I will not be able to pay you for participating in my research but your participation would be very valuable in helping to develop knowledge and understanding of my research topic

Your taking part will be safe and confidential
Your privacy and safety will be respected at all times:

- Information that could identify any person will not be used in any material resulting from the data collected, or in any write-up of the research;

- There is a potential risk that you may find participating in this project emotionally distressing. If this happens you will be asked if you wish to continue and you will be given information for further sources of support.

- You also do not have to answer any questions asked that are asked, and you can stop your participation at any time, without giving a reason.

What will happen to the information that you provide?
What I will do with the material you provide will involve:
- The written contact information you provide will be stored securely in a locked filing cabinet that only the researcher has access to;

- All photographs, written statements, questionnaire answers and interview transcripts will be anonymised by changing participant names and removing any identifying information. Your real name will not be linked to any research data.

- Only the researcher, the researcher's supervisor and the examiners will have access to the full set of anonymised data (photographs, written statements, questionnaire answers and interview transcripts).

- Academic journals and charity commissioners may have access to sections of the anonymised data via written reports of the research

- The dissertation containing anonymised data will be held in an online publicly accessible repository.

- The audio recordings will be deleting after the researcher has completed the project. The photographs, written statements, interview transcripts, and questionnaire answers will be kept in a secure digital format for 5 years, or until the research has been disseminated, whichever is soonest.

What if you want to withdraw?
You are free to withdraw from the research study at any time without explanation, disadvantage or consequence, until 01/02/2019.

Contact Details
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Elizabeth Corker e.corker@uel.ac.uk

If you have any questions or concerns about how the research has been
conducted please contact the research supervisor Dr Lorna Farquharson.
School of Psychology, University of East London, Water Lane, London E154LZ,

Email: l.farquharson@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Mary
Spiller, School of Psychology, University of East London, Water Lane, London
E15 4LZ.
(Email: m.j.spiller@uel.ac.uk)

Sources of support
XXXXX

Appendix 5. Consent Forms

5.1. Participant Consent Form

<u>UNIVERSITY OF EAST LONDON</u>

Consent to participate in a research study

THE EFFECTS OF A HIV DIAGNOSIS ON THE IDENTITY OF BLACK AFRICAN WOMEN, AN EXPLORATORY STUDY

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have ben explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the

researcher reserves the right to use my anonymous data after analysis of the data has begun.

Participant's Name (BLOCK CAPITALS)

…………………………………………………………………………………….

Participant's Signature

…………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

…………………………………………………………………………………..

Researcher's Signature

…………………………………………………………………………………

Date: …………………..…….

UNIVERSITY OF EAST LONDON

Consent to use images in research study

THE EFFECT OF A HIV DIAGNOSIS ON THE IDENTITY OF BLACK AFRICAN WOMEN, AN EXPLORATORY STUDY

I understand that the images I have produced as part of this project belong to me. I hereby give the researcher permission to use the following images as research data:

[NAME OF IMAGE}

[NAME OF IMAGE]

I hereby freely and fully consent for these images to used in the study. Having given this consent I understand that I have the right to withdraw these images from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun.

Participant's Name (BLOCK CAPITALS)

………………………………………………………………………………………….

Participant's Signature

…………………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

…………………………………………………………………………………………..

Researcher's Signature
……………………………………………………………………………………………

Date: ………………....…….

UNIVERSITY OF EAST LONDON

Consent to use images in research study

THE EFFECT OF A HIV DIAGNOSIS ON THE IDENTITY OF BLACK AFRICAN
WOMEN, AN EXPLORATORY STUDY

I understand that images taken of me will be used in a research project. I
hereby give the researcher permission to use the following images as research
data:

[NAME OF IMAGE}

[NAME OF IMAGE]

I hereby freely and fully consent for these images to used in the study. Having
given this consent I understand that I have the right to withdraw these images
from the study at any time without disadvantage to myself and without being
obliged to give any reason. I also understand that should I withdraw.

Participant's Name (BLOCK CAPITALS)

………………………………………………………………………………….

Participant's Signature

……………………………………………………………………………………..

Photography Subject's Name (BLOCK CAPITALS)

………………………………………………………………………………….

Photography Subject's Signature

……………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

………………………………………………………………………………….

Researcher's Signature
……………………………………………………………………………………

Date: …………………..…….

Appendix 6. Photovoice Workshop Slides

PHOTOVOICE:
IDENTITY AND HIV
ELIZABETH CORKER

OVERVIEW

- About me
- 'Identity'
- Photovoice and research
- Taking photos – having a go!

ABOUT ME....

ABOUT 'IDENTITY'

Brain Injury Identity Card
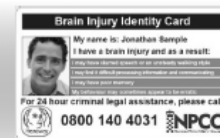
ABOUT 'IDENTITY'

- WHAT THE 'EXPERTS' SAY:
  - 'Personal Identity'
    - Refers to a person's beliefs, goals and values (Hitlin 2003)
      - Beliefs: spiritual, religious, cultural
      - Goals: what a person wants from life
      - Values: what a person takes to be important in life

ABOUT 'IDENTITY'

- WHAT THE 'EXPERTS' SAY:
  - 'Social Identity'
    - A group that an individual either chooses to belong to, or has been classified into (Correll and Park, 2005)
      - Nationality, ethnicity, religion, social class, generation, gender, health and illness
      - Community groups, special interest groups

ABOUT 'IDENTITY'

- 'Global' self
  - The combination of personal and social identity selves
  - Personal and social identity impact on each other
  - Can they be separated out? Or not?

'IDENTITY' AND HIV

- WHAT DO YOU THINK?
  - Can a HIV diagnosis impact on:
    - Beliefs, goals, values?
    - Groups that people belong to?
    - What are those changes?

ABOUT PHOTOVOICE

ABOUT PHOTOVOICE

- Community based photography for making social change (Spence)
- Principles that underlie codes of ethics for the health education profession:
  - Respect for autonomy
  - Promotion of social justice
  - Active promotion of good
  - Avoidance of harm
- Show experiences, challenges, barriers and strengths

SHARING STORIES

- Example photovoice project
  - Photos to 'show the world what we're going through': Women use images to talk about living with HIV/AIDS
  - Researchers: Michelle Teti; Jenne Massie; Nancy Cheak-Zamora; Diane Binson

Photos to 'show the world what we're going through': Women use images to talk about living with HIV/AIDS

Support networks: 'without our support, we would not be able to fight this thing'

Photos to 'show the world what we're going through': Women use images to talk about living with HIV/AIDS
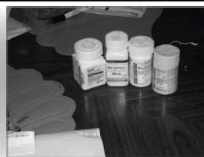
Living healthy and proud with HIV/AIDS: 'I call myself the diva, and I don't care what anyone say'

Photos to 'show the world what we're going through': Women use images to talk about living with HIV/AIDS
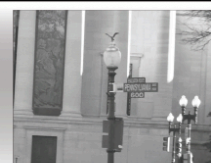
Daily stressors and socio-structural barriers

Photos to 'show the world what we're going through': Women use images to talk about living with HIV/AIDS

Transformation

THE PROPOSED PROJECT

- The effects of a HIV diagnosis on the identity of Black African Women, an exploratory study
  - Looking to find out if and how Black African Women's values, goals and sense of self is effected by having a HIV diagnosis
  - Participation will involve taking photographs using your phone and an interview with me
  - Group discussion of photos

THE CURRENT PROJECT

- What will I do with the photos?
- How long will the project run for?
- What happens next?

PHOTOVOICE: THE USE OF POWER, ETHICS AND RESPONSIBILITIES

1. Intrusion into private space
2. Disclosure of embarrassing facts about people
3. Images painting a false light
4. Ownership of images
5. Safety of participants

PHOTOVOICE: THE USE OF POWER, ETHICS AND RESPONSIBILITIES

1. Intrusion into private space

- Privacy law protects against "intrusion into one's private space, or even into one's privacy while one is in a public space if one has not consented to be filmed or photographed"

- We extend this notion of intrusion to apply not only to individuals but also to groups, neighbourhoods, and communities

PHOTOVOICE: THE USE OF POWER, ETHICS AND RESPONSIBILITIES

2. Disclosure of embarrassing facts about people

- Privacy law protects against "the disclosure of true but embarrassing facts about individuals, when these facts are not deemed a legitimate concern to the public"

PHOTOVOICE: THE USE OF POWER, ETHICS AND RESPONSIBILITIES

3. Images painting a false light

- Privacy law protects against being "placed in a false light by images which distort the truth and create false impressions of one's intentions, character, or actions"

PHOTOVOICE: THE USE OF POWER, ETHICS AND RESPONSIBILITIES

4. Ownership of images

- Privacy law prevents "the use of a person's likeness that results in depriving that person of some commercial benefit, or making a profit at that person's expense"

PHOTOVOICE: THE USE OF POWER, ETHICS AND RESPONSIBILITIES

5. Safety of participants

- When taking a photograph, we need to bear in mind the location and the environment

PHOTOVOICE: THE USE OF POWER, ETHICS AND RESPONSIBILITIES

TAKING PHOTOS

TAKING PHOTOS

- Posture

TAKING PHOTOS

- Don't use the zoom

TAKING PHOTOS

- Multiple shots

TAKING PHOTOS

- Lighting

TAKING PHOTOS

- Posture
- Don't use the zoom
- Multiple shots
- Lighting

TAKING PHOTOS

Let's give it a go!

Appendix 7. Interview Schedule

1. Meet participant and show to room;
2. Thank for time and for photographs;
3. Reiterate right to withdrawal, any relevant information regarding consent, answer any questions the participant has;
4. Explain tape recorder and switch on;
5. Clinical and demographic questions:
   a. Age;
   b. Nationality and first language;
   c. Length of time living in UK;
   d. Occupation category;
   e. Age when HIV diagnosis first received;
   f. Marital status, number of children and living arrangements;
   g. Currently accessing NHS services in relation to HIV diagnosis?

6. SHOWeD Questions:
   a. *What do you See here?*
   b. *What's really Happening here?*
   c. *How does this relate to Our lives?*
   d. *Why does this problem or strength exist?*
   e. *What can we Do about it?*

7. Questions regarding HIV diagnosis:
   a. *Has HIV changed how you feel about yourself?*
   b. *Has HIV changed your relationships with others?*

8. Switch off recorder;
9. Answer any questions the participant has;
10. Check-in with participant, explain next steps: analysis, member checking process, write up.

Throughout: remain vigilant for signs of distress, if necessary, follow distress protocol

**UNIVERSITY OF EAST LONDON
School of Psychology**

APPLICATION FOR RESEARCH ETHICS APPROVAL

FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

FOR BSc RESEARCH

FOR MSc/MA RESEARCH

**FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING &
EDUCATIONAL PSYCHOLOGY**

**If you need to apply to have ethical clearance from another Research Ethics
Committee (e.g. NRES, HRA through IRIS) you DO NOT need to apply to the School of
Psychology for ethical clearance also. Please see details on**
https://uelac.sharepoint.com/ResearchInnovationandEnterprise/Pages/NHS-Research-Ethics-Committees.aspx

Among other things this site will tell you about UEL sponsorship
Note that you do not need NHS ethics approval if collecting data from NHS staff except
where the confidentiality of NHS patients could be compromised. You do need NHS
approval is collecting data on NHS premises.

Before completing this application please familiarise yourself with:

The *Code of Ethics and Conduct (2009)* published by the British Psychological Society
(BPS). This can be found in the Ethics folder in the Psychology Noticeboard (Moodle)
and also on the BPS website
http://www.bps.org.uk/system/files/Public%20files/aa%20Standard%20Docs/inf94_code_web_ethics_conduct.pdf

And please also see the UEL Code of Practice for Research Ethics (2015-16)

HOW TO COMPLETE & SUBMIT THIS APPLICATION

1. Complete this application form electronically, fully and accurately.

2. Type your name in the 'student's signature' section (5.1).

3. Include copies of all necessary attachments in the **ONE DOCUMENT** SAVED AS **.doc**

4. Email your supervisor the completed application and all attachments as **ONE DOCUMENT**. Your supervisor will then look over your application.

5. When your application demonstrates sound ethical protocol your supervisor will type in his/her name in the 'supervisor's signature' (section 5) and submit your application for review (psychology.ethics@uel.ac.uk). You should be copied into this email so that you know your application has been submitted. It is the responsibility of students to check this.

6. Your supervisor should let you know the outcome of your application. <u>Recruitment and data collection are **NOT** to commence until your ethics application has been approved, along with other research ethics approvals that may be necessary</u> (See section 4)

ATTACHMENTS YOU MUST ATTACH TO THIS APPLICATION

1. A copy of the participant invitation letter that you intend giving to potential participants.

2. A copy of the consent form that you intend giving to participants.

3. A copy of the debrief letter you intend to give participants.

OTHER ATTACHMENTS (AS APPROPRIATE)

- A copy of original and/or pre-existing questionnaire(s) and test(s) you intend to use.

- Example of the kinds of interview questions you intend to ask participants.

- Copies of the visual material(s) you intend showing participants.

- A copy of ethical clearance or permission from an external institution or organisation if you need it (e.g. a charity, school, local authority, workplace etc.). Permissions must be attached to this application. If you require ethical clearance from an external organisation your ethics application <u>can</u> be submitted to the School of Psychology before ethical approval is obtained from another organisation (see Section 5).

Disclosure and Barring Service (DBS) certificates:

- **FOR BSc/MSc/MA STUDENTS WHOSE RESEARCH INVOLVES VULNERABLE PARTICIPANTS:** A scanned copy of a current Disclosure and Barring Service (DBS) certificate. <u>A current certificate is one that is not older than six months.</u> This is necessary if your research involves young people (anyone 16 years of age or under) or vulnerable adults (see Section 4 for a broad definition of this). A DBS certificate that you have obtained through an organisation you work for is acceptable as long as it is current. If you do not have a current DBS certificate, but need one for your research, you can apply for one through the HUB and the School will pay the cost.

  If you need to attach a copy of a DBS certificate to your ethics application but would like to keep it confidential please email a scanned copy of the certificate directly to Dr Mary Spiller (Chair of the School Research Ethics Committee) at m.j.spiller@uel.ac.uk

- **FOR PROFESSIONAL DOCTORATE STUDENTS WHOSE RESEARCH INVOLVES VULNERABLE PARTICIPANTS:** DBS clearance is necessary if your research involves young people (anyone under 16 years of age) or vulnerable adults (see Section 4 for a broad definition of this). The DBS check that was done, or verified, when you registered for your programme is sufficient and you will <u>not</u> have to apply for another in order to conduct research with vulnerable populations.

SECTION 1. Your details

1. **Your name**: Dr Elizabeth Corker

2. **Your supervisor's name**: Dr Poul Rohleder

3. **Title of your programme**: (e.g. BSc Psychology): Professional Doctorate in Clinical Psychology

4. **Submission date for your BSc/MSc/MA research:** September 2019

5. Please tick if your application includes a copy of a DBS certificate ☐

6. Please tick if you need to submit a DBS certificate with this application but have emailed a copy to Dr Mary Spiller for confidentiality reasons
(Chair f the School Research Ethics Committee) (m.j.spiller@uel.ac.uk) ☐

7. Please tick to confirm that you have read and understood the <u>British Psychological Society's Code of Ethics and Conduct (2009)</u> and the <u>UEL Code of Practice for Research Ethics</u> (See links on page 1)

☐

SECTION 2. About your research

8. What your proposed research is about:

Please be clear and detailed in outlining what your proposed research is about. Include the research question (i.e. what is your proposed research investigating?)

The proposed research is an exploratory study that aims to investigate and describe changes or challenges in relation to sense of self in Black African women in relation to an HIV diagnosis (living in London).
Additionally, the proposed research aims to determine if self-stigma influences identity in Black African women with an HIV diagnosis and if it does, to define this experience.

The proposed research question is:

> What are the experiences of living with a spoiled identity in Black African women with a diagnosis of HIV?

(please note: the term self-stigma is deliberately not referred to as; to do so assumes that self-stigma is an aspect of individuals lives. Moreover, as one of the aims is to determine a definition for self-stigma within this group, any pre-conceived notions of what self-sigma is need to be avoided. Additionally, the term 'spoiled identity' will not be used in any communication with the participants. This is a term that is used in the literature and referred to here for reference only).

9. Design of the research:

Type of experimental design, variables, questionnaire, survey etc., as relevant to your research. If the research is qualitative what approach will be used and what will the data be?

175

The methodology proposed for this research is Photovoice, a form of Participatory Action Research methodology.

Developed by Wang and Burris in 1997 to capture the narratives of a person's experience, Photovoice is theoretically developed from three sources (critical consciousness, feminism and documentary photography) (C. Wang & Burris, 1997)

Photovoice has three main goals: giving people the opportunity to record, by taking photographs and reflect on their and their communities strengths and areas for concern, promoting critical dialogue within communities and reaching policy makers (C. Wang & Burris, 1997). Photovoice allows participants to document their experience of a given phenomenon, in this case, the experience of living with a 'spoiled identity'.

Participants will also provide a written statement describing why the photographs represent their experience, and will attend one semi structured interview with the researcher using the photographs as a guide for discussion.

Therefore three sources of data will be produced: the photographs, a written statement regarding the photographs and the transcripts of the semi structured interview.

10. Recruitment and participants (Your sample):
Proposed number of participants, method of recruitment, specific characteristics of the sample such as age range, gender and ethnicity - whatever is relevant to your research.

Due to the specific population referred to in the research question, purposive sampling will be used for the proposed research.

Inclusion criteria:
> Self-identifies as female;
> Current diagnosis of HIV;
> 18 years old or over;
> Self-identifies as being from a Black African background
> Has private access to a camera phone

Participants will be recruited from KwaAfrica; an established charity working with Black African women who have a diagnosis of HIV. The researcher has had informal discussions with KwaAfrica and their involvement in the proposed research, including participant recruitment, and they are very interested in supporting recruitment to the study. Details of correspondence between the researcher and KwaAfrica are attached to this document.

A sample of 8 women will be recruited. As four data sources will be produced from each participant, a total of 8 participants is thought to be sufficient for answering the research question.

Participants will be recruited via a flyer, given to women who currently use KwaAfrica services, by staff within the charity and on display in communal areas. The researchers contact details will be provided for potential participants to request Participant Information Sheet (PIS) and/or talk through any questions they have about participating.

The proposed flyer is attached to this document.

11. Measures, materials or equipment:

Give details about what will be used during the course of the research. For example, equipment, a questionnaire, a particular psychological test or tests, an interview schedule or other stimuli such as visual material. See note on page 2 about attaching copies of questionnaires and tests to this application. If you are using an interview schedule for qualitative research attach example questions that you plan to ask your participants to this application.

A proposed topic guide is attached to this application. This is based on Wang and Burris' 1997 SHOWeD technique, and has been used in other Photovoice research (Michelle Teti et al., 2012; C. Wang & Burris, 1997; C. Wang & Redwood-Jones, 2001).

A short demographic questionnaire is also attached to this document. This will be used to provide some context for the other sources of data.

12. If you are using copyrighted/pre-validated questionnaires, tests or other stimuli that you have not written or made yourself, are these questionnaires and tests suitable for the age group of your participants?

YES / NO / NA

13. Outline the data collection procedure involved in your research:

Describe what will be involved in data collection. For example, what will participants be asked to do, where, and for how long? If using online surveys what survey software will be used, e.g. Qualtrics?

Potential participants that respond to the flyer will be given a Participant Information Sheet (PIS) via email that outlines the research, the reasons for doing the research, their role and their rights as a participant. The PIS contains the contact details of the researcher and potential participants are encouraged to ask any questions they might have regarding the proposed research. Participants will have up a week and at least 48 hours to read the information in the PIS before the researcher contacts them. Consent will be given by each participant in person to the researcher. The research will ask the participant to outline the research in their own words, in order to ensure that the aims of the research and the role and rights of the participant have been understood. If happy to consent to participate, the participant will then fill out and sign two copies of the consent form in the presence of the researcher, who will also sign. One copy of the consent form will be given to the participant to keep and the other will be kept by the researcher in a locked filing cabinet.

The PIS and consent forms are attached.

After informed consent has been gained, the participant will be invited to attend a workshop (dates and times to be confirmed with KwaAfrica) which will cover details of the Photovoice methodology. The workshop will be held in KwaAfrica premises, where regular groups for users of the charity are held. The workshop will include practical and ethical considerations of taking photographs to document their experiences. Wang and Redwood outlined the ethical considerations that need to be covered when using Photovoice as a methodology (C. Wang & Redwood-Jones, 2001), these are:

•   Intrusion into private space
•   Disclosure of embarrassing facts about people
•   Images painting a false light
•   Safety of participants
•   Responsibility and authority of participants

Each of these will be considered in detail. Wang and Redwood provide a 'PhotoVoice Ethics: Minimum Best Practices' guide which will be followed (C. Wang & Redwood-Jones, 2001).

If a participant cannot attend the workshop, and still wants to take part, they will be given the relevant information and guidance either over the phone or through Skype.

Although implied by the use of the participants own camera phones for capturing photographs, participants will be informed that the images they produce belong to them, and will be asked to sign an additional consent form in order for the researcher to use the images as a source of research data (consent to use images form is attached).

At the end of the workshop, participants will be told that they have 4 weeks in which to take photographs and decide upon 1 or 2 images that they feel best represents their experiences. They will also be asked to provide a short written statements describing why these image/s were chosen. Finally, an appointment will be made with each participant for an individual semi-structured interview. The interview is expected to last around one hour and will also be held in KwaAfrica premises, in a private room. Participants are only expected to complete one interview.

Interviews will be audio recorded and transcribed verbatim by the researcher. Audio recordings and transcripts will be stored digitally in encrypted files on the researchers home computer.

Details of time-lines, are found in the Gantt Chart attached.

SECTION 3. Ethical considerations

14. Fully informing participants about the research (and parents/guardians if necessary):
How will you fully inform your participants when inviting them to participate? Would the participant invitation letter be written in a style appropriate for children and young people, if necessary?

Informed consent will be gained by initially asking potential participants to read the participant information sheet. The potential participants will be given a minimum of 48 hours and up to a week to consider the information in the PIS. After reading the information sheet, the potential participant will be asked by the researcher if they have any questions and these will be answered. The researcher will then ask the potential participant to outline the research in their own words, in order to ensure that the aims of the research and the role and rights of the participant have been understood. Once this process is complete, the participant will be able to fill out and sign two consent forms in the presence of the researcher, who will also sign the consent form and keep one copy.

15. Obtaining fully informed consent from participants (and from parents/guardians if necessary):
Is the consent form written in a style appropriate for children and young people, if necessary? Do you need a consent form for both young people and their parents/guardians? How will you gain consent if your research is collecting data online?

Informed consent will be obtained via following the above procedure for informing participants. Once the above process is complete, the participant will be able to fill out and sign two consent forms in the presence of the researcher, who will also sign the consent form and keep one copy.

16. Engaging in deception, if relevant:
What will participants be told about the nature of the research? The amount of any information withheld and the delay in disclosing the withheld information should be kept to an absolute minimum.

NA – participants will be fully informed as to the nature of the research.

17. Right of withdrawal:
In this section, and in your participant invitation letter, make it clear to participants that 'withdrawal' will involve participants being able to decide to not continue with participation in your research and the right to have the data they have supplied destroyed on request. It is advised that you tell participants on your participant invitation letter that you as the researcher reserve the right to keep and use all data after the point at which you begin your analysis of data. Speak to your supervisor for clarification if necessary.

Participants will have, and will be informed via the information sheet, of their right to withdraw from the research at any time, up until the point of writing the research up, without needing to give any reason and without incurring any disadvantage to themselves. If a participant withdraws from the research, the researcher will remove and destroy any data source that has already been produced by the participant and these will not be referred to in any write up, presentation or discussion of the research.

When the research enters the write up stage, the researcher will not be able to remove an individual participants data, as this will impact negatively on the contribution of other participants, in that the analysis will only make sense as a whole.

18. Will the data be gathered anonymously?

This is where you will <u>not</u> know the names and contact details of your participants? In qualitative research that involves interviews, data is usually not collected anonymously because you will know the names and contact details of your participants.

~~YES~~ / NO

19. If NO what steps will be taken to ensure confidentiality and protect the identity of participants?

How will the names and contact details of participants be stored and who will have access? Will real names and identifying references be omitted from the reporting of data and transcripts etc? What will happen to the data after the study is over? Usually names and contact details will be destroyed after data collection but if there is a possibility of you developing your research (for publication, for example) you may not want to destroy all data at the end of the study. If not destroying your data at the end of the study, what will be kept, how, and for how long?

The names and contact details for participants will be stored in an encrypted folder on the researcher's password protected personal computer. Consent forms will be stored in a locked cabinet in the researchers home. The email address provided for participants will be the researcher UEL email account and e-mails will be sent from this account. Identifying features of individuals or services will be removed from all data sources used in the write-up of the study. Quotes from transcripts, the written statement and information from the photographs will be reported using pseudonyms chosen by the participant. The data will be stored for as long as necessary to publish in a peer reviewed journal, and deleted as soon as this is no longer necessary. Data sources will be deleted within 5 years of the end of the study.

The audio-recordings of the interviews will be used for transcription and then, deleted after the end of the study.

20. Will participants be paid or reimbursed?

This is not necessary but payment/reimbursement must be in the form of redeemable

vouchers and not cash. Please note that the School cannot fund participant payment?

YES / NO

If YES, why is payment/reimbursement necessary and how much will the vouchers be worth?

NA

SECTION 4. Other permissions and ethical clearances

21. Is permission required from an external institution/organisation (e.g. a school, charity, workplace, local authority, care home etc.)?
You need to have written permission from external institutions/organisations/workplaces if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation.

NHS ethical approval is NOT required for research involving staff. However, approval IS required if recruitment and/or data collection takes place on NHS premises.

Is permission from an external institution/organisation/workplace required? YES / NO

If YES please give the name and address of the institution/organisation/workplace:

KwaAfrica
Office G
Poynter House North,
1 Queensdale Crescent,
London W11 4TA

COPIES OF PERMSISSIONS (LETTER OR EMAIL) MUST BE ATTACHED TO THIS APPLICATION

Will your research be taking place on NHS Premises? YES / NO

In some cases you may be required to have formal ethical clearance from the external institution or organisation or workplace too.

22. Is ethical clearance required from any other ethics committee?

~~YES~~ / NO

If YES please give the name and address of the organisation:

Has such ethical clearance been obtained yet?   YES / NO

If NO why not?

NA

If YES, please attach a scanned copy of the ethical approval letter. A copy of an email from the organisation confirming its ethical clearance is acceptable.

NA

Ethical approval from the School of Psychology can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s as may be necessary.

SECTION 5. Risk Assessment

If you have serious concerns about the safety of a participant, or others, during the course of your research please see your supervisor as soon as possible.

If there is any unexpected occurrence while you are collecting your data (e.g. a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.

23. Protection of participants:
Are there any potential hazards to participants or any risk of accident or injury to them? What is the nature of these hazards or risks? How will the safety and well-being of participants be ensured? What contact details of an appropriate support organisation or agency will be made

The support organisation or agency that you refer participants to in your debrief letter should be appropriate. That is, is there a more appropriate support organisation than the Samaritans, for example (i.e. anxiety, mental health, young people telephone support help-lines?

There are potential hazards and risks of injury for the participants when they are collecting their photographs. Guidance on how to minimize these risks will be given in the Photovoice workshop, including guidance on taking pictures of other people. In this case, participants will be required to obtain a permission and a release form from the person the person they are photographing (Blackman & Fairley, 2007; C. Wang & Redwood-Jones, 2001).

There is the potential for participants to become distressed during the interview when recalling or talking about difficult experiences they might have had. The researcher will be looking for any signs of distress throughout the interview. Upon spotting them, the researcher will ask if the participant what they would like to do, this could include: would like to take a break, reschedule the interview or withdraw from the project. The researcher will also signpost the participant to the sources of support that are detailed in the information sheet.

24. Protection of the researcher:

Will you be knowingly exposed to any health and safety risks? If equipment is being used is there any risk of accident or injury to you and how will you mitigate this? If interviewing participants in their homes will a third party be told of place and time and when you have left a participant's house?

There are no specific risks to the researcher. The Photovoice workshop and the interviews will be conducted in KwaAfrica premises and the researchers supervisor will be aware of the dates and times of these.

25. Debriefing participants:

How will participants be de-briefed? Will participants be informed about the true nature of the research if they are not told beforehand? Will contact details of a support organisation be made available to participants via the debrief letter.

Participants will be given time at the end of the interview to ask any questions they may have. The proposed research contains no element of deception. Participants will be reminded about what will happen to the data and the write of the project. Furthermore, participants will be asked about whether and how they would like to be involved in the dissemination of the research findings. This may include presenting their photographs and/or writing about their experiences to present the results to KwaAfrica and their stakeholders, the researcher will facilitate this.

26. Other: Is there anything else the reviewer of this application needs to know to make a properly informed assessment?

No.

27. Will your research involve working with children or vulnerable adults?*

~~YES~~ / NO

If YES have you obtained and attached a DBS certificate?　　YES / NO

If your research involves young people under 16 years of age and young people of limited competence will parental/guardian consent be obtained.

YES / NO

If NO please give reasons. (Note that parental consent is always required for participants who are 16 years of age and younger)

NA

* You are required to have DBS clearance if your participant group involves (1) children and young people who are 16 years of age or under, and (2) 'vulnerable' people aged 16 and over with psychiatric illnesses, people who receive domestic care, elderly people (particularly those in nursing homes), people in palliative care, and people living in institutions and sheltered accommodation, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak to your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible. For more information about ethical research involving children see https://uelac.sharepoint.com/ResearchInnovationandEnterprise/Pages/Research-involving-children.aspx

28. Will you be collecting data overseas?　　　　　　　　　~~YES~~ / NO

This includes collecting data while you are away from the UK on holiday or visiting your

If YES in what country or countries (and province if appropriate) will you be collecting data?
NA

Please click on this link https://www.gov.uk/foreign-travel-advice and note in the space below what the UK Government is recommending about travel to that country/province (Please note that you MUST NOT travel to a country/province/area that is deemed to be high risk or where essential travel only is recommended by the UK Government. If you are unsure it is essential that you speak to your supervisor or the UEL Travel Office – travelúel.ac.uk / (0)20 8223 6801).

SECTION 6. Declarations

Declaration by student:

I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor.

Student's name: *typed name acts as a signature* Elizabeth Corker

Student's number: u1622854   Date: 01/12/2017

Declaration by supervisor:

I confirm that, in my opinion, the proposed study constitutes an ethical investigation of the research question. Declaration of supervisory support of an application is confirmed once an application is submitted via the supervisor's UEL email account.

Appendix 9. Ethics Review Decision

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: John Read

SUPERVISOR: **Poul Rohleder**

STUDENT: Elizabeth Corker

Course: Professional Doctorate in Clinical Psychology

Title of proposed study: What are the experiences of living with a spoiled identity in Black African women with a diagnosis of HIV?

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED <u>BEFORE THE RESEARCH COMMENCES</u>** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is <u>not</u> required but the student must confirm with their supervisor that all minor amendments have been made <u>before</u> the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY

(Please indicate the decision according to one of the 3 options above)

> 2. Minor amendments

Minor amendments required *(for reviewer)*:

> It is of concern that there is no mention at all of the potential risk of emotional distress in the PIS, or how that will be dealt with. The PIS just states the study is 'safe'.
>
> It will be necessary to shield participants from the researcher's apparent presupposition that they will all have 'spoiled' identities.
>
> I question whether the design (8 people talking about one or two photos each) can really address the stated research question in any meaningful way and, therefore, whether it is ethical to ask women to spend time (and potentially experience emotional distress) on the project. I can't actually tell what 'self-stigma influencing identity' means. I suggest more thought is given to either the research question or the methodology. As written, you run the risk of misleading potential participants in to thinking that they may be contributing to meaningful research that might help people in some way. Perhaps terms like 'exploratory' or 'the thoughts of eight women' should be included in the title?
>
> Check that the details of the Ethics chairperson are up to date.
>
> (Not an ethical issue, but perhaps avoid claims like taking photos reduces male bias?)

Major amendments required *(for reviewer):*

>

Confirmation of making the above minor amendments *(for students)*:

> I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.
>
> Student's name *(Typed name to act as signature):*   Elizabeth Corker
> Student number: u1622854
>
> Date: 12/03/2018
>
> *(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)*

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES

If the proposed research could expose the <u>researcher</u> to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

☐ MEDIUM (Please approve but with appropriate recommendations)

☐ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*:   John Read

Date: 8.2.2018

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

Appendix 10. Data Transcript Extracts with Initial Codes

CP interview Pt 3 4.12.18 Riverhouse

Pt: so I think we all wear that mask, because even here you meet people but you just don't know, until they tell you that, you wouldn't know so erm, for me that's what it means but also, it's kind of very erm, it's kind of closed, for me it's got a good message, when I look at the mouth, it's trying to say something or the eyes are much closer, they close instead of being open which is normal, to that, to be shy, that's what I, am I being shy when I come to things I don't want to say so I just kind of close my eyes, the erm, mouth is almost like you want to speak but you can't speak, or you want to tell something but you can't, you can't tell a story, so erm, so it's almost like you it's almost like, so many things that you want to say when I look at it, so many things that you want to say but you can't say it so your mouth is always open, it's always like this ready to go but you can't let things out, erm because of also erm the way the system is, the way the system, I look at people like us, and it's almost like we don't have a voice really, don't have a voice, we don't have a face, somebody usually does everything for us, no matter what we do, no matter what we speak, we don't have erm, we don't have a voice

Int: yeah

Pt: everything is done for us, everything is labelled for us so, it doesn't matter when when we speak, in fact that's why a lot of people don't speak about thing or don't talk about it because it's not going to make a difference, it doesn't make any difference, you know, it's always people category when your ill, when you can't do this, you know, there's no, you system of erm, of saying oh today I feel better, today I can do you know, like how people, there's a lot of people want to work but erm because of what it is or because of erm the benefits system is, stuff, they can't do that, because if you do that, then you, you do that, it's makes us understand why you chose not to do anything, because they are worrying about where they are gonna sleep, where they are gonna get the food, where they gonna thing, so far I think it's a lot needs to be changed so that people can have more voice, people can have, people can you start, their eyes, open their eyes, their mouth, be able to talk about, erm, people, people just trying to get heard really

Int: yeah, yeah, so it's something about having like you said, the mouth's open but, there's

Name
Reflections on interview five
Reflections on interview four
Reflections on interview one
Reflections on interview three
Reflections on interview two

•Reflections on interview one

1. The 'disease like any other' message is quite powerful - in contrast to the new denial, differences between populations of people living with HIV? How do staff at the charity view this, does the message have different meaning for men and women?
2. Religion - suprised at how strong this value comes through, need to ensure own views re religion are not influcing questioning, felt a little awkward to probe for details. Bring to supervision.

Appendix 11. Table of Initial Codes

Code	Number of references	N	Example
Description of Dx	43	5	"especially those living with this, what I'm living with' P3
Medication	74	5	"I am doing very well, my medication, very good, I am undetectable" P2
Disclosure	88	5	"you have to find a way, how you gonna say about it, how you gonna go about it and sometimes it works with the strategy you have come up with" P 1
Distress	56	5	"sometimes I get upset, I sit and cry and cry and cry" P5
Stereotypes	52	5	"women be just think that you've, you are like that, you know, you are a loose, that's what made you get that you know illness" P4
Education	78	5	"everyone needs to know about HIV…. even those that are not infected because there is public enlightenment" P2
Perception of self	101	5	"you know, kind and polite and erm, quite a passionate what I want to do in life" P4
Outdated messages	47	5	"I think it's just because the way it was, like AIDS before, it was you know, people died a lot and people think they can catch it, you know even, having a cup of tea they think they can catch it" P3
Support/supporting people	114	5	"it's a very happy family whenever we meet you forget that you are HIV" P2
Perceptions of others	90	5	"I know how people are gonna say, about it, because I've lived long enough to see it" P3
Shame	91	5	"I can't tell anybody, if I say to anybody, the people going to stare at me, going to look at me different, don't come near me" P5
Gossiping	26	5	"I decided to ignore or the nonsense, all the gossiping all the people who are talking about HIV, everything" P4
Lack of voice or power	65	5	"so many things that you want to say but you can't say it so your mouth is always open, it's always like this ready to go but you can't let things out" P3
Health/benefits services	86	5	"my medical records is already telling you what I am, why do I have to fill in so many forms to actually prove that?" P3
Political problems	33	5	"to be honest, it is, well there is always a political, erm, gimmick around it, because the politicians will always like to pocket the money and not give it to the service" P2
Differences between UK and African countries	54	5	"in African countries, they are, and the situation is really bad, those who can afford, those who have got money get it" P4
Denial	28	4	"he passed away because he lived in denial" P2
Exclusion	31	4	"you've got no sense of belonging" P3
Battles	25	4	"I say, you know what, I have to keep on fighting, keep on fighting" P1
Helping others	52	4	"if I can manage to help I will, you know, do my best, you know go the extra mile" P4
'Disease like any other'	11	3	"it is like every other dis, diabetes, everything" P1

Religion	14	3	"I thank God a lot for that, he brought me here, yeah and I get all of the, everything I need" P5
Strength	19	3	"Then I started getting well and better, a better person, I stand up, I sing, I dance" P2
Survival	9	3	"people live in fear all the time of not having a roof over your head, not having food, not having anything" P3
Children	14	3	"I remember my children, and I thought if that were to happen to me, what would happen to them and I started crying, and they asking me, and I say nothing, I keep to myself" P5
Activist	18	2	"for me I call myself an activist, I'm an activist, I no longer call myself a victim" P1.

Appendix 12. Example of Coded Data Extracts

CODE	EXTRACT
Disclosure	it's not everybody who is gonna say, oh, you told them I am HIV +, not everybody is going to P1
	you can't go up to a church and go oh I'm positive, in church, even when I am talking about HIV, yeah, it's not that I go everybody tell me I am positive, I look at the person and say, well perhaps say this one, I can tell, I am able P1
	where I come from in the country, in the northern part of of [XXXX], no-one will tell you that they are HIV, and you can't tell anyone you are HIV positive because the next thing is, they start telling others, oh she is HIV positive, beware P2
	he doesn't want nobody to know that he's sick or HIV+ because he become a, object of ridicule, so, a lot of people, even me like I told you, none of my family members know P2
	I've seen people talking, not because they are talking about me, they are talking about it, the way they behave, towards that, the way they talk about it, so why should I open my mouth to say anything? P3
	no, nobody knows about it, just my ex-boyfriend, nobody knows P3
	even if now things are different I'm not gonna say anything to anyone to be honest, yeah, I've gone through too much, I don't want to, like, I just don't want to have to worry about what people are talking about, out there, I don't want to be facing that P3
	there's a difference here, because back home, uh, I had a lot of them, they just die in silence, because they are afraid to come out P4

	some of them, they are shy to come out, to see if they've got it, so that they can go and be tested and get uh, go, you know, start you know, on the tablets, ART, and stop dying P4 I don't tell them my problem P5 Even, up to now, I can't tell anybody, if I say to anybody, the people going to stare at me, going to look at me different, don't come near me all that I don't know P5
Perception of self	I stayed focussed, nothing changed me, hmm, nothing changed me, even people who I see say, are you still al, I say I'm still alive P1 remaining as a fighter, my strength, for me, I have been a fighter for many, for HIV now, for me I call myself an activist, I'm an activist, I no longer call myself a victim P1 I thought, oh my end has come, like I told you it was in 2000 so I thought that I would see 2001 so that's how it went on and on every time, I'm going to do my checks, my blood tests, my medication constantly, I'm taking it, so I think my entire orientation regarding being HIV + has changed, I'm happy, I'm a positive person P2 I'm still in work, I'm just not getting paid, maybe do collaboration with people, art stuff, and fashion stuff so that I'm, I'm still in there you know, I'm not completely left, so that's my plan P3 I can just um, try and live normal, maybe, maybe in future I can get my agent, I always wanted to get an agent because I'm quite good at what I do and it's such a waste not to be doing it P3 I'm someone now who is erm, you know, erm, strong and you know, you know, I've been describing myself as someone who is uh, you know, independent P4 since I came here, I've been independent, looking after myself, working really hard to look after myself P4

	I feel like I'm blessed with big big flower, and…yeah, god brought me here, to have a good life P5
Support or supporting	That is one person, you help another person, two people, three people, by the time, by now, you have helped a lot of people they say every tree it falls, you come as one, you come as one person, but you help maybe 20 people, it is a forest, one tree, you only come as a person, but you see the people grow, grow some move on, some are still there but they are, you are still giving them advice, which is good, information is getting them, advocating, is doing activists for them P1
	I find a lot of people calling me, oh [NAME] how are you, checking sometime, oh well I've got this problem, can you help me, I know you know most of the things, so most of the people it has improved or even with the, in public, they know, most of them, fort, fortunately P1
	I am a very very good volunteer, of good services, wherever there is need for help, I'm happy to do it, I'm always happy to help, to assist, even when I go to see my doctor, some people don't like anybody there, they say oh we have student doctors, yeah, are you happy if I don't talk then they don't learn anything, how do we get to the next generation of people that can take care of people like me? So, I'm happy to do that P2
	people tell me about doctors, how nice they are, in this country, how they listen to you to get to the bottom of your problems, so I wasn't expecting anything less when I was diagnosed, and true to my belief, it picked up automatically, getting all the friendship and the support and love I need, yeah, I have never had any cause to complain P2
	people there worked so hard for me, you know and, so, um, I spent nine months in bed, I had to learn how to walk P3

	even if they've got this medication, that we're living longer, but by having that medication you really have to, you all have to work together, it's not only your consultant, it's not the nurses, it's you yourself as well, have to work hard, you know, they can give it to you but you have to work hard P3 My own support is here, I say hello, I tell my problems and I go home and if I don't see them in the week I don't have anything P3 I can access any you know, medical needs which I need erm, and want, easier than is occurring than if I was back home doctors are so caring as well, they are supportive P4 here is some support I don't complain of having enough support, if I need anything you know I just go to the communities which help and then I can say whatever, or problem I'm facing and then they can help me, I haven't had any problem at all, yeah P4 they help me a lot, I can't do anything for myself, but they help me P5 The doctor talk to me, they say I'm lucky I'm here, so everything is gonna be fine, since, when they find out so they can look after me, talk to me, they talk to me and I find out, and I calmed down, so calmed down after that P5

Appendix 13. Initial Thematic Map
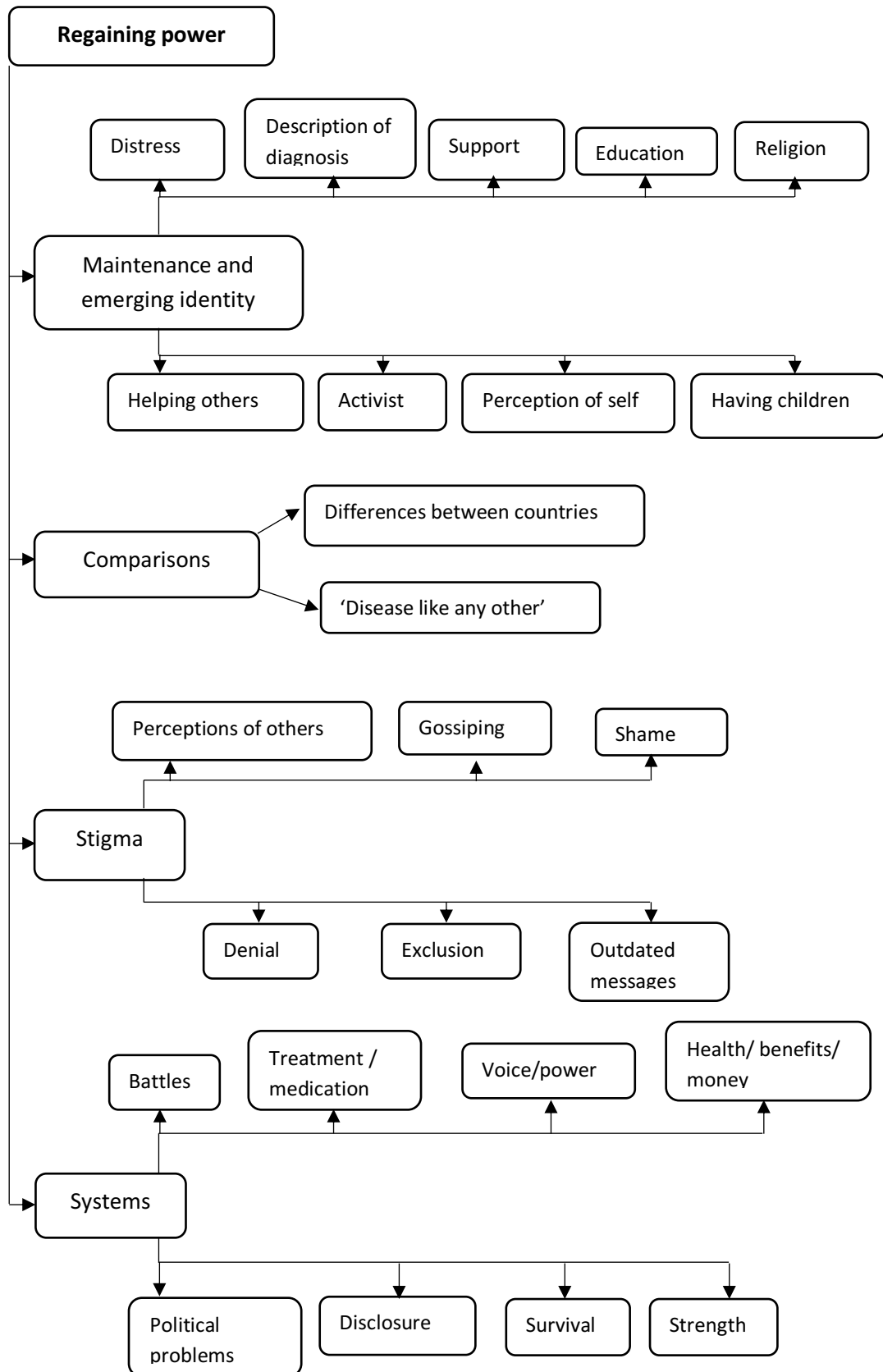
Appendix 14. Theme Development Table

CODE	INITIAL THEME	FINAL THEME
Distress	Maintenance and emerging identity	Retention of self
Description of diagnosis		
Support or supporting		
Helping others		
Activist		
Education		
Perception of self		
Children		
Religion		
Differences between countries	Comparisons	
'Disease like any other'		
Perception of others	Stigma	Prevalence of outdated information
Gossiping		
Shame		
Denial		
Exclusion		
Outdated messages		
Battles	Systems	
Medication		
Voice/power		
Health/benefits services		
Political problems		
Disclosure		
Survival		
Strength		

Appendix 15 Learning by Doing, Personal Reflection

Description (what happened?)
I became aware of the importance of religion in the first interview

Feelings (what were you reactions and feelings?)
I was aware of a further difference between my lived experiences and the participants lives, as I do not share these beliefs.

Judgement (what was good/bad about it)

Good: I was becoming more familiar with the importance aspects of the participants lives;

Bad: I was worried about appearing insensitive to important aspects of the participants lives .

Analysis (what was really going on?)

I can worry that I may not explore aspects of a participants life fully, as I do not want to cause offence by asking questions, also, I was worried about imposing my own views on the participants

Conclusions (general and specific)

General: Differences may provide a point of discussion and learning.

Specific: I prioritise an amiable atmosphere over probing for relevant information.

Personal action plan (what will you do next time?)

Set aside time for reflection and discussion with supervisors regarding early thoughts and feelings of the work, to maximise the learning potential.

Appendix 16. Learning by Doing, Epistemological Reflection

Description (what happened?)

Eight of the women who attended a Photovoice workshop decided not to participate. Reason given for not participating was that other things took priority

Feelings (what were you reactions and feelings?)

I felt that there may have been other reasons for women not wanting to participate, however, they may have felt uncomfortable when asked directly.

Judgement (what was good/bad about it)

Good: I was attempting to understand the barriers to the research;

Bad: I was aware that the researched/researcher dynamic was in play.

Analysis (what was really going on?)

I was worried that the principles of PAR and Photovoice were not coming through and worried about my part in setting up the dynamics between the participants and myself.

Conclusions (general and specific)

General: I have a 'default' position as a 'researcher'

Specific: My presence may have hindered critiques of the research.

Personal action plan (what will you do next time?)

Set aside more time for engagement and design the project around the timeframes and needs of the participants.