Active ageing and unfinished resilience amongst older heterosexual adults living with HIV in the United Kingdom

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Abstract

The UK is seeing a change in the lives of people living with HIV. Due to the advent of Anti-Retroviral Therapy (ART) in the mid-1990s, the landscape of HIV has changed rapidly in terms of people living longer with the virus. Due to this, the first major cohort population of older people will now grow older with the virus. This sociological study examines the lived experiences of older heterosexual people living with HIV in the UK. This study examines the lived experiences of ageing, to explore active ageing and resilience building within older heterosexuals living with HIV, despite the socio-historical backdrop as a marginalised demographic in wider HIV narratives. Furthermore, it reconceptualises Sontag's concept of 'social death' with HIV, to the contemporary *long shadow of social death,* recognising the changing nature of HIV-related stigma in the post-ART era. To gain insight into the lives of older heterosexual people and how they navigate this post-ART world, this study uses the theoretical lens of both *active ageing* and *unfinished resilience* to understand the lived experiences of older heterosexual people living with HIV.

Taking an interpretivist epistemological approach, and an in-depth life narrative method with nine older heterosexual people living with HIV, three key themes emerged in the data analysis: *changing bodies, changing communities, and changing mindsets and futures.* The research found that despite their socio-historical invisibility and marginalisation, older heterosexual people engaged in a process of unfinished resilience and active ageing. Notwithstanding uncertainty about their own bodies and sense of community, they actively engaged in social networks and took part in future goal setting, as opposed to the absolutist effects of stigma and the long shadow of social death, facilitating social withdrawal. This study represents an original contribution to the field of the 'Sociology of HIV' by bringing to light the voices of an under-researched group using these theoretical approaches, and the findings that it produced.

Keywords: *HIV, heterosexual, active ageing, unfinished resilience, long shadow of social death*

Contents

Glossary of Terms

HIV	Human Immunodeficiency Virus: A virus which can cause AIDS if left untreated (more information about this in chapter one)
AIDS	Acquired Immune Deficiency Syndrome: If left untreated, HIV will develop into AIDS in most cases, which is a collection of illnesses and when the body's CD4 cells fall below 200 per mm3 (more information about this in chapter one).
MSM	Men who have sex with men: a term used in public health instead of 'gay' or 'bisexual' men as not all men who have sex with men identify as a homosexual identity.
LGBTQI+	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex: an umbrella term for minority sexual orientation and gender identities.
ART	Anti-retroviral therapies: drugs used for the treatment of HIV.
PeP	Post-exposure prophylaxis: drugs used to stop the development of HIV for up to 72 hours after initial infection.
PrEP	Pre-exposure prophylaxis: the same drug regime as PeP which is used to block HIV infection in someone who is HIV negative.
Post-PrEP era	This is generally referred to as the era of new HIV treatments after the development of ART drug treatments in 1996.

Chapter One: Introduction to this Research

This chapter will contextualise the thesis by exploring its importance, as well as examining some of the key barriers that are faced by, and impact upon, older people living with HIV in the UK. In doing this, the general research question is set out, with the main aim, objectives, and key research questions, as well as the chapters of this research document to give a clear structure of the project, and an overview. Finally, this chapter will also examine the contribution and originality of this research project. Before this is all explored, the chapter will discuss a unique case study which frames the changing nature of growing older with HIV.

On October 16th, 2019, the world's oldest known person living with HIV, known as the 'Lisbon Patient,' died in a Portuguese hospital after celebrating his 100th birthday. Known as 'Miguel' in the popular press, he was originally given an AIDS diagnosis due to a low CD4 count when he was 84 years old, in 2004. However, due to medical advances, in 2019 before his death he presented an undetectable viral load. He was reported by the world's media, and by his own medical specialists, to be 'in good health' (Scheibelhut, 2019). Not only does this case study present a very public example of the first known centenarian to grow older and live with HIV, but Miguel also identified as heterosexual, having contracted his HIV through sexual intercourse with women. Miguel was one of the 7.5 million people worldwide aged 50 and above who were at that point growing older with HIV (UNAIDS, 2020). This case study highlights the changing present and future of HIV, and the lived experiences of those who are living and growing older with the virus in contemporary Western society. It was especially notable that the first centenarian to be documented to be living with HIV was a heterosexual male.

As case studies such as these start to emerge in the media and to mark significant events (in this case, the first-ever HIV centenarian), different demographic groups affected by the virus are emerging, and details of their process of growing older with the virus. Whilst HIV has often been framed as something which disproportionately affects Men who have Sex with Men (MSM) historically and still today (NAT, 2021), this is largely inaccurate, as heterosexual populations have been present from the beginnings of the history of the virus in the UK. The case study of the ‘Lisbon Patient’ neatly frames how HIV and ageing are seeing a significant sea change in the West due to better medical advances. This raises key questions about what it means to live with HIV into later life. Yet, Human Immuno-deficiency Virus (HIV), and if left untreated, AIDS (Acquired Immuno-deficiency Syndrome) continues to rise across the globe (WHO, 2020). It is important to start by examining headline HIV statistics globally and in the UK, to examine what this means for populations testing later in life, and growing older with HIV.

HIV and AIDS - from global to local

By 2020, approximately 37.9 million people were living with HIV and AIDS, 36.2 million being adults, and 1.7 million children under the age of fifteen (WHO, 2020). In 2020 alone, an estimated 1.5 million individuals became infected (known as ‘HIV incidence’) with HIV, with up to one million AIDS deaths globally. Of these, 28.2 million people living with HIV (73%) were accessing medication to prolong their lives and reduce viral loads through antiretroviral therapy (ART), seeing the global usage of ART increase by 1.6 million people since 2017, up from 8 million people in 2010 (WHO, 2020). By 2020, the United Nations set an ambitious global target to tackle the HIV and AIDS epidemic with their ‘90-90-90’ goal, setting three clear targets, which were: 90% of all people living with HIV who will know their HIV status, 90% of those who know their HIV status will be on ART, and 90% of people receiving ART will have viral suppression, meaning that the HIV virus will be undetectable in their system.

Whilst the 90-90-90 goal was not achieved universally by its expected target date in 2020, significant movement was made. As of the 2020 global figures, 84% of people living with HIV across the globe now know their HIV status. In addition, a further 87% of people are now accessing ART treatments, and 90% of people who are taking ART now have their virus suppressed and so are undetectable (UNAIDS, 2020). Furthermore, countries such as Botswana, Cambodia, Denmark, Swaziland, Namibia, and the Netherlands had all reached the United Nation’s targets. Significantly for this research, these nation-states were also joined by the UK who had also achieved the same targets by 2020, seeing a notable decline in new HIV diagnoses in 2019 (Public Health England, 2020). The development of medical advancements, a coordinated shift in treatment detection, and the dramatic growth in tackling HIV and AIDS on a global level, have had significant effects on local lives. This development frames the background as to why many older people living with HIV are living longer with ART, and yet it also presents unique challenges to the lives of older people living with HIV, which will be explored in this research.

This process of growing older with HIV is not only global, but there is an emerging population of older people who are both living with HIV and finding out their HIV status later in life in the UK (Public Health England, 2020). Despite not receiving significant public attention, and before the emergence of COVID-19, HIV remained one of the most important communicable diseases in the UK for older people (Ridgers, 2013; Public Health England, 2020). In 2019, of the overall 106,890 people living with HIV in the UK, around 5,150 were undiagnosed and unaware of their status, meaning they are likely to be diagnosed late when HIV which can present more challenging problems (Public Health England, 2020). Of those diagnosed late with HIV, 55% of these were heterosexual men and 51% were heterosexual women, compared to only 35% of MSM diagnosed late, with MSM seeing a significant fall of 18% in their demographic over previous years (THT, 2021). Whilst the number of late diagnosis of MSM have decreased, and have continued to do so since 2012, there was an increase of 1,559 in new infections amongst the heterosexual population (Public Health England, 2020). These figures highlight the need to understand more about older people growing older with HIV and importantly, the heterosexual demographic within this, who seem to be a significant ‘at risk’ group in the UK.

Whilst it is now increasingly common to live later in life with HIV in the West, the numbers of older people aged fifty and above in the UK living with HIV have still doubled over the last decade (NAT, 2022). More than two in five people accessing HIV care in 2019 were aged fifty or over (41,855 - 42.4%), and for the first time since 2010, the number of people living with HIV aged fifty and over matches that of the thirty-five to forty-nine-year-old age group (41,832 - 42.4%). This shows how effective treatment is in helping people to live longer with HIV (NAT, 2022). Due to older people within the category of fifty and over, being more likely to be diagnosed late, they are more likely to present unique challenges to their own health, and to medical, health, and social care services (THT, 2019). Yet, more people are now growing older with the virus due to better medical care and ART (Public Health England, 2022), with more people who receive specialist care now aged fifty and over compared to less than one in five in 2007 (THT, 2022). With this growing population in mind, the following section will highlight what is meant by an 'older person,' in line with these statistics, and for the purpose of this research.

What is an 'older person'?

The Department of Health's 'Framework for Sexual Health Improvement' (2013) refers to the older person demographic as, "people aged over 50" (DH, 2013: 20), and sexual health statistics recorded by Public Health England (PHE) now report on the age groups of over fifties (Public Health England, 2020). In line with these demographics and within this thesis, the 'older person' will be defined as men and women above fifty years of age, following best practice and the statistics taken by official organisations and government departments (Public Health England, 2020; NAT, 2022; THT, 2022). Working definitions of older people may vary, but for the purposes of this thesis the study will follow the demographic guidance as stated above, as applicable to the UK.

Why research older people living with HIV?

Older people living with HIV are said to be the first-ever generational cohort who will be growing older with HIV in the UK (THT, 2022), and in doing so, will present new challenges to the HIV sector, and wider services.

Older people's access to sexual health services and research into the needs of older people living with HIV, is a newly emerging field and so much of the academic and policy literature is still absent, or being explored (Rosenfeld, et al, 2021). Despite the range of and differing sexual health needs within the over-fifty age groups, there is a recurring theme that older people with sexual health needs and HIV are largely invisible in mainstream health-service provision (FPA, 2011; Marsillas, et al 2017; Rosenfeld, 2021). In light of this and the growing statistics outlined earlier, as well as the under-researched nature of older people living with HIV, all led to an interest on my part to examine their lives.

Literature also suggests that this 'greying' of the HIV epidemic is mainly due to three factors: 1) the success of antiretroviral therapy in prolonging the lives of people living with HIV and the emergence of Pre-Exposure Prophylaxis (PrEP); 2) decreasing HIV incidence among younger adults shifting the disease burden to older ages, and; 3) the often-unmeasured, and thus often overlooked, fact that people aged fifty years and older exhibit many of the risk behaviours also found in younger people (UNAIDS, 2013, 2019). Due to these shifts and with the success of antiretroviral medications, longevity has increased for those older living with HIV and there have been increased numbers of older people diagnosed. Improved screening methods have identified more new cases of the virus, and as a result of this, the number of older adults living with these conditions is said to increase in years to come (Population Reference Bureau, 2009; Roger, Mognone and Kirkland, 2013; NAT, 2022). The UK is now seeing more heterosexual and MSM older adults who are now ageing with HIV (Brennan, Emlet and Eady, 2011; Roger, Mognone and Kirkland, 2013; Public Health England, 2020; NAT, 2022).

Whilst under-researched, the literature on older people living with HIV suggests that this group may not always have a complete understanding of best practice with sexual health, and once older people are diagnosed with HIV they will face unique barriers. In particular, the barriers and issues faced by all older people living with HIV are broadly based around the following four topics, from some of the research initially available:

(1) lack of awareness of HIV transmission and older people's knowledge of their own sexual health needs;
(2) the effects of HIV on their physical health;
(3) the effects of HIV on mental health, and;
(4) stigma faced by older people living and ageing with HIV.

The following discussion will briefly touch upon these four issues and barriers for older people living with HIV, to set some brief context of the study, and to highlight a general overview of the problems faced by older people living with HIV. It will then justify why older heterosexual people as a demographic are to be researched in this study.

Barrier 1: Lack of awareness of HIV transmission and older people's knowledge of sexual health

The first key barrier faced by older people living with HIV is the lack of awareness of transmission and knowledge of sexual health. Whilst there is a growing prevalence of older people living with HIV in the UK and further afield, research into the lived experiences of older people has not followed the same trajectory. A number of studies come from the USA, with only a fledgling field of research within the UK. To date, there have been very few UK studies of provider knowledge about HIV issues related to older adults (Hughes, 2011; Brown, et al, 2019; Rosenfeld, et al, 2021). Although this field is growing, a significant amount of research so far has focused predominantly on older MSM, which is evident in this ensuing discussion and is the result of an already large visible population affected by the virus and who are living longer after ART. Although researchers have been aware of HIV and ageing since the early days of the AIDS epidemic, the limited amount of research about all older adults in the past twenty-five years has led to most older adults living with HIV as ‘overlooked’ (Furlotte, et al, 2012; Brown, et al, 2019).

The following section will dip into some of the research outlined so far about older people living with HIV generally, before examining why this research will explore heterosexual older people in particular.

A minority of research studies have examined how HIV and AIDS affect the ability of older adults to maintain their social networks, with few studies systematically examining the informal networks that provide critical support for the rapidly growing population of older adults living with HIV and AIDS (Shippy and Karpiak, 2005). With the ageing of HIV populations, there is currently a great deal of speculation, but less evidence-based understanding, about the impact of ageing with HIV and the long-term prospects of its treatment (Lawrence and Cross, 2013). As we enter the fourth decade and beyond with HIV, it is more vital than ever before to focus on the quality of this extended life which is now common amongst older people living with HIV (Shippy and Karpiak, 2005; Cahill and Valadez, 2013).

What is apparent from the available research and sexual health statistics, is that older people are engaging with sexual contact and sexual relationships with others. Although the prevalence of sexual activity may decline with age, research indicates that men and women engage in vaginal intercourse, oral sex, and masturbation even in their eighties and nineties (Lindau, et al, 2007). Therefore, many people remain sexually active well into their later years, despite prevailing assumptions and ageist attitudes to the contrary (Cahill and Valadez, 2013). For older men, the availability of erectile dysfunction medications through both prescription and non-prescription sources, provides more opportunities to take part in sexual intercourse (including commercial sexual intercourse) through the internet and social media, which may facilitate the capacity for and access to sexual activity (Brooks, et al, 2012).

However, older people are often less informed around the risks linked to their sexual behaviours, or the need to practise safe sex. For example, this age group may be less likely to use condoms, as they associate their use with pregnancy prevention rather than protection against STIs (Gott, 2005). Furthermore, lower rates of condom use among older adults may be linked to a lack of knowledge about HIV transmission and the effectiveness of condoms in preventing HIV and other sexually transmitted diseases (Cahill and Valadez, 2013). Older heterosexual people, who may include persons who have become recently widowed or divorced after being in a long-term monogamous relationship, often evidence a poor understanding of their risk for HIV transmission. As such, they often perceive HIV as something which affects predominantly young people or MSM (Brooks, et al, 2012). Some older people, compared with those who are younger, may be less knowledgeable about HIV and AIDS and therefore be less likely to protect themselves and as such, many do not perceive themselves as being at risk for HIV, do not use condoms, and do not get tested for HIV (Henderson et al, 2004; Lindau et al, 2006).

Sexual risk factors for older adults are largely the same as for younger people. These include unprotected sex, drug use, and lack of knowledge about how HIV and AIDS are transmitted. Although some risks may be lower in older adults, identification of these risks may also be less likely because physicians do not often initiate discussion of HIV testing with older adults. In terms of evidence of this, 73% of adults aged 57-64; 53% aged 65-74 and 26% aged 75-85 all report being sexually active, but fewer older people than younger people discuss sex with their physician (Shippy and Karpiak, 2005). Earlier studies of behavioural risk and prevention show that amongst the majority of adults aged between fifty and seventy-five, only a small percentage use a condom or have undergone HIV testing (Mack and Ory, 1998). Most HIV and AIDS education is tailored to a younger population, and much of the materials provided are not age-appropriate for older adults (Levy-Dweck, 2005).

In a survey of informal social support services of adults living with HIV over fifty, 40% felt it was difficult to access formal services due to lacking knowledge of where to go (Shippy and Karpiak, 2005) or many older people feel that the services are geared towards younger adults (Brown, et al, 2019). This neglect of older people may be a consequence of media images of lust and sex being reserved solely for young and 'attractive' people, which usually only serves to reinforce the myth that older people are, or should be, sexually 'retired' (Gott, 2005). However, despite society's perception of who fits into the sexually active category, and a general belief that sexual desires decrease with age, older people generally maintain sexual interest and remain sexually capable into their nineties (Gott, 2005). As a result of this, a key demographic of the population is not presenting knowledge of sexual health when seeking sexual contact and relationships. This creates issues in terms of not only HIV transmission to individuals, and onward transmission to others, but also through problems of those living with HIV and growing older with it once infected. Whilst these statistics give an indication of awareness of transmission and sexual health knowledge amongst populations, the effects of growing older with HIV have also been under-researched, which will be discussed below.

Barrier 2: The effects of living with HIV on older people's physical health

The second key barrier for older people living with HIV surround problems related to physical health. Living longer with HIV presents its own unknown issues in terms of physical problems associated with the virus. Due to the current age cohort being the first major generation to grow old with the virus, much of the physical effects are as yet unknown. It has been suggested that long-term exposure to ART (Anti-Retroviral Therapies) may increase the risk of heart attacks and heart disease resulting from specific classes of ARTs, and so adults living with HIV are at a greater risk of dying or contracting new illnesses (Cahill and Valadez, 2013). It is also suggested that even when the immune system is stabilised by the use of ART, HIV has the ability to accelerate the effects of ageing, especially in relation to cognition (Effros, et al, 2008; Desai and Landay, 2010; Deeks, 2011; Roger, Migliardi and Mognone, 2012) and this can lead to early onset of frailty and diminished functional performance. Finally, older people living with HIV and AIDS also report more general chronic medical conditions and limitations in physical functioning (Population Reference Bureau, 2009; Brown, et al, 2019). They also face a range of new and unique physical experiences and challenges as they age, which have yet to be identified (Rosenfeld, et al, 2012). This is as yet an unknown area within research. Physical issues may deeply affect the mental health of people living with the virus and the stigma around HIV, however, this is as yet speculative and needs further research.

Barrier 3: The effects of HIV and older people's mental health

As well as physical health, the third barrier faced by older people living with HIV is mental health issues. Depressive symptoms and suicide are regularly recorded amongst older people generally, especially the elderly aged sixty-five years and older (Brooks, et al, 2012). Yet, with complex health problems, scarcer financial resources, and greater isolation than many of their peers, older people living with HIV face major challenges, particularly regarding their mental health (Power, et al, 2010; Brown, et al, 2019). Although common amongst older people generally, people living with HIV of all ages experience much poorer emotional well-being compared with the general population, including patients with other chronic diseases, except for diagnosed depression (Cahill and Valadez, 2013).

'Minority stress theory' contends that minority populations, such as those living with HIV, can also be exposed to unique stressors that create strains on individuals as they attempt to adapt and function in their everyday environments, which in turn negatively affects their well-being (Wright, et al, 2012). Therefore, it is no surprise that older adults living with HIV are more likely to be diagnosed with depression compared with the general population, as well as facing a greater prevalence of substance use because of HIV diagnosis. The rate of depression has been shown to increase with age and to be linked with poorer physical health outcomes (Gebo, 2006; Grov, et al, 2010; Sanker, et al, 2011; Brown, et al, 2019). Furthermore, the mental health needs of older people living with HIV can often be overlooked by nurses and doctors who may focus their attention on the physical impact of HIV, even though depression can exacerbate immune-system dysfunction for those living with HIV (Peate, 2013).

There has been much discussion as to whether formal health and social care systems are prepared for a growing epidemic of older people living with HIV and whether mental health could be a limiting factor (Rosenfeld, et al, 2012). Although research on older people living with HIV in congregate living facilities is limited, evidence suggests that stigma persists among other residents, as well as staff charged with the care and well-being of their residents (Cahill and Valadez, 2013). Power et al (2010) found that older MSM living with HIV are fearful that social care services, care homes and sheltered housing may be HIV-prejudiced or homophobic, or both, and while the majority in their study thought highly of their personal HIV clinicians, many reported poor experiences in primary care.

The mental health and health and social care needs of older people living with HIV in the UK have not been suitably addressed (Peate, 2013). It is already known that health and social care systems are struggling to cope with the current demand made by society, and as older people live longer with HIV, the systems will be further challenged (Peate, 2013; Rosenfeld, et al, 2021). However, alongside a perceived and actual unsympathetic health and social care sector, poor physical and mental health as a key barrier are factors which potentially exacerbate social exclusion, loneliness, and the ability to meet others for involvement within relationships and sexual contact (Brown, et al, 2019).

Barrier 4: Older people living with HIV and HIV-related stigma

With issues around lack of awareness of sexual health, poorer physical and mental health, the fourth key barrier is the impact of HIV-related stigma faced by older people living with HIV. Whilst the research is generally limited as outlined already, not all research points toward negativity when growing older and living with HIV. Older people may also feel more optimistic due to the advent of new antiretroviral medications and the availability of PrEP, leading to undetectable viral loads. Having lived with stigma and discrimination, survived friends and lovers who have died and, in some cases, avoided HIV infection, some older MSM may experience a greater sense of freedom, power, and a positive outlook on life (Genke, 2004). Furthermore, stigmatisation does not always lead to disadvantage for the stigmatised and can be challenged; within certain contexts, people may gain status if they ‘come out’ about a stigmatised characteristic by becoming legitimate spokespeople for minority or marginalised groups in the process. This stigmatised status forms the basis for many minority HIV group identities, and so establishes their legitimacy in lobbying for government recognition (Deacon, 2006).

Although older adults, in general, can be affected by ageism and stereotyping, those living with HIV and AIDS face the additional stigma that may be associated with HIV and fear of the virus (Roger, Mognone and Kirkland, 2013). Emlet (2006) examined the impact of stigma and ageism in twenty-five older adults living with HIV and found that one-third of participants expressed sentiments or beliefs that they experienced perceived stigma related to the ageing process, particularly around their ‘invisibility’ as older people. This is illustrated by the perception that before diagnosis they were neither ‘at risk’ for HIV infection nor already infected. This attitude is driven by misinformation, stigma, and ageism (Shippy and Karpiak, 2005) not only from healthcare providers, but also the wider society around them and can impact the practising of riskier sexual behaviours. This also hints at the cultural memory of who is thought to be at risk of catching HIV, which will be analysed in chapter two.

Stigma is a complex reality where ageism, beliefs about HIV, gender, values regarding sexuality, addictions and mental health can combine to create a negative daily lived experience (Roger, Mognone and Kirkland, 2013). As mentioned previously, ageism, loneliness, and social isolation, which may be exacerbated in the face of ageing, are related to mental health issues such as psychological distress and depression among older adults living with HIV. Grov et al (2010) found that among older adults living with HIV over fifty years old, 39% exhibited signs of major depression; also that loneliness, stigma, and decreased cognitive functioning were significant predictors of depression.

This can all influence treatment adherence (Ware, Wyatt and Tugenberg, 2006), alter the use of social support and social networks due to fears of rejection (Emlet, 2007) and affect HIV testing and status disclosure with sexual partners (Frost, Parsons and Nanin, 2007; Cahill and Valadez, 2013). Many older people living with HIV experience social avoidance, the real or perceived loss of friends, and the sense that people are uncomfortable being around them due to their HIV status (Cahill and Valadez, 2013; Peate, 2013). Older MSM living with HIV often become disconnected from their friends, family, and society at large, with many men reporting feeling separated, alone, isolated and rejected by their HIV-negative community and peers (Power, et al, 2010). These are not issues unique to MSM, however, as some heterosexual women living with HIV also describe a diminished sense of sexual attractiveness following HIV infection, and similar levels of loneliness (Cahill and Valadez, 2013). More recent results show that one in six UK women living with HIV have not told anybody outside of healthcare settings about their status, and one in five have experienced discrimination within healthcare settings due to their status (Brown, et al, 2019).

These four key barriers give a flavour of the general issues faced when living with HIV as an older person; such as physical health whilst rapidly ageing with HIV, or the more insular mental health aspects of the individual and the impacts of depression and isolation. HIV stigma from the research so far appears to thread throughout this process and creates conditions of ignorance about older people's sexuality generally across all groups, but also perceptions of how HIV is seen by those within the wider social world, and the lived experiences of older people who live with HIV.

Research justification

The scarcity of research on heterosexual men and women living with the virus has already been highlighted; it is vital that the lived experiences of older heterosexual men and women are researched. Due to research bias, most HIV research has generally focused on younger or older MSM, and there is a pressing need for more research into older heterosexual people living with HIV (Peate, 2013; Ridgers, 2013; Ross, Humble and Blum, 2013; Brown, et al, 2019).

There is a paucity of research in the social sciences to explain the lived experiences of older heterosexual populations in the UK, as they have largely been overlooked by both service providers and researchers (Power, et al, 2010; Sophia Forum and THT, 2018). Much of the research into the lives of older heterosexuals living with HIV has tended to come from the USA (Persson and Barton, 2006; Millard, 2009; Higgins, Hoffman and Dworkin, 2010) or Australia (Grierson and Mission, 2002; Persson et al, 2006), though even these studies are not abundant.

The growing statistics of older heterosexuals, both men and women, living with HIV in the UK increasingly face late diagnosis, seek late treatment for HIV, and have potentially poorer outcomes as a result, mean that this is an important site to explore. Furthermore, the lived experiences of older men and women with HIV are significantly under-researched, which means the experiences of this demographic grow ever more in importance to justify the foundations of this research.

Research aim, objectives, and key questions for this research

This research project frames older heterosexuals living and growing older with HIV as a site of key importance. In a post-ART climate of living and growing older with HIV, and due to being an under-researched group, this research is both timely and relevant. Within changing and often uncertain times faced by the demographic of older people living with HIV (Rosenfeld, 2014), this research focuses on how this population of older people in the UK navigate ageing and resilience; as well as how this manifests in their lives, with the HIV stigma setting framing a wider backdrop. From this, I formulated a research aim, objectives, and key questions which will now be examined and then taken further into the study.

Research aim

To examine the lived experiences of older heterosexual people living with HIV in the UK and to investigate how this demographic navigates ageing and resilience as they age with HIV.

Research objectives

- review the existing literature on older people living with HIV in the UK, their experiences, and issues that they face as they age with HIV.
- critically examine the impact of social structures and wider socio-historical influences on the lives of older heterosexuals living with HIV in the UK, and what this might mean for them.
- critically examine whether the lived experiences of older heterosexuals living with HIV in the UK include a sense of agency whilst ageing with HIV, and what this means for them.
- examine the impact of ageing, resilience, and stigma on the lives of older heterosexual people living with HIV in the UK, and how they traverse their lived experiences in light of these.

- interpret the life narratives of heterosexual people growing older with HIV, to further an understanding of this under-researched group in the UK.

Key questions

The key questions which are central to this research project are as follows:

- What do the lives of older heterosexual people living with HIV look like, and what barriers, pressures, and opportunities do they face?
- How do older heterosexual people living with HIV experience their own sense of both ageing and resilience?
- If stigma exists for older heterosexual people living with HIV, what does this look like and how does it impact their lives?
- How do older heterosexual people living with HIV shape and mould their futures in a post-ART era?

The structure of this thesis

Chapter two outlines the socio-historical development of HIV and AIDS in the UK and how MSM were projected to the forefront of the HIV and AIDS epidemic. This is to frame the marginalisation and invisible nature of the lives of heterosexuals living with HIV in the UK as a wider conceptual backdrop to the research. This chapter analyses the legacy of HIV's construction on the cultural memory of HIV, and the framing of heterosexual populations within this, including what it means for this demographic today.

Developing from chapter two, chapter three outlines the key theoretical literature which will be analysed in the study. This chapter is split into three sections which examine theories and concepts taken up in this thesis, but before doing so, chapter three examines the life course approach to understanding ageing in order to set a foundation. Part one critically examines different theories of ageing, and then examines how active ageing will be taken forward in this study. While part two critically engages with theories of resilience, finding the existing models of ‘made’ and ‘found’ resilience to be unsuitable for this research; before settling on Aranda et al’s (2012) concept of ‘unfinished resilience’ as a useful tool in which to examine older heterosexual people living with HIV. In part three, the chapter examines theories of stigma. Then interlinked to this, re-conceptualises Sontag’s (1989) theory of ‘social death’ as applied to HIV; advancing it further in light of social changes to people living with HIV by introducing the notion of the ‘long shadow of social death’. With the backdrop of the socio-historical development of HIV from chapter two, these theories and concepts are then brought forward, deeper into the study.

Chapter four outlines the methodological approach used in researching older heterosexuals living with HIV, including the positionality of the researcher, the method used to research the respondents, their pen portraits, and the data coding and analysis method used in this research. Chapters five, six, and seven bring together the three key themes from the research from the respondents’ lives, bringing their voices to the forefront of the research. These key themes focus on: 1) changing bodies; 2) changing communities, and; 3) changing mindsets and futures.

In relation to the overall key research questions as specified in chapter eight, analysis of these three themes cuts across these research questions as a whole. The chapter then critically engages with the theoretical concepts brought forward from chapters two and three, applying them directly to the key findings of the research as a data analysis chapter, which frames the theoretical approaches in light of the main findings.

Chapter nine builds upon the findings and data analysis, offering a conclusion to the thesis by presenting the key findings and recommendations of the research. It argues that in spite of respondents’ ageing and uncertain bodies, their larger invisibilisation and marginalisation within wider historical HIV narratives, and the lack of wider HIV support for their needs, older heterosexual people living with HIV are not socially withdrawing under the threat of stigma, and the long shadow of social death. Instead, they are finding new ways in which to navigate and plan their present lives and future goals as they actively age and develop their unfinished resilience, finding ways in which to mitigate against stigma and the long shadow of social death. In light of an uncertain ageing process whilst living with HIV, unfinished resilience and active ageing are key to their lives. In the sense that respondents neither 'found' nor 'made' their resilience, but instead navigated obstacles and social pressures as they moved, and actively aged throughout their life course. This conclusion also considers what systematic improvements will be needed to enable older heterosexual people living with HIV to continue to thrive as they age, offering further recommendations for theory, policy, and practice.

What original contribution does this research make?

This research is a ground-breaking investigation of the experience of living with HIV amongst older heterosexual people. This research offers an original contribution to the social scientific literature on HIV through reconceptualising and updating an existing theoretical approach from Sontag (1989), examining this in light of the lives of older heterosexual people living with HIV. Furthermore, this research adds to the under-researched demographic of older heterosexual people living with HIV in the UK and is unique in that it uses active ageing theory and unfinished resilience as theoretical lenses to examine their lives. Finally, an original contribution also lies within the use of narrative methods with respondents, who brought their own uniqueness via their original life stories. To examine the backdrop of social forces that have impacted the lives of these older heterosexual people living with HIV in the UK, the following chapter will explore the socio-historical development of HIV and AIDS in the UK and what it means for older people living with HIV today.

Chapter Two: HIV, Ageing, and Heterosexuality

Chapter rationale

The history of HIV and AIDS has laid the cornerstone of how it, and those affected by it, have been constructed. The aim of this chapter is to show how HIV and AIDS emerged in the UK, and to situate this within a changing landscape, framing and the invisibility of heterosexual populations. This chapter will argue that the socio-historical framing of MSM as an ‘at risk’ population by various actors and institutions, has led to a subsequent marginalisation of heterosexual voices throughout the epidemic. This chapter will examine a more empirical focus on the research and data around heterosexual men and women living with HIV in the UK, focusing on their experiences, needs and the barriers faced by them. Using this data, the experiences of older people living with HIV will be discussed, revealing a general paucity of research focused on heterosexual populations, and especially on those who continue to age with the virus. It is important to firstly examine the socio-historical beginnings of HIV and AIDS in the UK, and to examine the framing of MSM as the dominant group most affected by HIV. This framing of MSM has impacted the invisibility and marginalisation of heterosexuals who were also at risk of HIV, within the larger HIV narrative. The following section will discuss this evolution further.

The history of HIV and AIDS in the UK – the early framing of Men who have Sex with Men (MSM)

In order to examine the history of heterosexual people living with HIV, it is important to put this within the wider context of the history of HIV and AIDS in the UK. In 1981, following reports that a number of young gay men had died of PCP *(Pneumocystis Carinii Pneumonia)* in New York and San Francisco, the first known cases of an unknown virus came to media prominence (Altman, 2002; Fowler, 2014). The first probable case of somebody in the UK dying of AIDS was a forty-nine-year-old man (sexual orientation unknown) admitted to Brompton Hospital with PCP and a weakened immune system, after returning from the USA and then dying ten days later of his condition (Altman, 2002). By 1982, signs of late-stage HIV and AIDS emerged in prominent media reports when one of the first high-profile UK victims, a gay man named Terrance Higgins, collapsed whilst at the gay nightclub, Heaven, in London. In 1983, it was discovered by medical professionals that a number of people had developed late-stage HIV, and the onset of AIDS, after being given blood transfusions. These were notably haemophiliacs (many of whom were later noted to be heterosexual) during the course of their treatment, as well as other blood transfusion recipients (THT, 2022).

During the time period above, some American nationals within the LGBTQI+ community were also dying, and this was gaining substantial press coverage globally, with the UK press naming and stigmatising this as the 'gay plague' (Weeks, 2000, AVERT, 2021). Due to this, powerful early messages of 'who' was more likely to have HIV and AIDS were heavily linked to homosexuality rather than heterosexuality, and so 'HIV and AIDS' and 'homosexuality' became almost synonymous in popular imagination (THT, 2022). Initial media-related scare tactics (Weeks, 2000), with a combination of public fears of the virus, helped to form an early HIV-related stigma which has continued throughout the epidemic, particularly toward MSM. From the moment scientists identified HIV and AIDS, public responses of fear, denial, stigma, and discrimination accompanied it (AVERT, 2022). Altman (2002) highlights this in his work, stating that HIV and AIDS mixed sex, death, fear and disease in ways that can be interpreted to suit the prejudices and agendas of those, "controlling particular historical narratives in any specific time or place. Fear of infection all too easily translates into fear of the infected. The disease has been used to stigmatize various out-groups" (Altman, 2002: 71). The then narrative around HIV and how certain groups (MSM) were highlighted, led to stigma around the virus, and the invisibility of heterosexuals in early discussions of HIV and AIDS in the UK, which will be examined next.

This stigma and discrimination were also seen quite clearly in some of the early and public reactions toward HIV and AIDS by moral entrepreneurs in the UK eager to connect a link between a problem of a particular way of life amongst MSM, who were already an unpopular minority, said to value promiscuity, irresponsibility and carelessness (THT, 2022, NAT, 2022, AVERT, 2022). The former Member of Parliament, and News of the World columnist, Woodrow Wyatt stated that "the start of AIDS was homosexual love making. Promiscuous women are vulnerable, making love to promiscuous bisexuals" (Fowler, 2014: 8). Around the same time in the UK, the 'Conservative Family Group' supported the idea that all members of the population should be screened and that people with HIV and AIDS should be put in isolation units.

Furthermore, the Conservative advisor to Margaret Thatcher, Sir Alfred Sherman, highlighted how HIV and AIDS were problems for undesirable minorities: "mainly sodomites and drug abusers together with numbers of women who voluntarily associate with the sexual underworld" (Fowler, 2014: 8). The British Social Attitudes Survey for 1983 showed an increase in hostility toward homosexual relationships as a result of the impact of HIV and AIDS and its early association with homosexuality. In 1983, 17% of the public thought that homosexuality was 'not wrong at all' with a significant number total of 50% thinking it is 'always wrong'. In 1987 the acceptance of homosexual relationships declined further to 11% of people in the UK who thought it was 'not wrong at all' (British Social Attitudes Survey, 2021). The influence of moral entrepreneurs, the media and public opinion formed a distinct category of 'who' had HIV and AIDS, erasing other groups as a priority, such as heterosexuals living with the virus in the UK. This influence was extended to governmental approaches and legislation, which will now be discussed.

Amongst a political backdrop of neoliberal Conservative rule in the 1980s, many Western governments did not tackle the emerging HIV and AIDS crisis as quickly as they should have. In some cases, governments actively did not engage with it due to concerns about the state getting involved in ‘private’ affairs. It was not until November 1986 before there was a major House of Commons debate about public health and what should be enacted, which was four years after the first British deaths (Weeks, 2000, Altman, 2002). Norman Fowler, the then UK Health Secretary, proposed a UK newspaper campaign in 1986, followed by a leaflet drop to all houses within the country, however, this came up against significant backlash and opposition from within his own party.

Concurrently to this, early debates were being discussed as to the future engagement with Section 28 of the Local Education Act (1988), which proposed banning the ‘promotion of homosexuality in local authorities.’ The links between the ‘other’ of homosexuality to undesirable sexual infections such as HIV and AIDS were part of a moral agenda, anathema to traditional family values pushed by the then Conservative government. As such, this begins to explain the slow reactions of the government to the crisis. A leaflet drop of HIV and AIDS advice to every household had never been attempted before, with a public health campaign and the then Department of Health having few illusions about getting the proposal through the ‘creaking’ government machine (Fowler, 2014). Deepening this further, Margaret Thatcher had already personally vetoed government support for a large-scale academic study of sexual behaviour, in order to track potential patterns of behaviour, which could have been potentially used to inform the science behind the spread of HIV and AIDS.

Framing HIV as ‘becoming’ a heterosexual virus

Whilst heterosexual populations were affected by the virus and were acknowledged by some sources, this was still a minority voice (NAT, 2022). As the virus and deaths spread, LGBTQI+ rights campaigners brought attention, in parallel with healthcare professionals, to HIV not being something which strictly affects MSM, and therefore, it was able to transmit to the heterosexual population. The recognition of the pandemic as a serious social problem was understood once ‘claims making’ was made by healthcare experts in the UK, and abroad, because of the presence of HIV and AIDS in their heterosexual patients (Best, 2008). Additional claims making from other medical practitioners helped highlight heterosexual patients as a key part of the discussions around HIV and AIDS, which will be explored further below.

By October 1986, the US Surgeon General produced a report on HIV and AIDS, which argued that it was spreading to heterosexuals. Alongside media reports of heterosexuals becoming infected in the UK, this report made it possible for the proponents of developing policy and medical consensus, alongside a paranoid press, to approach ministers (Best, 2008). Weeks (2000) argues that at this point, HIV had reached its 'critical mass,' which enabled the government to put it at the forefront of the policy agenda. This led to the 'Don't Die of Ignorance Campaign' (1987) which involved the aforementioned leaflet drop to all UK households as well as a high-profile media advert depicting icebergs and falling tombstones labelled 'AIDS.' The adverts stated that, "there is now a danger that has become a threat to us all. It is a deadly disease and there is no known cure" (Don't Die of Ignorance Campaign, 1987). The advert's message had a powerful public reaction and led to a much higher profile of HIV and AIDS within wider public discourse. Notably, this was the last widespread major government public health campaign discussing HIV, with much more voluntary sector-based, targeted, and less-resourced campaigns becoming the norm. Whilst there was a shift toward the concept of anyone being able to get HIV and develop AIDS, the imagery of MSM with the virus has been retained within the cultural memory of the UK due to earlier constructions of who was said to predominantly have it.

In March 1987, a UK government-sponsored Gallup (1987) report showed that over 90% of the UK public had seen the campaign, and that 94% thought that it was the correct thing to do by the government, with 7% of the public finding some of the things in the advert 'offensive.' The poll positively reported increased public knowledge of HIV transmission methods, as well as a decrease in the wider public knowledge of false transmission methods. Significantly, a third of the results importantly represented the main message of the adverts, which was that using a condom reduced risk (Fowler, 2014) and ultimately, “there is no doubt that it was the television advertisements which had the most impact and did most to save lives” (Fowler, 2014; 25). At this point, a wider public knowledge of heterosexual populations at risk of HIV was rising and this led to a policy shift and framing of heterosexuals in the media, which will now be discussed.

Policy changes in the mid-1980s, as a response to claims making and media coverage, were followed by HIV testing in GUM (Genito-Urinary Medicine) clinics and by 1985, the screening of blood for HIV was offered (gay and bisexual men had been banned from giving blood the year previously). In 1986, the AIDS charity AVERT was founded and it released a joint campaign pack with the National Union of Students (NUS) which denounced the way that the media had been covering HIV and AIDS. It gave examples of some terms that had been used in UK newspapers, such as The Sun and the Daily Mail, to describe HIV and AIDS, such as 'The Gay Killer Bug', 'The March of the Gay Plague' and 'Acquired Immoral Deficiency Syndrome’ so as to tackle some of the early stigma around HIV and AIDS, which linked it dominantly to MSM (Weeks, 2000, Altman, 2002). The following year, the National AIDS Trust (NAT) was set up to coordinate the emerging voluntary sector charities and organisations which had increased in number. By the early 1990s, well over five hundred HIV and AIDS voluntary agencies existed in the UK (Weeks, 2000), including emerging services for heterosexual people living with HIV.

Through the opening up of spaces for the voices of people as lived experts of living with HIV and AIDS in the 1980s, 1990s and beyond, “HIV research can critically engage with medical/scientific claims to be *the* experts on AIDS/HIV and can, thus, have a role in challenging the assumption, found in much AIDS/HIV research, that medico-scientific constructions of HIV and AIDS and PSW [people suffering with] HIV are given and unproblematic” (Barbour and Huby, 1998: 25). The increasing representation of MSM and heterosexual people living with HIV and AIDS in television, theatre, cinema and personalised accounts in popular magazines and newspapers, allows the public to see more ‘sympathetic’ narratives around HIV and AIDS. This then opened spaces for individuals living with HIV and AIDS to actively engage within medical and scientific discourse. Through a combination of high-profile media accounts, medical experts and their dual work with HIV activism through claims making (Best, 2008), this enabled organisations to undertake collective action to 'de-gay' HIV and AIDS, which will now be discussed.

The 'de-gaying' and 're-gaying' of HIV and AIDS

Another technique of both bringing heterosexual populations into HIV services and developing a positive public reaction, was through a self-conscious shift to alter the way HIV and AIDS had been constructed from an 'undesirable' disease, which only affects supposedly 'deviant' groups, to something which could also affect heterosexuals. As part of this shift, Patton (1990) argues that from 1985 onwards, there was a concerted effort to 'de-gay' HIV and AIDS by the LGBTQI+ community, to destroy the stereotypical perception that only MSM had (or were at risk of) HIV and AIDS. HIV organisations also helped this process through asserting that their group serviced anyone with the virus, and they were not 'gay', political or social organisations. Whilst this was strategically important for addressing the needs of heterosexual people living with HIV, it did lead to awkward and clumsy terms such as 'Heterosexually Acquired HIV' to describe HIV infection outside of the LGBTQI+ community.

The 1980s coincided with a weakening of LGBTQI+ politics under New-Right influenced governments in the West, which had both a moral agenda that disapproved of LGBTQI+ politics and an economic policy of state cutbacks in the welfare agenda (Weeks, 2000). In order to navigate this territory and to grow in influence, an assertive process of 'de-gaying' HIV and AIDS was strategically followed by various community and voluntary sector services which had been set up to deal with people living with HIV, many of whom were originally established by MSM. King (1993) describes the process of de-gaying as follows:

> "The denial or downplaying of the involvement of gay men in the HIV epidemic, even when gay men continue to constitute the group most severely affected, and when the lesbian and gay community continues to play a pioneering role in non-governmental (and sometimes) governmental responses, such as the development of policy or provision of services to people living with HIV" (King, 1993: 169).

This process of de-gaying also allowed, at a time when a link between the two 'diseases' of homosexuality and HIV and AIDS were analogous, to take it self-consciously outside of the deviant outsider category (Weeks, 2000). An attempt was made to shift the focus, with parallels being drawn to the epidemic in Sub-Saharan Africa, and also to groups and behaviours that were regarded as the riskiest, such as drug use, heterosexual sex, and unsafe sex. Weeks (2000) describes a process of LGBTQI+ organisations of losing their primary 'gay identity' and changing to that of a 'professional identity,' as organisations became more reliant on statutory funding. In terms of LGBTQI+ organisations developing a professionalised image as an HIV organisation, to create a "desire for respectability" (Weeks, 2000: 200) amongst the wider public.

Alongside this, statutory sectors had to undertake generic HIV-prevention work and targeted work with communities such as women, children, and young people, and BAME communities under the banner 'AIDS affects everyone.' Events such as World AIDS Day and candlelit vigils were becoming increasingly commonplace throughout the 1980s and 1990s in the UK and were led by HIV and AIDS community groups and organisations, with increasing numbers of heterosexual people involved with them. Public testing campaigns affected public reaction and led to a realisation that HIV and AIDS could affect anyone, as well as a burgeoning panic that heterosexuals could also be a target of the virus (Weeks, 2000, Altman, 2002, NAT, 2022). Twelve Western European countries with data for newly diagnosed HIV infections showed that HIV diagnosis in people who were infected through heterosexual contact had increased by 122%

between 1997 and 2002 (UNAIDS, 2004), which increased the priorities for HIV and AIDS funding, and gave more prominence to heterosexual populations.

However, this ‘de-gaying’ of HIV and AIDS in the mid to late 1980s and early 1990s was to have dramatic effects regarding HIV prevention work with MSM, as the shift in focus meant that it was no longer being carried out as rigorously as it had previously. There existed a wider assumption amongst local authorities that MSM were targeted as part of sexual health campaigns and outreach, as they had been previously. Prevention work with this group was taken for granted when organisational restructures from local authorities, non-governmental organisations (NGOs) and charities developed, to counter risky transmission behaviours and tackle other high-risk groups. This was to culminate in King et al’s (1992) survey of London’s health and local authorities and the Third Sector, which revealed ‘low levels’ of targeted work being undertaken, even though gay and bisexual men remained at the highest risk of transmission at that point. This led to what Weeks (2000) refers to as the ‘re-gaying’ of HIV and AIDS through the emergence of MSM-led organisations which captured media attention, such as GMFA (Gay Men Fighting AIDS), which focused on the gay press and used conscious efforts to recruit MSM as volunteers in order to mobilise the LGBTQI+ community. However, this process of the re-gaying HIV had other implications for heterosexual populations in light of growing medical advances to treat the health needs and transmission of HIV, which will be explored below.

The impact of PrEP and PeP – continuing the re-gaying of HIV?

The introduction of Anti-Retroviral Therapies (ART) in 1996 led to a rapid reclassification of HIV and AIDS by the World Health Organisation (WHO) in terms of severity, and now HIV is classified as a chronic illness along the same parallels as diabetes (Siegal and Lekas, 2002). In the same year in which ART became widely available to people living with HIV and AIDS, so did PrEP and PeP in order to reduce transmission. With Post-Exposure Prophylaxis (Pep) being recommended to healthcare workers exposed to needle stick injuries, and PrEP, which is a pill taken daily or on-demand prior to having sex, to prevent HIV infection, becoming available to restricted ‘high risk’ groups in the UK (NAT, 2022). PrEP in particular has led to the U = U (Undetectable = Untransmittable) campaign by Third Sector organisations in the UK and beyond, creating a ‘game changer’ in how people live with HIV, leading to lower HIV transmission levels (AVERT, 2021). As evidence of the effectiveness of PrEP, new infections between gay and bisexual men have dropped by 71% in the UK due to the use of PrEP, from the years 2012 to 2020 (BBC News, 2020).

Whilst PrEP has become a welcome move in tackling HIV transmission, much of the ongoing, “media coverage and conversations about the PrEP decision has focused on what this means to gay and bisexual men. The effect this will have on at-risk heterosexual women and men, especially those from black African communities, has been largely ignored” (NAT, 2016). PrEP in the UK has been prioritised for MSM, sex workers and Intravenous Drug Users (IDUs) for free on the National Health Service (NHS) and heterosexual populations have been largely ignored or overlooked in its rollout (Cáceres, Bekker and Godfrey-Faussett, 2016). It has been noted that heterosexuals were not included in any pilot studies for PrEP when it first emerged (NAT, 2016). Some authors have suggested that as new medications are approved for PrEP, cisgender heterosexual men, and in particular women, must be included in clinical trials as they are also at a disproportionate risk for HIV infection, and so should also be targeted for HIV prevention efforts (Brisson, 2018; Cernasev, et al, 2021). Cernasev et al (2021) argue that the current ‘PrEP narrative’ needs to be changed and redirected, as heterosexual populations at risk of HIV are not aware of the existence of PrEP as a viable preventive measure. PrEP has represented a significant social change, alongside ART, for people living with, or at risk of HIV. However, the promotion of PrEP has supported the re-gaying of HIV in that MSM were directed to be the group in most need of it, at the potential expense of others. The narrative of HIV has taken other turning points in the re-gaying process of HIV, as the invisibility of heterosexuals within the HIV narrative in the West (and in particular the UK) is discussed in the following section.

The invisibility of heterosexuals living with HIV

In recent years, the primary (implied heterosexual) face of HIV and AIDS increasingly represented and prioritised by global actors, such as UNAIDS and global HIV organisations, has been a woman from the Global South; implying sympathy and support, if not rescue (Higgins, Hoffman and Dworkin, 2010). Globally, heterosexual men remain a forgotten group in the epidemic and are almost entirely unaddressed in HIV prevention programs and responses to HIV (Millard, 2009; Higgins, Hoffman and Dworkin, 2010). Since the invention of ART and PrEP, and after the earlier days of the HIV epidemic, HIV has now receded from mainstream awareness in the West and is now existing on the periphery of heterosexual society. HIV in the UK has not cemented its place into mainstream heterosexual relationships, and it has not woven itself into language, relationships, and awareness in the way it tends to be among many MSM (Persson and Barton; 2006, Millard, 2009). The following section will look at the invisibility of heterosexual populations, the reasons why this is the case, and the effects of this invisibility on heterosexual men and women living with HIV.

Heterosexual women living with HIV

Similar to the UK, as outlined earlier in this chapter, heterosexual women were also invisible at the beginning of the HIV and AIDS epidemic in the United States (Higgins, Hoffman and Dworkin, 2010). Close identification of the virus with MSM in the West, and later injecting drug users, meant that many researchers and service providers failed to recognise the needs of heterosexual women. Despite 20,000 women dying of AIDS from acquiring HIV through heterosexual sex in the mid-1980s in the USA (Redfield, et al, 1985), women were still absent from clinical trials in the USA and the UK in the 1980s and early 1990s (Fox-Tierney, et al, 1999). Furthermore, their needs were not accounted for in service provision by HIV organisations in the UK (Sophia Forum and THT, 2018). As an example of this, when the UK government's public health campaign launched in 1987, stating that all populations were at risk and the 'de-gaying' of HIV from service provision, this emerging visibility did not translate to public health support for women. Global policy institutes such as the World Health Organisation (WHO) did take up the discussion of women’s vulnerability as early as 1990 (Higgins, Hoffman and Dworkin, 2010) reflecting women’s disadvantages in the epidemic. This later included important discussions around inequality and gender-based violence, but continued to frame women by utilising a *vulnerability framework.* This vulnerability framework recognised the ways in which women’s HIV risk is shaped by gender norms, however, it did not recognise men’s vulnerabilities, blaming men’s ‘bad behaviours’ as the unalterable source of the problem and their gender socialisation as ignored or immutable (Higgins, Hoffman and Dworkin, 2010). This framing of *vulnerable women* was to be found in a wider HIV discourse, which will be discussed next.

HIV discourse in the West from the 1980s and onwards saw three types of heterosexually infected women emerging as a dominant narrative; the raped woman who was infected with HIV, the pregnant woman who could pass on HIV to their infants, and the sex worker who could pass on HIV to their clients, and through the clients, to the rest of the population (Higgins, Hoffman and Dworkin, 2010). In the 1980s and early 1990s, some feminist advocates and women’s groups in both the UK and USA attempted to feminise the discourse around HIV but found this difficult after HIV and AIDS had been aligned in public attitudes as that of a ‘gay men’s epidemic’ for so long (Treichler, 1988). This growing invisibility of women living with HIV meant that the intersectional needs of other women were similarly ignored in response and provision.

As an example of this, Arend (2003) noted that women who have sex with women (WSW) living with HIV were also routinely overlooked by government researchers, health care providers, and the HIV and AIDS service community. This has also been reflected in UK research and service provision, where heteronormative standards have often assumed that all women living with HIV, by default, are assumed to be heterosexual. There is a lack of understanding of the diversity of sexualities of women living with and at risk of HIV. There is also a lack of targeted information and interventions to support the sexual health needs of lesbian and bisexual women, and women of other sexualities and gender identities (Sophia Forum and THT, 2018). Research from the USA has also noted socio-economic intersections with sexuality, with low-income African American WSW and Latina WSW living with HIV, facing not only culturally based stigmas and homophobia, but also being disproportionately affected by poverty, drug addiction, homelessness, sex work, and abuse (Arend, 2003). Transgender women living with HIV are also more likely to be affected by poverty and gender-based violence. It has only been in recent years that transgender women have been specifically separated as a group to document HIV statistics and information in the UK (NAT, 2022). Women are not a homogenous grouping, and of the little research into women living with HIV, it has highlighted the invisibility of their lives amongst wider HIV narratives. HIV has been shaped by an epidemiological approach that defines people by transmission routes in the UK, and makes invisible the breadth and diversity of women and women’s experiences (Sophia Forum and THT, 2018: 13)

In their joint research into the invisibility of women living with HIV in the UK, the Sophia Forum and THT (2018: 19) state that:

> “Even though women make up a third of all people living with HIV and a quarter of new HIV diagnoses, women living with and affected by HIV have so far been mainly invisible in the narrative and response to HIV in the UK. We know little about what it means to be a woman in the UK living with, or at risk of, HIV. We do not know enough about what women’s needs are or what interventions are in place to meet these needs.”

This research also highlights that women’s voices and their experiences and needs have not been sufficiently recognised, prioritised or met by service provision and generic services. Through interviews with women living with HIV in the UK this thesis frames the history and development of HIV, noting that the leadership of the HIV and AIDS response since the start of the epidemic has been too male-dominated, in particular, by MSM. Whilst there has been a rich history in the UK of women's political participation and leadership, there have been few senior leaders who are women and, even less so, women living with HIV. Whilst respondents felt that this has started to change a little in recent years, many respondents felt that there was a need for greater investment in the meaningful leadership of women living with, or affected by HIV, and that women should also be more visible (Sophia Forum and THT, 2018).

Furthermore, the findings from this research also show that very few respondents were able to cite women and HIV-specific resources (for HIV prevention or focused on women living with HIV) that they can call upon. An over-representation in academic and clinical studies of MSM was perceived, with a limited focus on women being the view of the respondents from HIV and sexual health charities. Respondents also noted that even when resources were focused on Black African communities, gender was rarely disaggregated. The use of PeP and PrEP has been framed as an intervention primarily for MSM in the media and through advocacy, and not something for heterosexual men and women. When resources were focused on women living with HIV, the emphasis was on pregnancy and the risk to the infant. Overall, it was felt by the majority of the respondents that there had been a disproportionate focus on MSM in the HIV response, with the Sophia Forum and THT (2018) suggesting that the sector had 'taken its eye off the ball' when it came to HIV and women. The invisibility of women living with HIV has emerged socio-historically, and whilst women with HIV have entered public consciousness in different ways, as outlined in this chapter so far, it has continued to be overlooked in wider HIV narratives, both within the HIV community and external to it. The next section will examine heterosexual men living with HIV, to see how they have been framed within the HIV epidemic and whether they have followed a similar trajectory.

Heterosexual men living with HIV

Thought for a long time as a ‘bridge’ to female infection, and as having acquired HIV through other practices, such as sex with men or drug use, heterosexual men have been largely forgotten by both interventions and by scientific involvement around HIV and AIDS (Grierson and Mission, 2002). Globally, there are very few publications regarding interventions with heterosexual men aimed at preventing HIV and AIDS, and very few organisations have been set up solely to do this. When heterosexual men are focused upon outside of the West, it is to frame their behaviours in light of interventions around circumcision, and amongst Islamic African polygamous cultures, where campaigns have stressed the taking on of fewer wives and more use of protection within polygamous settings (Leal, et al, 2015). In the field of sexual and reproductive health, heterosexual men have usually been regarded as mere facilitators, or as hindering the reproductive decisions of women (Leal, et al, 2015). The invisibility of heterosexual men in HIV narratives and provision has largely been due to the socio-historical course of the epidemic, as they were framed as active HIV transmitters, but not as active agents in prevention strategies (Grierson and Mission, 2002; Persson, et al, 2006).

Whilst the prevention and treatment for HIV and AIDS in MSM are grounded in strategies to use PrEP and PEP, they do not often measure the impact of these interventions on the behaviour of heterosexual men, particularly on those who are not involved in a serodiscordant relationship (where one partner is living with HIV, but the other is not) (Persson, et al, 2006). Despite the increasing importance of heterosexual transmission in sustaining the HIV epidemic in developed countries, very little empirical research exists describing the health and help-seeking experiences of heterosexual men living with the illness (Antoniou, et al, 2012). This next section will explore and unpack why heterosexual men living with HIV have remained marginalised in important discussions and narratives around HIV.

Unlike MSM, heterosexual men have never been politicised as a sexual community and do not have a history of progressive, innovative and negotiated sexual practice (Segal, 1990). For both heterosexual men and women, there are fewer opportunities to meet sexual partners (though this is opening up with online dating apps), few explicit casual sex venues and no real culture of HIV-positive sex (Leal, et al, 2015). The lack of a heterosexual safe sex culture further complicates the matter, along with the cultural construction of heterosexual sex as 'natural' and beyond change (Waldby, et al, 1993). The cultural script of heterosexuality largely relies on particular models of masculinity and femininity based around power, sexuality and reproduction. The stereotyping of heterosexual HIV as a sexual or moral transgression challenges both men's and women's capacity to enact certain conventional gender expectations (Leal, et al, 2015). HIV poses distinct challenges to heterosexual masculinity by not only raising questions around men's sexual orientation, but by compromising their ability to father children and, frequently, their physical ability to work and 'provide,' which are all significant tokens of heterosexual masculinity in many cultures (Connell, 1995).

The invisibility of HIV in narratives amongst heterosexuals also makes disclosures to sexual partners difficult. In the sexual script of the heterosexual encounter, HIV is regarded as an anomaly and people with HIV are often imagined as sexually deviant in some way, or as having no right to a sexual life (Persson and Barton, 2006). Heterosexual men (and women) with HIV may themselves be unfamiliar with the process of 'coming out.' Stigma is therefore likely to be an entirely new experience to them and so they have no 'role models' of disclosure on which to draw (Crawford, et al, 1997; Power, 2010). In one study of heterosexual men, the respondents attributed such ignorance to a lack of HIV education, yet at the same time, they saw HIV as highly stigmatised in heterosexual society; struggling to come to grips with the perceived homophobia they faced, or may face, and the 'politics of sexual shame' that besieges heterosexuality and HIV (Warner, 2000). The stigma of heterosexual HIV was overwhelmingly thought to derive from its association with socially unacceptable practices, primarily drug use and the ‘wrong’ kind of sex, such as promiscuity, infidelity, sex work, and homosexual contact (Persson and Barton, 2006).

Whilst MSM have increasingly occupied a position in the political, activist and academic spheres of HIV and AIDS since the emergence of HIV and AIDS, heterosexual men have been noted to be far less likely to engage in political and activist engagement in terms of HIV and AIDS activism (Leal, et al, 2015). This lack of engagement is also noted in HIV support services and in their usage. In some of the few studies focused predominantly on heterosexual men living with HIV, evidence suggests that heterosexual men are reluctant to utilise non-medical HIV services (Beedham and Wilson-Barnett, 1995; Grierson and Misson, 2002; Persson, et al, 2006; Kartikenyan, et al, 2007), and are less likely to seek any type of social, emotional support or support from the HIV community than any other group (Bartos and McDonald, 2000; Jenkins and Guarnaccia, 2003). Furthermore, they often perceive that the services do not meet their needs as they are targeted towards, and predominantly used by, MSM (Beedham and Wilson-Barnett, 1995; Persson, et al, 2006). Factors for this include a high number of MSM as clients, the clinic appearance and a focus on MSM health may deter heterosexual men from using these services (Beedham and Wilson-Barnett, 1995; Thorpe, Grierson and Pitts, 2008). A common theme emerging from these studies is that heterosexual men feel that they do not 'fit in' and are 'like outsiders' (Beedham and Wilson-Barnett, 1995; Persson, et al, 2006).

The findings above are mirrored in Antoniou et al’s (2012) research in Canada, which found that heterosexual men living with HIV saw themselves as ‘waiting at the dinner table for scraps’ (Antoniou, et al, 2012); in that they felt themselves to be pushed to the margins of a health care and service field they saw as developed historically within a context which privileges MSM and heterosexual women. Due to this, they perceived MSM in particular, as well as heterosexual women, as being better positioned than heterosexual men to use their social capital within services to push for specific support and recognition. This then allows, by virtue of group membership, control of decision-making with regard to resource allocation and the development of new programmes. It was also noted by respondents in this research, that heterosexual men are poorly positioned due to their negative symbolic capital, from the socio-historical perception as being the ‘guilty party’ in the context of heterosexual HIV transmission (Antoniou, et al, 2012). This has led to a position of invisibility for heterosexual men within the HIV narrative, and a lack of their own needs being addressed at a support level, as well as a marginalisation of their voices, leading to their lack of engagement with HIV services.

Specific literature on heterosexual men living with HIV in the UK is difficult to source and is vastly under-researched. The limited research gleaned so far reveals a framing of men as a transmitter of HIV and points to a lack of engagement with heterosexual men from wider institutions. It also shows their own perceptions and misgivings about HIV support services and community, and their non-engagement with a politicised HIV identity. Through this, they have become largely invisible within wider HIV discourse in the West and overlooked by HIV narratives within the HIV community in the UK. The following section of this chapter will now take forward these discussions about heterosexual men and women living with HIV, briefly framing them in the light of ageing with HIV, concluding at the end of the chapter with questions to take further into this research.

Older heterosexual people living with HIV in the UK

In recent years there has been a slow but promising shift in the engagement toward researching HIV and ageing, and as HIV is now recognised as a long-term condition, the needs and voices of older people living with HIV are, albeit slowly, increasingly coming into focus. Whilst some of the issues facing older people living with HIV have been set out as context for the research in the introduction in chapter one, this next section will explore additional data on HIV and ageing. This thesis argues that amongst the invisibility of heterosexual populations living with HIV, older people living with HIV are similarly affected by this process, and that this has effects on what we know about older heterosexual people as a result.

Research on older populations ageing with HIV is lacking, with authors generally pointing to the lack of lived experiences in research on older people living with HIV (Harris, Rabkin and El-Sadr, 2018; Wallach, et al, 2019; Rosenfeld, et al, 2021) and others who have described the data and research as ‘sparse’ (UNAIDS, 2014) or ‘overlooked’ (American Psychological Association, 2017). Following a similar trend in the UK, research on the lived experiences of older people living with HIV has been described as ‘invisible’ (THT and Sophia Forum, 2018) or as ‘uncharted territory’ (THT, 2018). Much of the research on older people living with HIV is still emerging, both globally and in the UK, however, some interesting results have emerged from studies so far, which will contribute to the questions asked at the end of this chapter.

Ageing with HIV. A ‘mixed bag’ of results?

Among older people living with HIV, it is clear from the development of ART that health improvements have improved, and survival rates have increased. Most research on older people living with HIV so far has focused on physical health, psychological quality of life indicators, HIV transmission and medicine adherence (Rosenfeld, 2014; Catalan, et al, 2017). Yet some emerging studies have begun to address the wider social consequences of growing older with the virus, and what the present and future look like to people living with it. Whilst some older people living with HIV have reported finding meaning in life and having a positive attitude towards the future, the social and psychological consequences of growing older with HIV are complex and in some cases conflicting (Catalan, et al, 2017). Some studies have reported positive individual impacts of growing older with HIV (Ribeiro, Kylma and Kirsi, 2012) and similarly, in Shippy’s (2004) work, he found that many older adults had better coping skills because they had been through other challenges in the past and had learned to recognise their strengths and limits. Noting that older people may also feel less ‘cheated’ by HIV because they have accomplished many of the goals in their lives, compared to people who are diagnosed at a younger age. McGowan et al (2017) found lower depression and anxiety rates amongst older people living with HIV, compared to younger people, urging further exploration of ‘successful ageing’ among people with HIV and the positive effects of age.

In contrast to this, other research points toward older people’s concerns about high levels of stigma (Emlet, 2006; Emlet, et al, 2015), uncertainty about the ageing process whilst living with HIV (Rosenfeld, 2014), memory loss (Catalan, et al, 2017) and concerns about HIV disclosure (Rosenfeld, 2016) which emerged from early research in this area. There is evidence from some research showing a poorer quality of life (QoL) in older people living with the virus compared to younger people, however, the findings are inconsistent and vary in different small studies (Catalan, et al, 2017). It is clear that much of the research is a ‘mixed bag’ of results for older people living with HIV when it comes to mental health and their future quality of life, reflecting the emergence of this field as an early area of study.

Community support and resources for older people living with HIV

Amongst the mixed results discussed so far, a common theme emerges amongst much of the research in that many older people living with HIV see their lived experience framed against, and heavily influenced by, the community context and HIV support mechanisms (Catalan, et al, 2017; Sophia Forum and Terrence Higgins Trust, 2018). For many MSM who came of age in the shadow of the HIV and AIDS epidemic of the 1980s and 1990s and who have lost close friends to AIDS, they “were more likely to know other people (and other older people) with HIV and HIV support organisations. However, heterosexual people living with HIV were less likely to have the same social support networks” (Rosenfeld, 2014: 25). Lacking some of these informal and formal support networks, Rosenfeld notes that some older heterosexual people living with HIV find it problematic to distinguish between the physical effects of ageing with HIV, or with HIV medications. It has also been noted that White heterosexuals were the least personally familiar with, and knowledgeable about HIV, and they lacked a community based on ethnicity or sexual orientation, and so lacked community support (Sophia Forum and Terrence Higgins Trust, 2018).

Due to this, there are few people who have already experienced ageing with HIV to whom older people can turn for guidance or a 'community of elders' (Rosenfeld, 2010). This makes it difficult to understand the significance of, or appropriately respond to, physical changes, even those that are ultimately not HIV-related. In the only large study of UK-based services for older people living with HIV, Cresswell and Levett (2017) could not find consensus on how issues of ageing should best be addressed for older people living with HIV, because of the breadth of opinion amongst HIV services and medical professionals. For many older heterosexual people living with HIV, who have not had the traditional roots within the HIV community, this becomes even more problematic.

In terms of access to HIV services and community resources, Cresswell and Levett (2017) found several challenges for older people living with HIV namely a) within individual healthcare encounters with HIV specialists; b) accessing non-HIV related health services, and; c) a lack of psychosocial, HIV community and residential resources addressing the intersection of HIV and ageing. Conversely, Wallach et al (2019) have highlighted a growing problematic silo, pointing to HIV-specialised and more generalised psychosocial services for older people living with HIV. They found that many HIV services and community groups failed to provide suitable responses to psychological difficulties associated with HIV and ageing, with many older people living with HIV noting the absence of programmes that specifically target the over-fifty population. Whilst the data in this research does not separate MSM and heterosexual populations, it reinforces the points mentioned previously. Finally, Wallach et al (2019) also note the gap that exists between the concerns of older people and younger people living with HIV, noting that older people would have more to gain by sharing their experiences and voices with their own age group, but had little opportunity, or conduits to do so.

Many traditional models of HIV care and support, that have been predominately provided by HIV specialists, may no longer meet older people's needs. The need for support for older people living with HIV with topics related to finances, housing and mental health issues have been highlighted, as have recommendations to meet the needs of an ageing population by joining up health and community care (Cooper, et al, 2016). Overall, the results of this emerging body of empirical research point to issues in addressing community support for older people living with HIV generally, and highlight the rarity of services that specifically respond to the needs associated with the intersection between ageing and HIV. However, little empirical information exists solely about older heterosexual people and their own engagement with the HIV community, as well as the services available to them. The following section will examine HIV-related stigma. Given the centrality of HIV-related stigma in the socio-historical development of HIV (Weeks, 2000), it is important to touch upon this to see whether it may become central to the research findings later in the study.

HIV stigma – what does the research say about older people living with HIV?

Research focusing on older MSM living with HIV, and their experiences of stigma, has been heavily documented in a range of sociological, health and psychological studies, with little focus on similar studies on older heterosexual people living with the virus. This section of the chapter will discuss some of the key findings of the studies of older MSM living with HIV, to examine whether there is any overlap or dovetailing with the limited research on older heterosexuals living with HIV.

The current cohort of older MSM ageing with HIV share certain socio-historical factors (such as the AIDS epidemic) and lived experiences (such as the emergence of LGBTQI+ activism) that influence their lives significantly (Jacobs, et al, 2010). Within the context of Europe, North America and Australia, MSM have historically borne the disproportionate brunt of stigma in the HIV pandemic (Skinta, Williams and Fekete, 2019). Key government bodies responded to the HIV crisis by confining the individuals most affected by HIV within socially destructive caricatures (Siegal, 2013). Due to public ignorance and a lack of political action, HIV has primarily thrived among socially excluded and politically disempowered groups with HIV stigma, crippling the relief effort and validating inequality (Siegal, 2013). Throughout the history of HIV, support for HIV exceptionalism has waned and HIV funding has declined (Dalton, 2016) which has resulted in fewer resources and public health policies reaching out to those who presume themselves to be ‘unaffected’ by HIV. This has heightened the divide between those who are living with HIV and those who are not, as well as not presenting a challenge to older socio-historical narratives of ‘who’ has HIV and who does not (Siegal, 2013).

Older MSM living with HIV diagnosed pre-1996 are typically ageing after long periods of ill health, high levels of stigma and un/under-employment. In Rosenfeld’s research in the UK (Rosenfeld, 2019 cited in Westwood, 2019) participants situated their social status within two ways. Firstly, low cultural worth due to damaging myths about HIV’s infectiousness and that transmission was by ‘deviant groups’ through ‘immoral’ activities such as sexual excess and improper behaviour. The stigma was found in enduring fears and myths about HIV being a ‘black’ or ‘gay’ disease. The endurance of this social myth was not helped by the abandonment of HIV health promotion messages since the beginnings of the epidemic and as such the HIV-negative population misunderstood HIV, through the early government advertisements such as the infamous ‘tombstone’ adverts.

Secondly, Rosenfeld’s (2019) research argues that these myths create intersections with ageist attitudes, which link to prejudices around disability, sexuality, and age, setting a normative understanding that with age sexual activity should diminish and rational thinking should increase. Participants in the study, especially MSM, were at risk of loneliness due to seeing friends and partners die due to AIDS, those who they wished had grown old with it, are no longer alive. Most participants who had considered long-term care were MSM who feared homophobic attitudes, alongside HIV-related stigma and ageism, which would affect their long-term care (Rosenfeld 2019). In another study, the greatest concern of older MSM living with HIV, was partner rejection following disclosure of status in sex, with every respondent reporting this occurrence within their sexual stories. This had a significant impact on their self-esteem and confidence and as such, developed social distancing from other (negative) MSM in their community (Bourne, et al, 2009).

Within the UK, older MSM living with HIV are considered to be part of the 'lowest rung' of the ladder of the 'gay social hierarchy' (Dodds and Keogh, 2006) and are regarded as dependent upon the state and entitled to live on benefits that younger MSM living with HIV are not able to access. Older MSM face multiple forms of actual and perceived stigma, due to sexuality, HIV status and ageism due to the emphasis placed on youth by commercial LGBTQI+ culture (Slater, et al, 2015). Although research on ageism in older adults with HIV is extremely limited (Slater, et al, 2015), the few studies that exist have shown that older people living with HIV face stigma and ageism due to their older age. As well, as HIV stigma, ageism has been postulated to have a negative effect on active engagement in life and thus a barrier to successful ageing (Vance, et al, 2011).

Regarding views within the MSM HIV community, other studies have documented HIV-related discrimination and marginalisation based on age (Dodds and Keogh, 2006; Schrimshaw and Siegel, 2003) finding that older MSM living with HIV felt stigmatised, undervalued, and believed that they received less compassion than younger MSM living with the virus. Paradoxically, younger HIV-positive men have reported antipathy from older MSM living with HIV who feel that since they have better access to HIV information and services than they did, they should be more responsible for their sexual behaviours (Smit, et al, 2012). Older MSM living with HIV also experience higher levels of internalised stigma (Pryor and Reeder, 2011; Williams and Fekete, 2019). Furthermore, the anticipation that people will experience stigma because of their positive serostatus is related to psychological distress and shame amongst some older MSM (Starks, et al, 2013). Internalised homophobia and stigma, when applied to the self and when mixed with the consciousness of societal views of deviance, religious perspectives asserting orientations as chosen, as well as beliefs about the unstable nature of same-sex relationships, can all impact an individual's mental health (Bailey, et al, 2016).

In one study, older MSM living with HIV described their experience of messages associated with internalised homophobia they had discounted after coming out. They remarked that earlier fears of associations of stigma by association with attitudes toward MSM as a medical disorder and of it posing risks to health, returned with a stronger emotional resonance after seroconversion. Other older MSM expected stigma to increase with age and saw stigma as a significant contributor to their own social withdrawal, uncertainty about the future and increased isolation (Lawrence and Cross, 2013). As such, many older MSM living with HIV are more likely to face social avoidance, self-loathing, and fear, as well as a perceived or real loss of friends, and a feeling that people are uncomfortable around them as a result of their status (Peate, 2013). This has been evidenced by an increase in trauma, which disproportionately affects older MSM living with HIV and AIDS (Kamen, et al, 2012). This trauma fosters a fear of rejection by sex partners, and internalised stigma has been associated with lower rates of disclosure (Burnham, et al, 2016) as well as higher rates of depression and anxiety disorders than the general population (Lyons and Heywood, 2016).

Within their research, Dispenza, et al (2015) noted that 90% of all MSM persons over the age of sixty knew someone who had died of advanced HIV and AIDS-related causes and found that the HIV and AIDS epidemic was such a profoundly contextual and historical event that it significantly shaped the lives of older people. Many older MSM, for example, witnessed, "significant loved ones die in their lifetime, possibly rendering older MSM with feelings of loss and loneliness" (Dispenza, et al, 2015: 40). Older MSM with HIV often become disconnected from their friends, family, and society at large, with many men reporting that they feel isolated, alone and rejected by their own communities and peers (Power, et al, 2010). Ferlatte et al (2017) in their study into suicide amongst MSM living with HIV, argue that stigma is a driving force behind suicide among people living with HIV, finding that MSM were 1.5 times higher in terms of suicide ideation than their negative status peers. Whilst this is a largely under-researched area, one small study by Cramer et al (2015) also found that internalised HIV stigma was positively associated with suicide. Though the demographics of the age of respondents are not given in the studies, it is reasonable to state that older MSM living with HIV may be at a greater risk of suicide ideation due to their increased isolation, fear of rejection, and stigma.

Many older adults, especially MSM living with HIV also rely heavily on formal care providers due to rejection from family members, yet there is a marked lack of training for the unique needs of older MSM living with HIV amongst health and social care workers (Cahill and Valadez, 2013). Older MSM in nursing homes and assisted living facilities often feel that they must hide their sexual orientation from staff and other residents, and those who are in long-term relationships with same-sex partners have received abuse and neglect by staff (Fairchild, Carrino and Ramirez, 1996). Although the research is limited in the UK, evidence points to similar results (Cahill and Valadez, 2013; Peate, 2013). Whilst interventions to decrease HIV and AIDS stigma have focused mainly on the individual level and on internalised stigma and personal attitudes, few interventions have attempted to address both HIV stigma and homophobia simultaneously and at the community level (Frye, et al, 2013). Cases have been found whereby MSM living with HIV were refused assistance from aged-care services due to their sexuality and HIV status (Barrett, 2008) leading to further feelings of abandonment and isolation as they age.

Public opinion about HIV and AIDS, as well as minority sexual orientation, is fundamental as to how MSM view the ageing process, especially because older adults tend to hold more conservative views on LGBTQI+ rights, older MSM living with HIV may find relationships with their heterosexual peers difficult (Peate, 2013). Therefore, older adults living with HIV may in turn experience difficulty in their relations with their ageing peers and so may internalise their own feelings of guilt or shame when accessing health and social care services (Anderson and Fetner, 2008). Whilst the heteronormativity of policy making in the UK has erased the needs of older LGBTQI+ people until recently (Heaphy and Yip, 2006), there have been some improvements. It is interesting to note that an Age UK (2017) resource guide for professionals was designed to help health and care professionals meet the needs of older LGBT people, yet it did not refer to HIV despite the disproportionate HIV prevalence amongst MSM.

However, this stigma is not all-encompassing, as due to the socio-historical development of HIV being linked to communities of MSM, support can be easily accessed by peers and communities of elders to buffer against some of the strains faced and to offer opportunities for resilience amongst older MSM living with HIV. This raises a number of questions going forward, as some of the general issues faced by older MSM and older heterosexuals are perhaps shared, such as the process of ageing with the virus within uncertain times, mental health issues and isolation, and as such, this will be explored in the later research findings. However, there is perhaps evidence that older MSM living with HIV have different social and cultural experiences as well as needs that are different from their heterosexual counterparts (Pugh, 2005). With a clear 'HIV community' to engage with, developed largely by MSM for the needs of MSM, perhaps social networks are not as fragile as stated by other authors (Shippy and Karpiak, 2005). These may form important sources in which to seek out community support for older MSM to balance against the complex pressures, stigma and intersections that they face. What is clear, is that older MSM living with HIV face a difficult mix of issues, such as ageism within their own community, HIV-related stigmas (Pryor and Reeder, 2011), and structural homophobia. They also make up a population at severe risk of isolation and poorer mental health outcomes, leading to greater risks of social withdrawal.

In 1995, the first report into ageing and HIV was produced in the UK which pulled together the then scant literature on the topic (Stewart and Askham, 1995) and upon updating this in 2009, Pararini (2009: 2) notes that “14 years later, research on life with HIV for older adults in the UK is almost as scant as it was then.” Literature is starting to gain pace and quantity when exploring the lives of older MSM, particularly in American scholarship, with some emerging literature from the UK. Whilst there is more written about older MSM living with HIV in the UK and their experiences of stigma than their heterosexual counterparts, more research is still needed. The following section will examine the literature on stigma, which has been focused on older heterosexual people, to see whether there is any overlap or similarities to take forward into the study.

Similar issues? What about older heterosexuals living with HIV?

Very little has been written specifically about older heterosexual people living with HIV and the effects of HIV-related stigma, however, it has had passing mention in a number of studies (Wallach, et al, 2019; Kall, et al, 2020; Rosenfeld, 2021).

In one of the few major studies into older people living with HIV in the UK which mentions stigma, the Sophia Forum and Terrence Higgins Trust (2018) noted that Black African heterosexual participants in the study had more intimate personal histories with HIV than White heterosexuals, having witnessed high rates of AIDS-related deaths in their home countries. However, they were much less likely to disclose their HIV status to others, such as the MSM in the study, due to high rates of stigma within the Black African community and because of worries that the news of their status would reach family members in their home countries. This research highlights that across all populations of older people living with HIV, a shared vulnerability to age-related stigma was felt. Due to this, respondents in this study imagined that their own HIV status would be interpreted by other people as evidence of sexual activity that they feel is inappropriate for older people. They also noted that acquiring HIV in later life can threaten relations with friends, family, and other forms of social support upon which many older people had assumed they could rely in their later years.

In addition to this, many of the older individuals ageing with HIV also felt that the virus impacted negatively on their friendships, family and romantic relationships, due to HIV-related stigma. As evidence of this, 78% of respondents listed friends as among the people to whom they felt the closest, but only 63% listed their friends as among those who knew that they were living with HIV. Although a third of the sample was partnered, many of the respondents who were primarily heterosexuals felt that their chances of having a romantic relationship were compromised or even erased entirely due to their HIV status and the stigma surrounding it. Many stated in the qualitative elements of the study that forming a partnership with someone who was also living with HIV would provide more support and make the issue of disclosure much more manageable (Sophia Forum and Terrence Higgins Trust, 2018).

As mentioned previously in this chapter, some studies have shown older people living with HIV as being more resilient in coping with living with the virus and have shown positive effects of growing older with HIV (Shippy, 2004; Ribeiro, Kylma and Kirsi, 2012; Wallach, et al, 2019). This needs further exploration as to whether these coping methods can negate HIV-related stigma and the wider social challenges of living, and ageing, with HIV. In a wide-ranging UK qualitative study on growing older with HIV, Rosenfeld et al (2021) noted through the use of biographical methods that participants invoked biographical and specific features of their own lives. Whilst recognising that HIV-related stigma exists, and that certain elements of growing older with HIV were problematic, respondents often used ‘narrative anchors’ for evaluating their own quality of life.

In order to do this, Rosenfeld et al (2021) talk about the respondents' use of ‘pros and cons’ as a method in which older adults living with HIV use. In the sense that these narrative anchors are used to balance, mediate or compensate for the wider social and personal challenges faced. By granting more significance and weight to certain positive factors over others, they were able to use their own conscious effort to focus on the factors that gave them a better quality of life. Another tactic to complement this was through the framing of the 'lives of others', whereby participants compared their own quality of life to the quality of life that they knew, or imagined, other people in a similar position to themselves would have. Rosenfeld et al (2021) note that more positive factors have the capacity to be undermined by concerns for the future, and that the respondents navigated a tenuous line between a good and a poor quality of life. This does begin to highlight pertinent questions for further research in this study about coping strategies and resilience amongst older people living with HIV, and whether this is also prominent amongst older heterosexuals. Taking forward the discussions from this chapter, the following section will examine the emergent questions for this research study.

Questions to take further into the study

A range of complex factors faced by older heterosexuals living with HIV have been set out in this chapter. Due to the socio-historical development of how HIV and AIDS emerged and was constructed by various actors, heterosexuals have largely been marginalised or framed in certain ways throughout the epidemic (for example, heterosexual women as victims and men as 'spreaders' of HIV). Yet overall, there has been a notable invisibility of heterosexual populations throughout much of the HIV narrative which accompanied the rise of HIV and AIDS in the UK. This has been compounded further, as the voices of MSM have historically dominated HIV services, community networks, activism and the public 'face' of HIV (and were both positively and negatively framed by this). The 'gaying' of HIV has led to a marginalisation of heterosexuals, which was further reinforced by a strategic 're-gaying' of services after the virus was seen to spread to all populations.

The limited research into general heterosexual populations living with HIV in the UK has aided this invisibility, and the paucity of research produced so far does reveal that heterosexual men and women living with HIV have clear needs, problems, and issues that they face, which are distinct in themselves. Much of the research on stigma into people living with HIV has tended to skew toward MSM, and this is especially true in research conducted on older people living with HIV. When heterosexual populations are discussed in these research studies they have tended to be featured as one element of more generic research projects exploring 'older people living with HIV,' and so it is still relatively uncommon to see heterosexual groups as primary research participants, or in research studies addressing this. Nonetheless, the research discussed so far has highlighted key areas of importance, such as ageing with HIV and what this means for the future, problematising what it means to belong to an HIV 'community,' and whether stigma and issues with ageing with the virus can be fought with techniques of resilience or coping strategies. The direction for this research project is to now utilise these findings as a framework to examine older heterosexual people living with HIV in the UK.

The overall concentration of factors as discussed in this chapter brings to light key questions to take forward for this research, such as: what does it mean to grow older with HIV as a heterosexual person in the UK? Due to the socio-historical background of HIV and AIDS, has this impacted upon heterosexual populations feeling invisible as they age with the virus? Is stigma something that older heterosexuals face and if so, how do they navigate this? Do older heterosexual people living with HIV find a sense of community or support systems if they are already marginalised, and if so, how do they do this? Are older heterosexual people living with HIV a resilient group? The following chapter will now examine the key theoretical approaches in which to take forward this thesis, by examining the concepts of stigma, active ageing and resilience.

Chapter Three: Ageing, Resilience, Stigma, and Social Death

Chapter rationale

This chapter will discuss the underlying theoretical concepts behind this research. In light of the previous chapter which focused on the socio-historical aspects of HIV, and the invisibility of now older heterosexual populations within it, it is now important to examine some of the key theories which will underpin this research to explore their own lived experiences. For conceptual clarity, this chapter is split into three theoretical parts, which will focus on: 1) theories of ageing; 2) theories of resilience, and; 3) theories of stigma and social death. In part one, this chapter will discuss a number of ageing theories before settling on a theoretical approach to take forward to potentially highlight the lived experiences of ageing with HIV. In part two of this chapter, the concept of ‘resilience’ is then theorised, in order to explore how the notion of resilience is navigated by respondents as they age with HIV and live in their social worlds. In part three, and noting a lack of empirical research on older heterosexuals living with HIV and the role of stigma, a theorisation of stigma theories will be presented as well as a reconceptualising of social death.

Part 1: Theories of ageing

This section of the chapter will explore the differences between ‘age’ and ‘ageing’ and locate the difficulties in measuring age as only a chronological process. It will explore both the life cycle and life course models before settling on the life course model as a suitable method of conceptualising the ageing process. Examining social structural, agency-led and late-modern and postmodern theories, it will explore the classic and emerging theories put forward by theorists to examine the process of ageing within society. This section will then critically engage with the ageing theories presented and take forward relevant theories of ageing into the research process.

What is meant by ageing?

Throughout civilisation, human beings have recognised a progression through the life course leading from birth to death. Whilst this may seem universal to many, the time between birth and death has been organised in unique and distinctive ways by distinctive societies and cultures (Moody and Sasser, 2012). On a simplistic basis, the distinction has often been made into a division between ‘childhood’ and ‘adulthood,’ however, societies are increasingly complex, and as longevity increases, they have developed a greater number of life stages. For example, retirement is tied to dominant institutions like school, education and capitalism, and so exists partly because society needs to make way for younger workers in employment (Moody and Sasser, 2012). Today, an ‘older person’ will spend on average a third, or more, of their life in retirement and so distinctions have begun to form, between ‘the young old’ (aged 65-74), the ‘old old’ (ages 75-84), and now the ‘oldest old’ (ages 85 and over). These terms have emerged from practitioners working alongside older people and in academic writing (Kholi, 1987). Whilst these distinctions have emerged within a chronological age sequence, newer cultural concepts of a ‘third age’ and ‘fourth age’ have also appeared, which will be explored later within this chapter.

A central concept of what ‘ageing’ actually means is to discuss the meaning of ‘age’ itself. Age identification is partly an acknowledgement of a chronological process, but it is also a powerful and often a fluid social and psychological dimension within our lives. From early childhood we are socialised to think about what it means to ‘act your age’ in order to age differentiate ourselves and our behaviour and in doing so, we learn what roles and behaviours are socially and culturally appropriate depending on whether we are a toddler, teenager, adult or older person – a process known as ‘age grading’ (Moody and Sasser, 2012). As a development of this, we begin to age stratify ourselves and emphasise a person’s position in the age structure with appropriate behaviour or attitudes (Moody and Sasser, 2012).

The narrative of ‘ageing’ as a process is something which emerges from a person living a (potentially) long life whereas this is different from that of ‘old age’ which has been represented as a category inferred upon individuals at a particular point in their lives, usually via a certain set of physical signs, character traits and social markers (Higgs and Gilleard, 2015). Therefore, the processes which lead to a person being labelled or designated as ‘old’ are distinct to that from the processes which embody ageing. As part of this, it has been recognised that humans may have a shared ‘social clock’ concerning the appropriate age for life events (Helson, Mitchell and Moane, 1984), however, the timetable of life events can change and vary with regard to social class and occupation. Ageing as a concept can only be explored within the life course and so the proceeding section will set out an argument for using the life course approach, offering a rejection of the often-used life cycle approach.

The life cycle and life course approach

Rather than discussing ‘old age,’ ageing itself should be viewed within the ‘life course’ which means studying the movement of individuals throughout both time and socially created transition periods such as childhood, mid-life and retirement (Bond, et al, 2008). As well as this, the social sciences have begun to emphasise the impact of this change as cohorts are born, grow older and die, as well as how attitudes alter as they are replaced by new cohorts. This recognises that structures are not fixed and that they alter historically (Riley et al, 1999; Foster and Walker, 2021) and so ageing can only be understood within the context of social environments which shape an individual’s journey throughout the life course. Ageing, therefore, becomes something which is constructed through social institutions that provide the basis of ‘youth’, ‘middle age’ or ‘old’ (Schaie and Achenbaum, 1993). Age cohorts within these classifications change societal views of what institutions are developed and needed and how they play a part in the way these cohorts view themselves in relation to others.

The ageing process has been represented in previous research and theory as a 'life cycle,' which is envisaged as a series of fixed stages and roles through which individuals shift through as they age. This was seen as cyclical and repetitive and as something which remained unchanged across generations (Hockey and James, 2003; Foster and Walker, 2021). Early theories of ageing insisted upon culturally defined expressions of how people are expected to behave. This, it was argued, would lead to a series of statuses, roles and relationships, according to the society and cultural markers, of what is expected of the ageing process as the body's biology ages (Eisenstadt, 1956).

These markers act as rites of passage, as well as status acquisition, and so define an individual within a society at different stages of the life cycle approach. Until the 1970s, ideas of a coherent set of transitional stages were popular, for example, marriage, retirement and death. However, it emerged that there are limitations with this model as societies have altered and changed through a mix of modernisation, changing roles, behaviours, identities and cultural markers. Some authors have pointed out the archaic nature of the traditional life cycle model with its fixed stages, claiming it is no longer useful to prepare people for the challenges of the future (Jarvis, 1997; Foster and Walker, 2021). The 'life course perspective' (Elder, 1974) argues that ageing and 'old age' cannot be fully understood until it is viewed as a part of an entire human lifespan, and so cannot be isolated as a specific and isolated lived experience (Setterstein, 2003). Within this viewpoint, old age is seen as one phase of the entire course of life and so it is important to document the effects of the influences that shaped a person beforehand (Markson and Hollis-Sawyer, 2000). Gerontology allows for a study of the person, not as a fixed and limited identity and the associated characteristics of old age tied to only biophysical changes. Instead, it views the life process as a more complex framework of all experiences and an individual's interactions and influences, regarding their social status, cohort effects, ethnicity and gender (Moody and Sasser, 2012; Foster and Walker, 2021).

In addition, this life course model examines individuals and cohorts as one phase of the lifetime whereby they are shaped by historical, social, economic and environmental factors that occur at different stages. The three key features of this model show that firstly, ageing occurs from birth to death and thereby distinguishes itself from other approaches which focus only on older people; secondly, it involves a social, psychological and biological approach, and finally, cohorts have unique historical factors that affect their individual and shared experiences. Therefore, this approach considers both the social surroundings of an individual and a dynamic approach which traces people's lives in an ever-changing (and not static) society (Hunt, 2005). This rejects the 'life cycle' approach which sees cohorts in the life process as linear, whereby, "one rolls along in life, just like items on the production line in a manufacturing process" (Estes, Biggs and Phillipson, 2003: 32) as people in a society may experience a stage of life differently from one another, or not at all (Hunt, 2005).

However, this is not to state that age-based cohorts do not share similar characteristics. The unique aspects of an individual's location impact their experience of the world and there are social and cultural patterns which may carry throughout their time. This notion of "time and place" (Gielle and Elder, 1998: 9) begins to show how a cohort of people with common characteristics, such as age, may have been influenced by economic and cultural trends so that members of this cohort display attributes and values from similar experiences. An example of this may be younger cohorts of people entering adulthood in an economic recession today, who may have different values from the cohort who experienced the optimism of the 1960s post-war boom years (Hunt, 2005). Indeed, what we are learning about ageing today is forcing us to re-examine traditional ideas about what it means to grow old (Moody and Sasser, 2012). Due to this, some have argued that a new 'third age' has grown from developments or increased living standards amongst retired people, which have risen faster than that of working people (Jones, et al, 2008; Higgs and Gilleard, 2015). This contrasts sharply with that of the narrow definition of *old age* which was previously constructed via institutions which housed the ‘real old age’ such as workhouses and long-stay hospitals for the *old* and *infirm*.

This fashioning of a ‘third age,’ whereby people are living longer, and healthier lives (Laslett, 1989) has necessitated a rethink about old age in the social sciences, and gerontology and has begun to blur this previously fixed and stable category in a life cycle approach. As an effect of this, discussions have begun around the concept of a ‘fourth age’ as a binary to a fit, healthy and productive third age. This fourth age does not necessarily affect everyone in the life course, and it can be variable in length depending on the individual and their circumstances (Higgs and Gilleard, 2015). The script for the fourth age builds upon the ‘young-old’ versus the ‘old-old’ distinction (Neugarten, 1974) whereby the aged, ill and disabled are consigned to the fourth age bracket. However, it is argued that these divisive categories separate the common bond between older people flowing from a shared experience of discrimination and marginality (Neuberger, 2009) and the fourth age simply acts as a negative metaphor for the ‘black hole’ of ageing (Gilleard and Higgs, 2010). In contrast to this, the third age advocates diverse lifestyles, new narratives of ageing and third age cultures (Higgs and Gilleard, 2015) which work in binary opposition to a seemingly darker narrative of the fourth age. In order to understand the nature of the life course and how it works, it is now important to investigate the theoretical camps which have begun to develop within the field of gerontology and social sciences, therefore both the classic and emerging theoretical developments will now be evaluated.

Theories of ageing

Theories discussed so far, of how we age throughout the life course, are a relatively recent phenomenon in gerontology and the social sciences, and theory construction has been described as “data-rich and theory-poor” (Birren, 1999: 459). However, there are a range of ways in which ageing can be conceptualised, such as modernisation and disengagement theories, age stratification theories, age as self-construction, and active ageing.

For example, age stratification theory builds upon the role of social structures in determining individual ageing in society. This argues that age groups are stratified and so ‘age strata’ groups (for example ‘middle-aged adults’) show clear differences not only in their age but also in their shared historical experiences (Riley, 1987). In opposition to these more deterministic structural approaches, Giddens (1991) argues that an individual’s identity is a continuous process of self-construction throughout the life course, from choices picked and rejections made. Modern identity is ‘becoming’ rather than ‘being’ and so it is not something that is held down or stable. This means that previous ideas about childhood and adulthood, and even old age, cannot be held in fixed spaces and times in which an individual makes a transition (Giddens, 1991).

On a more individual level, ‘old age mask’ theory discusses the nature of both the biological and personal identity further, highlighting a contradiction between a stable youthful ‘inner’ self and a negatively perceived physical decline, or “the body as a cage” (Rapoliene, 2015: 4). This perspective highlights the relationship of the self to the body, whereby a tension between the surface of the ageing person (the face and body) decreases, whereas the youthful inner sense of self, does not. As such, the ageing body becomes an inflexible mask and it, “conceals the essential identity of the person beneath” (Featherstone and Hepworth, 1993: 148). Paradoxically, whilst external appearance ages and changes, it is argued that it does not touch the more subjective and inner self, or the notion of *feeling young inside.* With a societal focus on youth and looking younger a youthful mask helps to protect an ageing individual from a hostile society (Rapoliene, 2015) and allows them, “not to be classified as old” (Woodward, 1991: 159).

Some of the most popular theoretical approaches to ageing which have received the most attention from researchers and practitioners, have been from the disengagement theorists (Moody and Sasser, 2012). This approach argues that changes such as industrialisation and urbanisation meant families were dispersed and technological changes began to devalue the wisdom of elders, leading to a loss in status or power (Cowgill, 1986). Urbanisation favoured younger people and concerns were raised over older people becoming poor and the effects of this leading to pauperisation, which was part of the state-led old age pension as a means of securing old age (Higgs and Gilleard, 2015).

Whilst modernisation has affected the shape of old age, there was never a universal growth for all people as sometimes older people were either granted power or abandoned, and this itself varies according to culture, ethnicity, gender, and social class. What has emerged from modernity and industrialisation has been the growing rationalisation and bureaucratisation of the life course and a stronger rigidity of childhood, adult life and old age (Moody and Sasser, 2012). To some authors (Estes, 1979; Walker, 1981) this has led to a political economy perspective of ageing, whereby capitalism and the state have contributed to the domination and marginalisation of older people through the power of labour, the state, social policy and business, leading to inequalities and inabilities in being able to work. There are some clear parallels to the concept of disengagement theory here, which has its roots within functionalist schools of thought and this will be discussed below.

The concept of disengagement theory (Cumming and Henry, 1961) argues that old age is a time whereby the older person and society engage in mutual separation, such as retirement from employment. This process works as a ‘functional’ aspect where it serves both the society and the individual. Similar to modernisation theory as mentioned above, it assumes that the status of older adults declines as society becomes more modern and so there is an innate naturalness for older adults to want to disengage. The ageing person is seen as having an increased preoccupation with their self and a decreased involvement with others, whilst at the same time, the society begins to separate from the older individual. This is an irreversible process, and it prepares the individual’s later years and death (Wadensten, 2006).

However, disengagement as a global pattern of behaviour cannot be viewed as natural or inevitable, as many older adults work in employment until death (Moody and Sasser, 2012). Disengagement theory has also attracted heavy critique from Hochschild (1975), who argued that there is an ‘escape clause’ within this theory, stating that within the original dataset there were noticeable numbers of older people who had not retreated or disengaged, and that the research had simply labelled them as ‘unsuccessful’ adjusters to old age or as ‘elites’ of older people. Furthermore, changes in social factors, such as early retirement were noticed by Walker (1999) who argued that it reconstituted old age from an age-related status into a far broader category, which stretches from the age of fifty to death. This has developed into a widespread functional separation of the third (50-74) and fourth (75+) ages, the ‘young-old’ and the ‘old-old’ which has become relevant to universal guidelines, which have discussed ‘older people’ as aged fifty and onwards.

The value of disengagement theory is less in its underlying premise, and more in “spurring debate and resistance” (Daatland, 2002: 4) and it has brought gerontological theories into the spotlight as a discipline (Estes, Biggs and Phillipson, 2003). In contrast to disengagement theories, ‘continuity theory’ argues that people who grow older, who see a decrease in social interaction, are explained better by poor health, mental health or disability rather than a functional need for society to disengage them from their previous roles (Moody and Sasser, 2012). Complementing this, the work of Carstensen et al (2003) has pointed out that the perception of a downward shift in social interaction, seen as a decline in social functioning, is inaccurate as older adults become more invested in meaningful, existing relationships and spend less time creating new friendships. Yet, disengagement theory still holds significant sway and currency in the construction of older people within public discourse and how individuals relate to their own sense of ageing and so it should not be entirely jettisoned as a perspective (Novak, 2016). This concept is important to be mindful of in this research as little is known as to whether disengagement is common amongst older heterosexuals living with HIV. However, this stands in contrast to the ‘active ageing’ approach which will become the main focus of this thesis, which is now explored below.

Active and successful ageing

In sharp contrast from the more deficit models of ageing, such as disengagement theory, is the multi-dimensional model ‘active ageing’ developed in the 1990s (Foster and Walker, 2021). This alternative approach advocates a broader perspective and more active part in the ageing process, rather than simply withdrawing from wider society. Active ageing theory has gained in momentum as a theoretical approach, as broader factors have been introduced to the development of health and independence, such as lifestyle, quality of life, engagement in tasks and activities, perceptions of the ageing process and planning for the future (Grant, 2008; Foster and Walker, 2021). Active ageing was originally used as a theory for policy development and has gained currency in policy-making circles in Europe, with its counterpoint ‘successful ageing’ emerging at the same time in the USA (Foster and Walker, 2021), which will be discussed in comparison to it.

Both of these theoretical approaches embrace the life course approach to health, which recognises that impacts from early life may impact ageing. Active ageing has led to policy implications with the World Health Organisation (WHO) adopting it as an official stance toward the well-being of older people, at the Madrid International Action Plan on Ageing (Walker, 2015). However, in active ageing, to be ‘active’ is to be defined as involved in the “continuing participation in social, economic, cultural and civic affairs, not just the ability to be physically active or to participate in the labour force” (WHO, 2002). This more multi-faceted approach is designed to challenge stereotypes of older age which focus on dependency and passivity, emphasising autonomy and participation and highlighting the roles older people play in society (Tanner and Harris, 2007; Foster and Walker, 2021). Active ageing recognises a view of the possibility of ageing not purely in economic terms, but holistically, including concepts such as mental, physical well-being and social participation. The use of the life course approach built into this theory enables a more preventative policy approach which recognises that earlier life events determine well-being later in life (Hamblin, 2013; Foster and Walker, 2021).

Similar to ageing as self-construction, active ageing recognises that deterioration within the biological body will still occur yet the individual agent who is ageing will attain chosen goals desirable to them, rather than a social withdrawal as stated by disengagement theory. Active ageing is a process which is built up throughout the life course and does not just ‘appear’ in later life, as it is an outcome of an individual’s development and their ability to grow and learn from past experiences, to both cope with the present and to maintain a sense of self (Bowling and Dieppe, 2005; Novak, 2012). Therefore, it recognises that an individual is affected by social structures yet also has a sense of agency in their actions, to construct their own identities.

Active ageing has not been immune to critique. However, the critique toward it has often been conflated with the approach of ‘successful ageing’ by researchers and academics, presenting the two terms as the same thing (Foster and Walker, 2021), despite both being different. In successful ageing, Rowe and Kahn (1987) in their original work characterised ‘successful’ ageing as a rejection of older age as a series of losses, through individualised and personal success, choice and effort. Whilst also positive in its outlook and using the life course approach, successful ageing has a number of limitations in that it prioritises physical and mental capabilities over engagement with social life and any structural barriers faced by older people (Baltes and Carstensen, 1996). The term ‘successful ageing’ is deeply value-laden with the term ‘successful’ creating a binary notion of winners and losers in the ageing process, further problematised by ways in which successful ageing under neo-liberalism is viewed as being part of economic production (Torres, 2009).

Furthermore, not all people age ‘successfully’ across the globe, as many face wider structural ageism and often the ‘old-old’ or ‘fourth age’ become ignored via this approach (Walker, 2015). As a result of this, successful ageing has been criticised for ignoring larger health and socio-economic difficulties that may restrict older people from maintaining familiar or new activities and so, therefore, limit their choices (Hoff and Perek-Bialas, 2015). Finally, this has led to a subtle shift in research and policy focus from, “those doing poorly to those doing well” (Walker, 2015: 2) which has ignored the ‘oldest old’ stratification represented by the ‘fourth age’ which reinforces social isolation and ignores the potential of active ageing as a means through which see ageing in a more multi-faceted way (Stessman, et al, 2009). Due to active ageing gaining prominence in policy discussions and gaining currency as a growing conceptual tool, this thesis will be mindful of the potential of disengagement and ageing, but will bring forward active ageing as a conceptual tool to avoid the more deficit approach of ageing. Active ageing in older people living with HIV has been poorly explored, with research often focusing on disengagement (Walker, 2015) and so this will be examined in light of this.

Ageing: How will ageing be framed for this research?

This research takes the life course approach and concept of active ageing in light of exploring the life narratives of older heterosexual people living with HIV. Unlike the more deficit functional approaches of disengagement and modernisation theories, and the highly deterministic approaches of age-stratification theory, active ageing acknowledges the wider structural approaches represented by these, as well as borrowing approaches from theorists who see ageing as a self-construction under late-capitalism. Active ageing encapsulates the complex interplay between structure and agency, allowing for both (Marsillas, et al, 2017).

Due to the under-researched and invisible nature of older heterosexual people living with HIV as highlighted in chapter two, this research considers whether active ageing is present in their lives and what this means to them. This will help to develop a lens in order to see how an under-researched group living with HIV view, construct and navigate their own lived experiences of ageing within the social world, including their own sense of agency and the structures that may impact them. However, it is important to note that there is potential for the research to also reveal elements of disengagement amongst this group, and so I will also remain cognisant of this throughout the process.

This then develops key questions which emerge for the research. Do older heterosexual people living with HIV actively age or do they disengage? What issues do they face? When they face structural problems how might they overcome them? How might resilience be formed in their lives, if at all? The following section will examine different theories of resilience to decide which one to take forward in the research, alongside active ageing.

Part 2: Theories of resilience

‘Resilience’ is a relatively novel and decidedly complex concept (Woollett, 2016). Theories of resilience have only recently begun to be interrogated as a field of study within sociology and have a much longer pedigree within psychology (Woollett, 2016). However, despite this theoretical field continually growing, it needs much further analysis as there is no agreement as to what resilience is in social scientific theorising. In fact, Breda (2018) argues that the term resilience has become, “an empty word that can be filled with almost any meaning… these multitude of meanings for the same term have led to severe criticisms about the validity of resilience theory” (Breda, 2018: 1).

For many years, well-being (usually used as a concept in pre-resilience studies) was commonly associated with an absence of unpleasant life events (Domajnko and Pahor, 2014), however, in the early 1990s novel definitions of ‘resilience’ started to conceptualise this as a ‘bouncing back’ from adversity, to move on throughout the life course successfully despite this adversity (Rutter, 1985). Echoing that of active ageing, other authors observed that despite facing adversities older people were observed to optimise resources, compensate for losses and adapt throughout life (Baltes and Baltes, 1990). Therefore, older people could foresee events and adopt preventative strategies and actions. By utilising this ‘pro-active coping’ (Aspinwall and Taylor, 1997) older people could prevent potential stressors and losses to minimise negativity and use support-seeking strategies instead. This ‘resilient ageing’ meant that by ‘being’ resilient, older people could have relative immunity from adverse effects of life changes, such as ill-health (Gattuso, 2003). Since the early definitions of resilience emerged, various descriptions of what resilience is said to be, have emerged, which the following section will discuss.

Definitions of resilience

The UK’s Government Office for Science (2015) adopted the following definition of resilience in their systematic literature review for policy-making, in which they define resilience as, “the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaption or ‘bouncing back’ in the face of adversity” (Bennett, 2015: 7). This report also sets out an attempt to operationalise the definition, with a focus on personal and emotional resilience. Therefore, resilience is seen as a process whereby the following factors take place:

- a significant challenge;
- no obvious signs of (di)stress;
- maintenance of a life of meaning and satisfaction (bouncing back);
- active participation in life (managing);
- a sense that current life is positive (adaption) (UK’s Government Office for Science, 2015).

Prior to this, the UK Centre for Policy on Ageing (2014) also produced a literature review on resilience in older people and though they found that whilst there is no agreed definition of what resilience is, they agreed upon the older ‘bounce back from adversity’ model whereby a person, after significant stress, will enable themselves to return to a state of equilibrium. Their summarised findings discovered that older people do not see a decline in resilience with age, they are at least as resilient as younger adults and that better health, well-being and better levels of socio-communal interaction are associated with improved resilience. However, this policy implication has side effects on further theorisation, which will be discussed below.

Estevao, Calado and Capucha (2017) point out that the meaning of the concept of resilience is unclear. On one level it is defined as an outcome of action, in others it appears as an innate ability that some people and communities possess, and others do not. The stress on abilities seems to also imply deeply voluntarist overtones, with a lack of emphasis on social structures in how people deal with stressors and shocks. Resilience in this context seems to refer to a community’s capacity to survive and regenerate with its own resources and means, to avoid social disruption and to use alternative mediation structures such as spaces of collective participation (like social groups or churches) in mitigating against oppressive systems and upholding the community’s identity and cohesion.

Resilience in this lens appears to be ‘thriving against the odds’ under what (Estevao, Calado and Capucha, 2017) define as a ‘heroic’ approach to resilience. They use the example of poverty to outline this heroic framework, whereby approaches to resilience focus on everyday individual practices for creating or harnessing previously hidden or overlooked resources and self-esteem, culminating in what Marsten (2010) critically called ‘ordinary magic’ in all of us to tackle any stress or shock in our life course and to then rebound back afterwards. However, this concept of ordinary magic folds into an increasingly neoliberal ideology, which will be discussed later in this chapter, but before this, early emerging theories of resilience as either ‘found’ or ‘made’ will be discussed.

Theorising resilience as ‘found’

Policy and resilience in practice settings in the UK have used resilience as a valuable resource in which to promote health and well-being and it has become central to discussions on health inequalities, however, it has largely taken a deficit approach to health (Aranda, et al, 2012). Therefore, any individual’s capacities and resourcefulness to respond to this are now central to planned interventions (Wilkinson and Pickett, 2009). Aranda, et al (2012) discuss the ‘found’ and ‘made’ perspectives in resilience research which will now be explored further.

As Marsten (2011) has argued, after several decades of research on resilience in children growing up in socio-economic disadvantage and marginalisation, the great surprise has been the ordinariness of the whole phenomenon of resilience (Aranda, et al, 2012). This ‘found’ version of resilience ensures that people negotiate their development amidst mounting adversity around risk and protective factors in the child and environment. This story of resilience found within individuals assumes an a-priori psychological state and tends to assume an essentialist biological or psychological Cartesian subject, in possession of a unified coherent identity, whose actions are due to rational choice and full agency (Aranda, et al, 2012). This is problematic, however, as the non-resilient subject is held in opposition to the psychological norm. As Forst and Hoggett (2008) have argued, this individual becomes framed psychologically as deficient or lacking in natural qualities (for example, subjects of social welfare) and which positions them further as dependent and unable to act within their own interests, requiring psychological interventions and surveillance. Powerful social norms and the authority of experts, which control and regulate what is normal or healthy means that normative understandings of what the resilient subject is, serve to create difference and exclusion (Ungar, 2008).

In contemporary debates, resilience has often been framed and viewed as the ability to cope with stress and to return to some form of normal condition after a period of stress. In its broadest sense, resilience is a measure of a system to withstand stresses and shocks and so to persist in an uncertain world (Olsson, et al, 2015). Olsson et al (2015) have argued that resilience has been treated as a normative concept, in that it has been viewed uncritically as neither ‘good’ nor ‘bad,’ suggesting that the concept needs further social scientific theoretical engagement as there are tensions in relation to power, agency, conflict, and knowledge. They state that resilience has analytical potential, and has made serious efforts to integrate across sectors, spaces and scales, but it is problematic in that it seeks to combine adaptation, a dynamic process, with resistance, which is more static, in one framing concept overall. The concept of resilience also seems to be conservative when extended to social change and our social relations with others. One person’s resilience may be another’s vulnerability. For example, tackling poverty is not a pro-poor concept and so efforts to reduce poverty or to find a direct route out of poverty, cannot simply be replaced by building resilience. Therefore, the ‘found’ notion of resilience, typified by earlier theorising and research, is deeply problematic and is made further so, once unequal power structures are analysed, which will now be discussed.

A model of interaction between the individual and the social world has been used to advance earlier resilience theorising further. Once an individual has a shock which affects their existence and identity, this shock also causes the reconfiguration of social structures in three areas: 1) the allocation of the existing resources; 2) the distribution of risk; and 3) in its power structures (Estevao, Calado and Capucha, 2017). Therefore, social structures around the individual should not be viewed as static, and the transformation of the person arises from the action of social agents in the process of developing resilience. Resilience processes are part of a mobilisation of resources (Estevao, Calado and Capucha, 2017) and the mobilisation of resources include networks of kinship, friendship, and interest groups or Non-Governmental Organisations (NGOs) at a social level, or economic and cultural resources (science, technology, or law). However, the mobilisation of these resources to individuals is heavily influenced by social inequalities and power in society (Estevao, Calado and Capucha, 2017). Simultaneously, risks also become distributed at the same time as the mobilisation of these resources, especially if they are unequal and so they can be mutually reinforcing. For example, shifting risks, such as a pension-dependent older person supporting their own children financially, incurs their own increased risk of poverty. Therefore, the 'heroic' notion of resilience as mentioned earlier, which is seen as an attribute that is evenly distributed throughout individuals and which manifests through individual practices, becomes an issue. Resilience it can be argued is a complex and multilevel process, and this needs a shift from the individual to the social, which will be discussed below.

Theorising resilience as 'made'

In opposition to the 'found' narrative of resilience, the second version of resilience as 'made' follows a more constructionist lens, whereby resilience is not something that agents have, but is something that they do (Ungar, 2008). Drawing on Foucauldian perspectives, Ungar (2008) argues that resilience becomes a social practice, rather than simply describing reality, and therefore is something which either reproduces or challenges the dominant order. This perspective questions the power to define what becomes defined as 'risk', a 'protective feature' or a 'resilient outcome' to something. In this perspective, resilience is not homogenous and held by all, but is culturally and socially contextual and so is diverse, complex, fluid and relative (Ungar, 2009). Notions of well-being and resilience are terms that are in constant tension between the agent, communities, environments and wider social structures and therefore, individual notions of risk are not moral failings or individual vulnerability but are due to social disadvantage and inequalities.

To show this interrelation idea, Breda (2018) pulls together three connected components of resilience: 1) adversity, 2) mediating process (resilience as a process) and, 3) better than expected outcomes (resilience as an outcome: resilient). They argue that this process is multi-level and can occur across multiple levels of the person in the environment, rather than only within the individual, and so thereby, no one is either resilient or not resilient, it is about a range of outcomes extending from more negative to more positive. Whilst a person may have 'better than expected outcomes' in the face of adversity, these may not meet or conform to societal notions of 'success' (Breda, 2018). Importantly, focusing on agency without structure can lead to the oppression of people by social systems, while too much focus on structure without agency can lead to the disempowerment of people, and therefore, their marginalisation. Agency and structure, and the interactions between them are necessary for resilience and development (Breda, 2018) and so, therefore, this resilience theory provides a useful framework to bridge the micro-macro divide.

Meyer (2015) places the concept of resilience into minority stress theory. Resilience, like coping, is inherently linked to minority stress and so studied it in the view of 'minority coping' (Meyer, 2015). According to stress theory, the impact of stress on health is determined by countervailing effects of pathogenic stress processes and salutogenic coping processes. Resilience only has meaning in the face of stress and therefore becomes a key part of understanding minority stress (Meyer, 2015). Minority stress is based on the notion that prejudice and stigma directed toward minority groups bring about unique stressors and that these stressors cause adverse health outcomes, such as mental and physical disorders (Meyer, 2015).

Distal stressors are life events, everyday discrimination and microaggressions whilst proximal stressors include internalised feelings and expectations of discrimination or felt stigma. Coping and traditional social support services can buffer the effect of these stressors, so that negative health outcomes can be avoided or reduced, which is where resilience becomes key. Coping refers to the effort mounted by the individual in response to stress, meaning their effort to adapt or defend against the stress, yet one vital difference between coping and resilience is that coping refers to the efforts the person makes to adapt to the stress, but coping does not always mean a successful adaption. Resilience is inferential as it depends on identifying adaptive functioning in the face of stress. We may see somebody coping with stress, but resilience is identified by the impact that it makes on health outcomes and so resilience is implied by the fact that the person has withstood the stress (Meyer, 2015). The resilience as ‘made’ theory recognises the wider social structures around an individual, the role of power and the impact of the social world on others, however, it tends to position an individual as only buffeted by social forces and lacking in agency, emerging out of the other side as resilient or not. Useful though this constructionist perspective is, empirical research into resilience often retains the binaries of individual and society, with research on an inner and outer social world rather than both as relational (Gergen, 2009).

Neoliberalism and the problematic nature of ‘ordinary’ and ‘heroic’ resilience

As argued already, the term resilience is imbued with conceptual ambiguity as to whether it is an internal property of individuals (an ordinary magic or heroic sense of resilience), or it is a set of social practices. Estevao, Calado and Capucha (2017) critique the inborn heroic notion of resilience in that they outline that one is always in a state of adaption due to conditions around us, and therefore they argue, everyone, barring the dead, is resilient. What is problematic about the previous notion of ‘heroic’ resilience is that it is a concept connected to neoliberal (and policy) ideological agendas as resilience as a ‘hidden resource’ becomes something that could be made into a costless, and more efficient, alternative to welfare state intervention in dealing with social issues.

On a cultural and social level, this framing of resilience would suggest that an individual focus is on Western and neoliberal ideology, which highlights meritocracy, individualism and a politically endorsed revival of older discourses of ‘character building’ (Ecclestone and Lewis, 2014). This ideological positioning exalts personal triumph over adversity, as the essence of resilience. However, this ideology can lead to negative outcomes in terms of health on disadvantaged populations due to thinking that personal resilience is an attribute of the person, however, not everyone has the same opportunity for resilience when the underlying social structures are unequal and ignored in resilience theorising (Meyer, 2015).

As an example of this, people with chronic illnesses and disabilities are increasingly asked to be experts in their own treatment, to take ‘control’ of their life through advocacy, health literacy skills, and self-management (Waverjin, et al, 2016). These shifts in treatment management have been critiqued by authors in disability studies for the governmentality built into this system, which specifies that there is a requirement for the individual to manage their health and illness away from the state and to follow ‘established scripts’ in order to become experts (Young, 2016; Rosqvist, Katsui and McLaughlin, 2017). Compliance with this version of self-management encourages a stigma against those who do not comply to this script, focusing on the individualised neo-liberal subject (Rosqvist, Katsui and McLaughlin, 2017).

After the global financial crash of 2008 and under subsequent pressure to reduce expenditure and welfare, new categorisations and assessments of people with disabilities have emerged, which have aimed to redefine people’s abilities to perform paid work and receive state benefits (Grover and Soldatic, 2013). The recategorisation of ‘disability’ meant that a strict eligibility criterion was used to pressure disability claimants into paid work, separating those who were ‘really disabled’ and those who can gain paid employment (Grover and Soldatic, 2013). Under neoliberalism, citizenship is increasingly seen in terms of the responsibilities and obligations affecting people with disabilities around the world (Goodin, 2002). In the neoliberal discourse of the structuring of ‘able’ and ‘non-able’ bodies through austerity, all bodies are evaluated in terms of their success or failure in achieving health, wealth, or career realisation (Ruckert and Labonte, 2017). This increased push toward ‘self-reliance’ on open labour and consumer markets, whilst minimising the support for overcoming barriers which have prevented disabled people from accessing systems in the first place, creates a duel-edged sword (Mladenov, 2015). The ideology of the ‘ordinary magic’ or ‘heroic’ resilience becomes problematic for people living with disabilities under neoliberal policy reforms, as it requires ‘bouncing back’ with fewer resources at hand.

When individual resilience becomes an ideology it can lead to adverse health outcomes, especially when that leads to policy implications and an actual increase to stress exposure in disadvantaged groups (Kwate and Meyer, 2010). Under neoliberal ideology, a focus on resilience can lead to a victim-blaming attitude (Mohaupt, 2009) by noting that individuals can simply ‘be resilient’, which risks assuming that individuals ought to be resilient. In social attitudes and policy terms, assumptions that highlight how everyone exposed to stress can, and therefore should, survive by the sheer virtue of their own resilience. This ‘ordinary magic’ becomes something that is not extraordinary (Masten, 2001). A focus on individual resilience from a public policy perspective can remove or reduce social responsibility to protect disadvantaged populations as it creates a site of expectation for individuals. As a consequence of this, is an effect of moving the discourse to the individual response and their own resilience rather than the stressor itself (Meyer, 2015). Critical work in areas such as Mad Studies and critical health studies are critiquing current policy initiatives which encourage the individual to adapt to social problems by tracing the neoliberal ideological underpinnings via state intervention, and the role of non-governmental agencies in their provision, which is based on contractual performance targets (Olin, 2017; Rosqvist, Katsui and McLaughlin, 2017; Timander, 2020).

Whilst this structural approach is important as a critique of resilience as ‘found,’ it overlooks the role of the individual in their own cultivation of resilience. It also cynically suggests that resilience is only a product of neoliberal ideology (Wright, 2021), and so this following section will attempt to provide more nuance to some of the theoretical approaches outlined so far which posit resilience as made or found.

Community resilience and resilience as ‘unfinished’

Wright (2021) argues that resilience can be disentangled from neoliberalism, and it can be understood in other ways in which it incorporates diverse expressions of resilience. Merely viewing resilience as a “passive submission to structural disadvantage opens up space for exploring transformative, disruptive and subversive modes of resilience as well as everyday modes of coping which are often overlooked” (Wright, 2021: 2). Wright (2021) argues that ‘community resilience’ should be considered as it has been overlooked in sociological thinking, and by this, she argues that it is the collective ability of a social group to sustain its well-being in the face of challenges and to cope or recover from stresses.

Whilst careful to not provide a ‘recipe’ for resilience due to its ‘nebulous’ nature, Wright (2021) argues for a more nuanced understanding of resilience which is shaped at multiple levels (not just ‘top down’ or ‘bottom up’) and collectively built, culturally mediated and historically situated. A key argument through the case studies presented in their work is that people are resilient in many ways, both individually and collectively. However, their resilience is often overlooked or misrecognised and so attempts should be made to humanise it, moving beyond abstract accounts, models and conceptualisations to exploring the everyday lived realities of people’s lives. Wright (2021) notes that resilience is not necessarily only a conservative force and can entail transformational action, despite the relationship between vulnerability and resilience being interlinked. Furthermore, vulnerability is not a stable property and is instead a dynamic process, which needs to be understood in relation to specific kinds of crises, conditions and change. Within this, people use resilience strategies through what people have available to them, with these resources distributed (equally or not) and shaped by the wider context of society.

Rejecting psychological standards of resilience measurement, and arguing that it cannot be quantified, Wright (2021) argues that it must be understood in context, historically and structurally, as something that evolves and appears over time and in particular settings. As opposed to much of resilience literature which has focused on ‘sudden events’ and ‘mystical events and characteristics’ (see ordinary magic), rather than the slow and unfolding processes or conditions faced by people in their everyday life course. This shift in understanding resilience as less of a behaviour, as being ‘found’ or ‘made,’ means to understand resilience as something by which people work hard to cope individually and is something by which people secure safety and well-being when facing wider adversity, potential threats and vulnerability.

Parallel to the work of Wright (2021), Aranda et al (2012) have also argued that the ‘found’ and ‘made’ dichotomy is problematic, and we should consider resilience as ‘resilience unfinished.’ They outline that the subject is imbued with agency and everyday modes of being but also equally constrained and subjected to wider structural forces, such as neoliberalism as discussed previously. The resilient subject is produced through personal and collective identifications, as well as dis-identifications, wider governance, and performativity. If the resilient subject is re-imagined as performative, rather than a stable and fixed socially constituted identity, then their resilience becomes something which is unfinished and is always within a process of making and becoming.

Across their biography, individuals identify and misidentify in complex ways with demands to be resilient, and therefore can comply or resist discourses, narratives and governance in areas of health (Aranda, et al, 2012). As such, there is space here to view resilience as temporal and not a linear process, which suggests that it builds or does not, as a person ages developmentally or chronically. This definition of resilience sees a person as neither a passive agent of dominating social structures nor as a full agent immune to the wider social effects of society. Resilience as ‘unfinished’ is something in which individuals do not have located as a mystical quality or ordinary magic, nor is it simply ‘topped up’ by external forces, but instead is something in which individuals work at throughout the life course as they age with HIV.

Resilience: How will resilience be framed in this research?

To take this research further and to conceptualise resilience for this research, I will use the previously discussed theoretical notion of ‘unfinished resilience’ (Aranda, et al, 2012), which is something that is both relational between the individual agent and the social structures around them, in which these structures are always in flux alongside the identity of the agent. As stated, unfinished resilience is not something inherent or ‘topped up’ in an individual, but instead is something that is cultivated in a person’s identity, resources and skills as they move throughout the life course, and as they face ways in which to form resilience to social structures and pressures. Resilience is not necessarily something in which an agent ‘bounces back’, as some authors suggest. Furthermore, it is not something that is only tapped into when faced with a crisis. Instead, unfinished resilience is something in which an agent nurtures and uses available resources in negotiation with their own sense of identity, resources, and the resilience offered (and restrained) from the social world around them. This allows some room for agents to resist master narratives and social forces where possible and imbues them with a sense of agency, where needed, to comply with social messages if suitable.

Placed within this research and within an active ageing theoretical framework, this thesis asks whether heterosexual people living with HIV, who have often been ‘outsiders’ in the HIV community, see their lives as limited or as fulfilling. This research also asks how they have withstood resilient adaption to their life in terms of living and growing older with HIV. Furthermore, unfinished resilience becomes something which is then formed when systems are changed to adapt (or not) toward individuals and how to recover from them, using resources on hand (Ecclestone and Lewis, 2014). Within a minority group (those living with HIV) this creates interesting ways in which to examine the lives of older people and how resilience has formed due to social stressors, as they limit and open up opportunities to those living with the virus in later life.

Resilience has largely been a neglected area of sociological theorising (Wright, 2021) and few published studies have examined resilience among adults generally, particularly those living with HIV. Most research close to this has been on the mental health of adults living with HIV and AIDS and it has focused on risk factors and vulnerability amongst individuals, especially MSM (Fang, et al, 2015). When resilience has been explored sociologically it has been analysed either as a secondary side effect of a traumatic life event using the ‘bounce back’ model, with resilience being framed as either found or made (Fang, et al, 2015). This is problematic and it is time to examine a different perspective to advance these arguments further. There is a much greater need for understanding resilience in both the context of living and ageing with HIV and also, locating resilience within the interaction between the level of agents and their lives and the changing social structures around them. It is also vital to consider how people growing older with HIV engage with their own adverse futures, what types of future they envisage and what kinds of knowledge, belief and insight they will have for their own future (Wright, 2021).

As such, unfinished resilience fits into an underexplored gap as a concept to take forward. Additionally, it also becomes important to examine how theories of ageing (as either active or disengagement) impact and frame this concept of unfinished resilience. Furthermore, to also explore how this is a relational concept between an agent and the social structures around them, where resilience is neither found nor made but is navigated and unfinished. Against these theories of ageing and resilience, the final part of this chapter will investigate the importance of stigma as something which has the potential of causing vulnerability in the lives of the respondents living with HIV, and impacts their own resilience and how they navigate it.

As chapter three outlined, the wider-ranging research on stigma faced by older MSM living with HIV highlights a lack of research into older heterosexuals, stigma, therefore, becomes an important and potential site of resilience navigation or depletion. To do this, the final part of this chapter will outline various stigma theories, from early stigma theories to later contributions, in order to consider how HIV and stigma are interlinked, and what this may mean for the respondents in this research.

Part 3: Theorising stigma

Stigma is wrapped up in socio-cultural and historical processes, and as such, has altered and changed over time. This section will begin to explore some of the classic and more modern theories around stigma in health and illness in order to understand how stigma operates, the effects of it, and how this is bound up with the development of HIV. Firstly, 'stigma' as a concept must be defined in order to set an understanding of it as a concept. Stigma is defined sociologically as the occurrence of, "labelling, stereotyping, separation, status loss, and discrimination in a context in which power is exercised" (Hatzenbuehler, Phelan and Link, 2013: 1). It overlaps and intersects with discrimination and racism for example, but it differs from these in different respects. Whilst ethnicity can be a stigmatised status, the stigma itself encompasses multiple statuses and characteristics (such as obesity, HIV, and sexual orientation). Similarly, discrimination, at both an individual and structural level, are features of stigma. However, what sets stigma apart from discrimination is that it incorporates other elements such as labelling and stereotyping, shame, status loss, and the process of discrimination is only part of the larger stigma picture (Hatzenbuehler, Phelan, Link, 2013). Indeed, discrimination only becomes an effect, or manifestation, of stigma when society defends or encourages it (Herek, 2002) and as such, discrimination is not always an inevitable outcome of stigma itself (Deacon, 2006).

It is vital to recognise that stigmatisation works on many levels, it can be overt and can manifest in various forms, such as aversion, avoidance, social rejection, dehumanisation, discounting, and turning others into stereotypical characters (Bos, et al, 2013). However, it can also be much subtler than this and it may even arise through non-verbal expressions of discomfort such as a lack of eye contact, creating tense social interactions (Hebl, Tickle and Heatherton, 2000). Stigma is not a recent concept and is bound up in historical processes. The term 'stigma' itself dates back to the Ancient Greeks, who would cut or burn obvious marks onto the skins of criminals, slaves and traitors to identify them as tainted or immoral people and who should be avoided (Goffman, 1963). This combination of socio-historical attitudes and shifting cultural attitudes in a globalised world has shown stigma to be a global psychosocial phenomenon (Guan and Liu, 2014). The following section will outline some of the key early stigma theories, which have subsequently been built upon or expanded by later authors, which will be discussed in this chapter.

Early stigma theories

Much of the early literature around stigma advanced the notion that stigma was rooted in deviance and social solidarity, and so this will now be explored in the light of health, disability and illness. Parsons (1951) originally defined illness on the grounds of being an act of deviance, in that illness disrupts the social system as it alters or inhibits a person's normal functioning social roles. Society then aims to minimise the behaviour associated with the illness as it cannot be prevented with sanctions, and so control is exercised via the prescriptive roles for the sick and physicians. In short, the temporary role of the 'sick person' is a universalist criterion whereby social actors can be released from their role and are then obligated to get well and to cooperate with the medical profession to do this. Physicians act as gatekeepers in order to pull upon general and specific criteria in determining who is regarded as sick or not, and what type of sickness they have, but importantly, they spur on the sick to leave their sick role and return as a healthy social actor. This, it is posited, creates a stable and healthy society. However, Parsons' (1951) sick role can become problematic for people who have long-term health problems and so the public may lose sympathy for those who are deemed to have become ill through their carelessness, which is often levelled at people who are living with HIV (Scambler, 2008).

In his seminal work, Goffman (1963) argues that stigma is an attribute which serves to discredit an individual or group. It operates by tainting and diminishing them, rendering them abject and inferior. Goffman (1963) pulls upon examples to show this, for example, the 'homosexual' or the 'criminal,' that have engendered negative stereotypes (Pescosolido, 2013). Stigma is associated with ‘abominations of the flesh’, the ‘soul’ and the ‘tribe’ (meaning in order: deviant bodies, deviancy mentally/behaviourally and ethnic/national characteristics). Goffman (1963) argues that these are either controllable or uncontrollable and also visible and invisible. Individuals with visible deviant characteristics are deemed to have a ‘discredited’ stigma, displaying visible signs of difference and those who have invisible ‘discreditable’ characteristics can pass as ‘normal’, but they must manage the risks associated with this. Individuals with discreditable characteristics fear their characteristics being discovered by others in their interactions (Goffman, 1963; Scambler and Hopkins, 1986; Balfe, et al, 2010).

Though stigma is often presented as something that resides within the individual, it is more a language of relationships rather than attributes, and as a result, these change over time. They are salient, depending on what is regarded to be normal or acceptable in particular social contexts. Those who do not have a stigmatic characteristic, Goffman (1963) termed ‘normal’ and those who are ‘normal’ experience their bodies as absent or unproblematic. Stigma creates a boundary between ‘us’ and ‘them’, confirming a moral superiority of the stigmatising group and reinforcing their claim to normalcy. Important in this approach is that the stigmatising of ‘others’ is an identity-producing practice. ‘Normal’ identity, which does not deviate from social expectations, is produced through the enactment of exclusionary practices (Nairn, et al, 2006).

Cultural stereotyping is of paramount importance when discussing stigma, as those afflicted with a deviant condition might be expected to confirm to stereotypical notions of what that condition might be. Earlier studies suggest that people who are blind are often attributed distinctive characteristics of their personality, such as ‘helplessness,’ ‘dependency,’ a ‘gravity of inner thought’ and ‘aestheticism’ (Scott, 1969). Whilst these stereotypical constructs may be far from the actual personality of the individual, the blind person cannot ignore them and so may alter their behaviour or ignore key factors in their interaction with other people. Scott (1969) argued that blind people adapt to cultural stereotyping, from both society and health professionals, in five ways; either concurring with the stereotype; ‘cutting themselves off’ to protect themselves against this process; deliberately adopting a façade of compliance for the other person; making people pay for a ‘performance’ (for example, begging); or finally, actively resisting.

Davies’ (1964) research found that physically disabled people pass through three stages when interacting with someone new. Upon meeting strangers, a ‘fictional acceptance’ is developed whereby they are ascribed a stereotypical identity and accepted on that basis, however, the second stage involves them ‘breaking through’ the earlier stage, involving people in interactions normally, which leads to the third and final stage of ‘consolidation.’ However, Davies (1964) noted that this involves sustaining this ‘normal’ definition of themselves to others over time. Yet, this involves significant resources, strength of will and psychological stamina to engage in ‘deviance disavowal’ (Scambler, 2008). In some cases, such as deaf or hearing-impaired people, individuals may actually avow deviance by acting mute in order to smooth over or simplify contact and relations with the hearing, as written messages and lip-reading can save time and misunderstanding (Higgins, 1980). Cultural stereotypes also provide, “scaffolding for stigmatized world views” (Arboleda-Florez and Stuart, 2012: 457) for those without a stigmatised condition, and for those who do have a stigmatised condition, it creates a “threat in the air” (Pinel and Bosson, 2013: 58).

Other early authors have made clearer links to the process of stigma itself through the literature on deviance such as Mankoff (1971), who made a clearer distinction between ‘ascribed’ and ‘achieved deviance.’ Ascribed deviance is a condition ascribed to individuals for which they are not held accountable and so no blame is attached to the individual. However, achieved deviance sets out the notion that the condition of the individual is in some way culpable for their actions. Examples of this could be blindness as an ascribed deviance and HIV, through sexual transmission, as achieved deviance. There is a significant overlap between the two, which was not accounted for by Mankoff (1971), as blindness may be caused by a mishap on the part of an individual and so their behaviour becomes judged irresponsible and implicated to their condition. Similarly, a child born with HIV may have their deviance ascribed and so they are not blamed for it.

Giddens (1991) argues that individuals sustain their group membership through a sense of 'ontological security', indicating a sense of security about *being* in a world which is often chaotic and purposeless. For most people, there is a sense of optimism about continuing in life, which is developed from birth by developing a sense of trust, and so fundamental anxieties develop when a person loses their sense of ontological security that things will get better and that social norms will not be reinforced. As Giddens (1991) states, ontological security is "…a sort of emotional inoculation against existential anxieties – a protection against future threats and dangers which allows the individual to sustain hope and courage in the face of whatever debilitating circumstances she or he might later confront" (Giddens, 1991: 39).

These anxieties can lead to 'projection' (Davey and Seale, 2002) whereby stigma is projected toward other people or groups who appear to be a cause of social conflict, such as those who are diagnosed with a stigmatised disease and illness, such as HIV or leprosy. Ontological 'offence' is experienced as the display of disease or deformity which reminds the viewer of the capacity of their own body or mind to deteriorate. On another level, the 'unpleasure' that this provokes projects ill-feeling onto the ill person, 'accusing' them of behaviour that has caused this discomfort to the onlooker. This may cause accusations of moral deficiencies in the person stigmatised. Ultimately, this leads to a tribal identity, a reinforcement of solidarity and a sense of togetherness in the face of a threat (Davey and Seale, 2002; Balfe, et al, 2010). Aside from reinforcing social norms and deviant behaviour, what also emerged later from the early literature on stigma has been the notion of stigma as internalised, and 'self-stigma' will be explored in the proceeding section of this chapter.

Stigma as internalised and as self-stigma

As well as earlier links to deviance and reinforcement of social norms, other authors have identified stigma as being internalised by individuals with detrimental consequences on the psychological well-being of those who are stigmatised (Meyer, 2003; Stutterheim, et al, 2009; Bos, et al, 2013). ‘Self-stigma’ results from an acute awareness of a stigmatised person’s own social devaluation connected to their condition or illness and like public stigma, it has cognitive and behavioural components (Bos, et al, 2013). Self-stigma can be part of a ‘felt’ process and can lead to individuals hiding aspects of their condition (or the condition entirely) from others and being receptive to perceived ideas of shame about and guilt for their condition, such as HIV.

Stigma and deviance can be either ‘enacted’ or ‘felt’ whereas enacted stigma and deviance, “denote discrimination by others, felt stigma and deviance denote; (1) an internalised sense of shame and blame respectively, and; (2) a frequently distressing and disruptive fear of being discriminated against” (Scambler, 2008: 209). In terms of hidden illnesses, individuals may manage their illness and information about it with extreme caution in order to ‘pass’ as normal. This can be seen in the work of Scambler and Hopkins (1986) and their study of people with epilepsy and recurring seizures. Respondents felt that the diagnostic label given to them by physicians was unpleasant and most contested it, largely due to the stigmatising label of epilepsy which discredited them (Goffman, 1963). Fearing discrimination, respondents hid or minimised their seizures and developed ‘stories’ to explain the fact that they were not allowed to drive.

However, this is not always a straightforward process, and as Goffman (1963) argued, people who choose to ‘pass’ as ‘normal’ by hiding their stigma remain ‘discreditable’ as long as there remains the potential that the stigma can be revealed, which can lead to significant distress amongst those who conceal their condition. When people voluntarily disclose their stigmatised status or who have a visible stigma (such as an obvious physical disability) they do not face the issues around disclosure concerns, but they still must endure the potential of continually being discredited in front of others (Stutterheim, et al, 2011).

Stigmatised individuals can attempt to mitigate the negative effects of this by employing coping strategies such as selective disclosure, compensating for the stigma during social interactions (for example by being particularly outgoing) and also through disengagement, to avoid situations where stigmatisation is more likely (Bos, 2013). However, others may use different coping methods as discussed, such as being more politically aligned through seeking or setting up social support. People living with an invisible stigmatised condition who meet others experience a mood lift in the presence of others who share their stigma (Hatzenbuehler, Phelan and Link, 2013). In some cases, by alignment with others in social, political, community (or any public-facing) groups (Pinel and Bosson, 2013), stigma can pass to others by association, who do not have the stigmatised condition. This will be explored below in what Goffman (1963) called ‘sticky’ stigma.

Stigma as ‘sticky’

Disease and illness stigmas can also be felt by those close to the individuals who have the condition, such as partners, friends, and family members. Originally called ‘sticky’ or ‘courtesy stigma’ (Goffman, 1963) this was further illustrated in the findings of MacRae (1999) whereby 54% of spousal caregivers and 53% of child caregivers had felt embarrassed and ashamed by their family members’ outbursts with Alzheimer’s disease. This was especially felt when their family members’ behaviour was in violation of social norms. Furthermore, other studies have shown that these very groups, in the case of families and caregivers, can also be routinely devalued as a result of their connection to those with a stigmatised condition (Hebl and Mannix, 2003). This process of devaluation does not only take place when a person is intimately or connected in a familial sense, but also arbitrarily and out of pure proximity (Pryor, Reeder, and Monroe, 2012).

Perceptions of stigma by association result in lower self-esteem and higher distress in those connected to stigmatised individuals, which is often family members (Mak and Kwok, 2010). In some cases, stigma by association leads people to hide their relationship with a stigmatised family member or encourage that member to hide their illness or condition, especially where public feelings of shame may be felt or enacted. This concealment advice is detrimental to the individual with the stigmatised condition (Stutterheim, et al, 2009) as it impacts upon their sense of self and psychological well-being. However, it is not only family members who are affected with courtesy stigma, as this can spread further onto wider social connections who have developed different relationships with stigmatised groups, for example, volunteers who support people living with HIV (Snyder, Omoto and Crain, 1999). Courtesy stigma can also be further compounded by larger structural stigma, as noted by Angermeyer, Schulze and Dietrich (2003) in their research on relatives of schizophrenic patients, as they experienced additional stigma around distorted media-based mental health images, as well as structural discrimination from psychiatry. Whilst stigma by association is a key strand of stigma research, it is also placed within larger social trends, cultural attitudes, and ideologies at a larger structural level, which has been advanced by Sarah Ahmed (2005).

Ahmed (2005) argues that the ‘sticky affect’ can be found in emotions that are not *within* people, but instead they *shape* people, with emotions being cultural practices and not psychological states. As Ahmed (2005: 4) states “emotions shape the very surfaces of bodies, which take shape through the repetition of actions over time, as well as through orientations towards and away from others”. Pointing to the example of politicians and their repeated use of ‘sticky words’ used to describe people seeking asylum, such as ‘swamped, ‘flooded’ and ‘overwhelmed.’ The repeated use of these terms and the highlighting of individual cases of ‘bogus’ asylum seekers then informs and elicits wider public emotional anxieties, fears and stigma, attaching emotions to collective bodies, whereby stigma becomes, “an effect of the histories of contact between bodies, objects, and signs” (Ahmed, 2005: 90). This allows the definition and signalling of the ‘bogus’ asylum seeker becoming detached from a particular and individual body, to become then re-attached to *all people who seek asylum or who seek asylum in the future,* as being potential bogus applications.

This collective group then becomes seen as an object of suspicion, hate, stigma and a useful ‘economic currency’ which can be continually framed by those in power as a ‘threat’ to nationhood. Mobilising emotions into collective bodies and political alliances links concepts together, such as individual bodies, emotions of hate, the sticky effect and the collective future of a nation together, where some groups may be seen as threatening (Ahmed, 2004, 2005). Due to past histories of association that ‘stick’ (for example, HIV fears from the 1980s) fear gets “contained in a body, which henceforth becomes an object of fear which allows the object of fear to be generated in the present” (Ahmed, 2004: 127). The failure of emotions to be linked in a particular person, and instead be applied (or ‘stuck’) to a ‘body’ and collective, allows these emotions to reproduce and continue to generate inequalities. Ahmed (2004, 2005) raises important points about power and stigma at a structural level, and so critiques Goffman’s notion that stigma simply has to be managed by an individual, and is only contained within an individual person, with no links to wider power structures (Tyler, 2021). As noted in the history of HIV in chapter two, structures, governments and power regimes have played significant roles in manifesting and using HIV-related stigma. Building upon the work of Ahmed (2005), the following section will explore this further.

Stigma as structural

In other recent literature on stigma, there has been a move toward political economy (Link and Phelan, 2001) whereby stigma interacts with power, culture and difference and societal ideologies and institutions perpetuate a stigmatised status (Corrigan and Lam, 2007). Relations of stigma are pivotal for social order, promoting the interests of dominant groups as well as clear hierarchies of rankings between them. As a result of this, stigma tends to follow the existing unequal ‘fault lines of society’ and act as a ‘layered stigma’ (Deacon and Stephney, 2007). For many people living with leprosy, HIV, or tuberculosis in poorer nations, they may be unable to hide it and so are more likely to suffer both publicly and to suffer structural discrimination. Whilst the poor can also stigmatise the wealthy (Scambler, 2008) it is the affluent and those with power who are positioned to ignore or avoid cultural sanctions, as well as having far better access to resources. For example, at a global level, HIV-related stigma has been far more intense against marginalised groups such as the poor, women, African Americans, and gay men (Deacon and Stephney, 2007). Similarly, Scambler (2004, 2006) has argued that the study of stigma and deviance must consider, and cannot be conducted without reference to wider social structures and forces such as class, gender, ethnicity, and age. Stigma leads to a downward placement of the stigmatised individual or group in a status hierarchy (Links and Phelan, 2001) and it can encourage direct and indirect social and economic discriminatory behaviours that affect an individual’s life expectancy (Balfe, et al, 2010).

Structural stigma is also linked to poorer life outcomes and poor health, maladaptive coping behaviours such as smoking, drinking and increased social isolation, leading to poorer health outcomes (Hatzenbuehler, Phelan and Link, 2013). This led to what Goffman termed the ‘normal,’ to justify their treatment of the stigmatised individual as seeing them as contagious, dirty, dangerous, or ‘not quite human’ (Balfe, et al, 2010). However, stigma also has effects on high-status groups in society, especially in terms of illness, whereby members of high-status groups may spend considerable resources, both personal and financial, to conceal stigmatised conditions because they fear status loss. This was highlighted in Bond et al’s (2003) research where they found that blame is sometimes directed at high-status members by communities, if they contract a stigmatised illness because they ‘should have known better’ and so stigma does not always result in specific of having a negative effect (Deacon, 2006).

Yet, stigma is located within shifting social, historical, and cultural contexts and so its significance changes over time (Nettleton, 2013; Tyler, 2021). Echoing Parsons' (1951) notion of the sick role and deviance, discussed earlier in this chapter, Scambler (2006) argues that changes in UK government policy and a shift towards 'personal responsibility' has meant that the stigma associated with chronic and disabling conditions has been layered with deviance toward those who resist re-integration into employment, shifting away from previous versions where disabled people were excluded from the sick role model. The onus for many disabled people has shifted, and those who were once regarded as 'socially excluded' are now encouraged to 'self-include' in regard to employment. Failing to do so has led to negative perceptions of the disabled as 'lazy' and impacted the rising hate crime toward disabled people in the UK (Guardian, 2015).

In a recent reworking and critique of earlier theories of stigma, Tyler (2021) argues that stigma is a 'history of practices'. Building on the work of Ahmed (2005) and Scambler (2006) as already outlined, Tyler troubles the widely used Goffman view of stigma as a micro-personal attribute removed from wider structural processes. Through the lens of viewing stigma as 'vertical' (looking upwards at the sites of stigma production), as well as stigma as temporal (taking a long view of stigma as socio-historical), Tyler (2021) connects the personal and the biographical to larger structures, institutions and historical accounts, highlighting stigma as embedded within the social relations of capitalism, and as a form of power entangled with histories of capitalism, colonialism, and patriarchy. Through case studies of 'benefit cheats,' the European 'migrant crisis' and the implementation of austerity politics within nation-states in Europe, Tyler (2021) draws threads of connection between historical practices of stigmatisation and the rise of a twenty-first-century 'stigma politics.' Through this, new media and narratives are harnessed by the elites to manufacture stigma by dividing communities against Muslims, refugees, disabled people, women, and the 'undeserving poor' with an aim of dehumanising and devaluing people.

Through ‘sites of stigma production’ such as divisive political narratives from institutions and technologies via the use of ‘stigma power’ (Tyler, 2021), politicians, spin-doctors, think-tanks, journalists, digital corporations and everyday stigma interactions, create racist, disablist and misogynistic hate speech in face to face and online settings. Tyler (2021) argues that by ‘looking up’ and ‘looking back’ at wider social structures, there is a ‘stigma machine’ made of interconnected parts which coalesce together to maintain stigma, which is beyond that of the personal lived experience as suggested by earlier stigma writers, such as Goffman (1963). This reconceptualisation of stigma becomes particularly heightened when discussing HIV, as ‘stigma power’ was used heavily by governments, moral entrepreneurs, religious (and secular) bodies and other institutions, in a similar way as already outlined in chapter two, to devalue people living with HIV. Advancing this argument of Tyler (2021) further, much of the modern-day stigma around HIV is also still structural (vertical) and related to the socio-historical (temporal) background of the virus within the public imaginary.

The changing nature of stigma as located within socio-cultural contexts alters, however this process of change can also lead to positive outcomes. As in, a stigmatised identity can lead stigmatised groups to push for political action and activism (e.g. become HIV campaigners). Some authors have argued that social transformations have effectively reduced the levels of stigma associated with long-term disease, illness and disability as these changes have weakened its potency (Green, 2009). An example of this is pressure groups within the political landscape that have promoted positive images to counteract stereotypes and shape anti-discrimination legislation and provide support systems to move toward the social model of illness. Whilst acknowledging that stigma is somewhat omnipresent around HIV, others have argued that more positive images of illness have been given space to present proud and positive identities (Fukuyama, 1989; Pinel and Bosson, 2013).

Resistance to stigma

Technological advances have also affected the identities of people living with illness and made them more complex and not as easy to claim as deviant or stigmatising. For example, the development of anti-retroviral therapies for people living with HIV or cancer drugs, allows the illnesses to be managed (though not cured). These overlapping factors work together to, “provide effective resistance to stigma and minimise the power and impact of stigma upon the people living with a range of long-term conditions” (Green, 2009: 124). Furthermore, due to changing societal attitudes and wider dispersal of knowledge, some authors have argued that illnesses have become more accepted, such as epilepsy which in the past attracted magnetic attributions such as demonic possession, hypersexuality and aggression, but that we now know to be a medical condition (Jacoby, et al, 2005; Pinel and Bosson, 2013). Whilst this does not mean stigma around disease and illness has gone away or has vanished due to these advances, Green (2009) does note that the future is hopeful, and the effects of stigma can be diluted by this ongoing process. Furthermore, in certain circumstances and contexts, people may ‘gain status’ (and thus self-status) if they come out about a stigmatised characteristic and so they become legitimate spokespeople for marginalised groups in the process.

The stigmatisation can become the formation of a minority group identity and establish the group’s legitimacy for lobbying and political change (Berbrier, 2002). In doing so, this can develop an individual or group’s confidence in using their own stigmatised status to gain social progress or reward. However, stigma can be encompassing and so resistance to it can be problematic, and the outcome of some stigma can be through social death, which will be discussed in relation to HIV, below.

Social death

The term ‘social death,’ or the process or state in which an individual ceases to be an active participant in the social worlds of others and is often an outcome of stigma (Caswell and

O’Connor, 2015). The concept of social death emerged from earlier studies, such as Glaser and Strauss (1966), who outlined the social death toward people dying in medical hospitals by the reactions from medical staff and their relatives. In addition to this, Sudnow’s (1967) study of the social processes surrounding death was based on hospital observations and the presumed social value of patients, and their treatment by medical personnel and the efforts used to revive them. This study conceptualised the notions of a clinical, biological and social death, whilst the actions of others treat the person as deceased, despite them being alive both biologically and clinically.

Ideas of social death have also been related to ideas of the ‘non-person’ (Goffman, 1961), ‘homo scaer’ (Agamben, 1998) and the ‘ex human’ (Biehl, 2004). Goffman’s (1961) earlier research within mental hospitals showed how a person is not only removed from their social setting, making them lose their social roles, but also placed within an environment that removes aspects of their identity to become a ‘non-person.’ Agamben (1998) discusses the concept of ‘homo scaer’ in Ancient Roman law, which was inflicted upon that of criminals, whereby they could be killed by anyone at any time due to losing social and legal protections. Like the stigma attached to patients in hospitals in the findings of Goffman (1961), the homo scaer marks out people as stigmatised and leads to their social abandonment. Biehl’s (2004) idea of the ‘ex human’ suggests a person who has lost economic capital, and so with this a loss of social identity, integration, and creates feelings of inadequacy in the eyes of others. For all of these three concepts, social abandonment is reinforced by the stigma of association (Kralova, 2015) and it is enforced upon the agent. Studies since then describe genocide (Card, 2010) and the process of slavery with slaves who are alive, but socially dead (Turner, 1967). The concept of social death and its association with stigma is heavily linked (Kralova, 2015).

In more recent theoretical developments, Kralova (2015) points to the multi-dimensional factors which further social death, which include exclusion from a community of belonging, a weakening or withdrawal of legal protections, economic vulnerability, stigma, and loss of social identity. A general trend has been to use the term social death when a person, or group, has had a profound and extreme loss, such as social exclusion, the loss of social networks, citizenship, indeed the loss of economic capital, social identity or social capital (Kralova, 2015).

Other recent theoretical developments from theorists in the geographies of disabilities have argued that the location of disability can be analysed in terms of its (dis)locations and locatedness, as people with chronic and mental illness are often placed outside the category of legitimate social beings (Rosqvist, Katsui and McLaughlin, 2017). As Rothe (2016) argues, with reference to social death, people with mental illness or dementia, are:

> "Imprisoned, first within their minds, and secondly by the state… Consequently, they become socially unworthy – the socially dead. The seriously mentally ill experience both spatial and moral dislocation. They are cast out as flawed consumers and failed workers, and more importantly, due to the stigmatisation of mental illness, they are disavowed of their humanity, rendering them socially dead." (Rothe, 2016: Abstract)

Other research into dementia has shown that despite parallels between frail old age with dementia and social death, people living with dementia can remain partially socially alive due to their carers' active involvement, partly mitigating the unchosen circumstances faced by this group (Gillard and Higgs, 2015). Therefore, it is not sufficient to say that all people with dementia, or all those who appear to be frail or elderly, are also socially dead (Caswell and O'Connor, 2015). Indeed, individuals may be cast as socially dead by some players in their social lives, but the same individual may appear prominently in the lives of others. More contemporary accounts of social relations surround dementia in favour of the continuing role of 'personhood' (Dewing, 2008; Gilleard and Higgs, 2015). In light of this, Borgstorm (2017) and Caswell and O'Connor (2015) note that some individuals may move in and out of periods of social death and social life, and they may at times be cast by some as socially dead, and cast at other times by others, as socially alive. As such, social death is not as rigid or as permanent as some of the earlier studies about social death suggested, and instead, it is more fluid, temporal and complex, having more concept of agency to it.

However, “this exercise of agency does not take place in a vacuum” (Caswell and O’Connor, 2015: 251) and all individuals and even those who have little contact with others, live within a wider social context which influences the choices they make and the options available to them, when they make those choices. This relational context to the social world in which people live can be a source of opportunity or constraint (Gardiner, et al, 2009; Caswell and O’Connor, 2015) whereby supportive family, carers or friends may provide a utilisation of opportunities for one individual, whilst the lack of a network may leave another individual aware of only constraints (due to the lack of support). In terms of ageing, Gilleard and Higgs (2015) in their work exploring social death and the ‘fourth age’, argue that the automatic assumption of a fourth age of frailty and dementia and loss of all social relations deprives people within this demographic of their human rights and becomes itself, a stigmatising practice as ‘ageing without agency.’ Instead, they argue that the fourth age is not a fixed bio-chronology or an individual stage of life, but instead is a ‘social imaginary’ given to people by society and its institutions, rather than showing the agency, active ageing, and the continuous social relations of the people within the ‘fourth age’ (Gilleard and Higgs, 2015). Not only has the term social death been used in terms of ageing, dementia and mental health, but it has been allied to other disabilities such as HIV, which will now be discussed.

Social death and HIV

The concept of ‘social death’ was first applied to HIV and AIDS by Susan Sontag (1989) who described HIV and AIDS as a social death before that of the physical death, creating a metaphor of a thing that belongs to ‘someone else.’ The metaphors used, whereby HIV and AIDS were described as a ‘plague’, were common terms at the time of the HIV and AIDS crisis in the 1980s, which were widely used by the media, social actors and institutions, and which reinforced the notions of judgement and punishment. Sontag (1987) argued that a person infected with HIV becomes ill as soon as they are infected, whether or not they have shown any symptoms of it. As such, they face a social death of isolation by the communities, networks and institutions in which they live. This becomes more apparent as people living with the virus are identified and separated, both literally and metaphorically, from that of ‘mainstream’ society through segregated hospital wards, quarantines, or via government silence and inaction. This led to groups seen as ‘undesirable’ to fend for themselves and through fear of contagion, ensured that many MSM (and others who caught HIV) died alone or only with people who were willing to care for them (France, 2016).

Our social identity is connected to and enacted through our bodies (Hockey and Draper, 2005) and this is more visible in our bodies as they age, become ill, and decay. The body’s deterioration at the height of the HIV and AIDS crisis led many people living with HIV and AIDS to present public bodies which were visibly disintegrating due to the symptoms of the virus. This undermined social identity and prevented interaction with others (Hockey and Draper, 2005). Whilst these deteriorating bodies still had autonomy and agency, they added to the social death of people living with HIV as individuals largely withdrew from society, were hospitalised, and/or lost their identity and social networks due to their status. This is not to say that all people living with HIV faced this, as a significant activist movement built up within the LGBTQI+ community (France, 2016), however the visible signs of a social death, before a physical death, were clear (Sontag, 1987).

Whilst Sontag’s (1987) work conceptualised HIV and AIDS as an extreme version of social death, at the time of her writing and at that liminal point in time, her ideas held relevance, as confusion reigned about transmission methods and who was/was not infected. However, decades later, the nature of HIV and AIDS has now altered and with life expectancy growing and the narrative around the normalisation of HIV appearing due to PrEP and medical advances (Mazanderani and Paparini, 2015; Dalton, 2017) some of the potency (and perhaps relevance) of her argument has been diluted. Other factors which have contributed to this have been an increasingly sympathetic media which is less likely to stigmatise certain groups in the West, and the highlighting of other groups, aside from MSM, living with HIV. After Sontag (1987), no other work, or advancement of this theory has discussed the concept of social death in people living with HIV and AIDS in the West. This is important as there is a socio-historical legacy and impact of HIV and AIDS as discussed in chapter two; bringing forward theories discussed so far, this will be reconceptualised below.

The 'long shadow of social death'

For this section, I will recognise the underpinnings of the social death argument as applied to HIV and as set out by Susan Sontag (1987), but I will build upon their original theory and apply it to people growing older with the virus. Instead of directly utilising the original concept and meaning of social death as applied in her work at that period of time, I will reconfigure this to recognise that advances in medicine, and some social change, have happened in regard to HIV and AIDS in the West. In addition to this, alongside contemporary theorists of social death (Dewing, 2008; Gilleard and Higgs, 2015; Caswell and O'Connor, 2015; Borgstorm, 2017), I also recognise that social death is not an absolutist concept in all aspects of an individual's life, but is instead imbued with aspects of agency, flexibility, and fluidity, whilst also being cognisant of structural barriers that may impact upon a person.

With these concepts at the forefront of this, I introduce the concept of the *long shadow of social death* to be used as a reconceptualised term to explain how the lived experience of HIV has advanced positively since the crisis of the 1980s and 1990s, yet it has still held onto some of the stigma of its socio-cultural and historical origins. The argument presented here is that the long shadow of social death, when applied to older people living with HIV in the modern-day West, still maintains some of its stigmatising roots and of the associations it had formerly, through new forms of exclusion. The long shadow of social death is similar to what Jonsson (2015) deemed as having a ‘partial social death’ or as a ‘profoundly compromised well-being’ (Kralova, 2015) whereby people see the loss of some of the social deaths facets and so are neither fully socially dead nor have full participation and engagement, due to a complex interplay of ageing, stigma, and HIV and AIDS.

Rather than being a clearly defined event, Norwood (2009) describes this concept of social death as a series of losses, for example; loss of identity, the ability to take part in activities, loss of community, and loss of social relationships. Cumulatively, these losses can result in a person becoming further disconnected from social life. Both authors view social death where isolation may occur, but agency is not lost, challenging the conceptualisation of social death as a total loss of agency and personal identity (Borgstorm, 2017).

Therefore, the original concept of social death as set out by earlier authors and by Sontag (1987) has evolved, as it is not quite as all-encompassing upon individuals’ lives as it was socio-historically in the West. This is partly because government policies have become more interventionist regarding HIV, activists have shaped drug trials (France, 2016) and lives have altered as a result of medical practice and public sympathy. However, this thesis still recognises that some of the isolationary practices and forms of exclusion from the early days of the crisis have not yet gone away. Still in contemporary Western countries, with advanced medical practices, people living with HIV are affected by the ‘long shadow’ of cultural, social, and historical baggage from the original social death set out by Sontag (1987). This new form of social death is different to that of the 1980s and early 1990s, in that it still casts a ‘shade’ or ‘shadow’ and therefore brings ongoing HIV-related stigma to people and groups living with HIV. As research into older MSM living with HIV in chapter two highlighted, clearly stigma is still a significant issue and this deserves to be considered, especially in light of the invisibility of, and lack of research into older heterosexuals living with HIV, including any stigmas they may face.

Whilst not as structurally obvious in terms of its outright prejudice toward older heterosexuals living with HIV, which was evidenced in previous years through government inaction, and discrediting policy proposals as well as the mass panic toward people living with HIV, stigma has taken on a new form. The long shadow of social death for older people living with HIV instead brings historical roots of stigma, exclusion outside of and within communities, as well as isolation and the invisibilisation of lives (see chapter two). Perhaps subtler than seen previously in the HIV epidemic but from previous research into older MSM living with HIV, this long shadow of social death still casts its shade over MSM and their communities; this can be applied to some of the lives, narratives, and experiences of older MSM living with HIV, even today. However, little is known about how stigma and the long shadow of social death apply to older heterosexuals, due to being under-researched and invisible throughout much of the HIV pandemic in the UK.

Stigma: How will stigma and the long shadow of social death be framed in this research?

Very little academic research has examined older heterosexuals living with HIV, and the stigmas that they face in the UK. To this date, only one study in the UK conducted on older heterosexuals and older MSM has taken place, which explored HIV stigma in a more generalised sense (Rosenfeld, et al, 2015). It is, therefore, more uncertain what type of specific stigmas older heterosexuals living with HIV face, and with stigma theories lacking a coherent model, this thesis will keep a broad perspective on how stigma operationalises within respondents' lives. What is known, however, is that stigma practices have been found socio-historically around HIV, and this has led to the marginalisation of heterosexuals living with HIV. The nature of stigma has also evolved alongside the long shadow of social death, and this will be taken forward in the study.

Importantly, the potential mix of stigma, the long shadow of social death, as well as the unique experience of heterosexuals growing older with the virus in the UK, this thesis asks whether older heterosexuals are likely to be more prone to disengagement as they age as a result of this, or whether they actively age. It also asks whether their resilience will be impacted by the virus, and this research helps to illuminate how they navigate a new and changing social landscape. This final section will bring together some concluding points from this chapter and will raise further questions for the research study.

Questions to take further into the study

Reflecting on the discussions from chapter two, highlighting the gap in knowledge of what it means to grow older with HIV as a heterosexual person in the UK and the questions which emerged from the empirical data, this chapter has built upon this by offering theoretical tools in which to explore this demographic group. The invisibilisation and under-researched nature of heterosexual populations (particularly older people) emerged from the previous chapter, which means that little is known about their lives and now they navigate growing older whilst living with HIV. As such, it is vital to examine a framework of theories of ageing and resilience to see how this group are ageing with the virus and what this means in light of growing older with it and living with it. Furthermore, little has been known about the role of stigma in the group and whether it affects older heterosexuals differently, or not, due to their own unique place in the socio-historical background in the HIV and AIDS epidemic. Whilst evidence from research into older MSM living with HIV shows stigma being a significant presence in their lives, as evidenced in chapter two, it is important to bring stigma forward to see how this applies to older heterosexuals living with HIV.

As a result, this chapter outlines three key theoretical approaches together to take forward into the study. In part one, the importance of the life course model and the role of *active ageing* as a theoretical approach are outlined, giving attention to the roles of both structure and agency to develop a fuller understanding of whether older heterosexual people living with HIV actively age or not. In part two, an outline of the theoretical approaches to resilience is provided, framing resilience for this research as *unfinished resilience;* an ongoing relational process and like the perspective of active ageing is impacted by the wider social world and the agency of the individual. In order to understand the lived experiences of older people living with HIV and how they navigate their own social worlds, resilience provides a key approach in framing how they may do this. Finally, as evidenced in the lives of other people living with HIV such as older MSM in part three, theories of stigma are highlighted so as to understand how various types of stigma may impact the lives of older heterosexual people living with HIV. This chapter also reconceptualises social death into the *long shadow of death* in contemporary society, whereby HIV medication has improved the lives of many, alongside less alarmist public and governmental responses, but HIV-related stigma still abounds and is attached to its own socio-historical origins.

Pulling out the various perspectives outlined in this chapter together, some key questions emerge from both of the literature chapters so far. What does the ageing process look like for older heterosexual populations? How do older heterosexual people ageing with HIV navigate their social lives? Do older heterosexuals find a similar 'HIV community' to MSM in which to seek support, despite not always being part of a larger socio-historical community of people living with HIV? Do they also face stigma and what does this look like? Does this also mean that older heterosexuals are even more at risk of social withdrawal and isolation, and therefore their active ageing and resilience are diminished? Or do they actively age with their HIV and find alternative meaning in their lives? These are key questions and thoughts to consider and take forward in this thesis, to examine how heterosexuals with HIV live their lives, whether or not the long shadow of social death affects older heterosexual people, or whether unfinished resilience is a factor which mitigates against this, offering new spaces for self-agency.

However, before accounts of older heterosexuals living with HIV are brought into this thesis it is vital to examine the research process in the following chapter and to present the methodology for this research.

Chapter Four: Methodology

The aim of this research is to examine the lived experiences of older heterosexual people living with HIV in the UK, and to see whether their experiences are similar, or not, to older MSM living with HIV. Further to this, this research aims to explore older heterosexual people's experiences of resilience, and whether active ageing is part of their ageing experience. By interviewing heterosexual older people living with HIV, the aim is to centralise their experiences and life narratives in this study, as they are an often bypassed and overlooked group within previous HIV research, as stated in the literature review (see chapter two). Drawing on the key points raised in chapter three, this thesis aims to address the following research questions:

- What are the lives of older heterosexual people living with HIV like, and what experiences and issues do they face as they age with HIV?
- How are the lives of older heterosexual people different, or not, from that of older MSM living with HIV?
- Do older heterosexual people living with HIV experience social withdrawal as they age with HIV? Or are they 'actively' ageing?
- What are the coping mechanisms faced by older heterosexual people as they age with HIV, and what does resilience look like to them?

Research ontology

Ontology is the study of the nature of reality and whether a fixed and immutable reality can be 'found' (Silverman, 2017). In terms of the focus of this research, constructionism is the ontological lens used, which asserts that reality, social phenomena and their meanings are constantly and continuously being accomplished by social actors (Bryman, 2012). Social worlds are in a constant state of revision and an ongoing accomplishment, and so aspects such as HIV-related stigma, resilience, and ageing become social constructs informed and altered by the wider social world. This perspective also recognises that the accounts of the social world in this thesis are also constructions which the researcher brings to the research process (Bryman, 2012). This thesis presents a subjective and specific version of social reality which cannot be claimed to be definitive, discussed in detail in the positionality section later in this chapter.

This approach recognises that only estimates or shifting views of reality can be hoped to be gained from this research, and so it will only posit a snapshot of reality at a given moment in time (Silverman, 2017). Due to this, I could not aim to give a full and complete understanding of the ‘reality’ of all lived experiences and narratives of growing older with HIV amongst heterosexual populations and this research recognises this. From this constructionist position, “narratives are tools for engaging with an external reality, much more than constrictors of that reality” (Squire, et al, 2014: 80). Therefore, this thesis can only attempt to highlight a fraction of my respondents’ subjective lived experiences and realities, which can/will change due to ongoing and changing constructions of what it means to grow older with HIV.

A benefit of this constructionist approach is that it allows the respondents to make sense of their own reality through their own life narratives and by, “locating stories of experience with descriptions of the contexts in which they occur” (Somekh and Lewin, 2006: 156). As an example of using this approach, many respondents discussed their experiences of living with HIV currently, but also discussed their experiences of living through time periods where HIV has taken centre stage in public dialogue in the 1980s and early 1990s, and since then, has become increasingly muted or bio-medicalised (Dalton, 2015, 2017). Respondents could see how their own social realities were part of wider social constructions, and how this impacted their own lives (Bryman, 2012). This constructionist position alongside narrative research methods, allows the respondents to become a witness of their own constructed social realities as well as informants of changing narratives in their own social worlds. These constructed realities and the meanings attached to them are shifting socio-historically through a build-up of interactions, and therefore can only be interpreted by a person's particular knowledge.

The epistemological position of this research

Interpretivism is a theory of knowledge which posits that knowledge is produced by exploring and understanding the social landscape of the people being studied, including how people make sense of their world and assign meanings to it (Sarantaakos, 2009). This approach recognises my understanding of the social world, as well as the research participants' understanding of their social worlds and their own knowledge and perspectives. In order to examine growing older with HIV using qualitative methodologies it was not possible to be objective-free, as knowledge is personal, subjective and unique to the individual and their own life narratives (Elliot, 2005; Silverman, 2017). This interpretivist approach explores how meaning is constructed through narratives in the wider cultural, social and interpersonal resources (Squire, et al, 2014).

Constructionist ontological approaches can be used with interpretivist epistemological approaches to understanding life narratives as a whole (Squire, et al, 2014) and so a blend of the two can often blend the best elements of both. Stories are linked to the wider social realities that exist (Squire, et al, 2014). With this understanding in mind, this research takes a *narrative co-construction* approach. Narrative co-construction is the most appropriate way to approach this research so that interpreting a respondent's particular life experiences becomes a way in which to understand that experience for the narrator, the connection between individual stories and their wider contexts (Squire, et al, 2014). Andrews (2002) argues that individuals tell these narrative stories as members of a situated and historically specific generation, and that each generation has ways of creating, constructing, and narrating their lives. These narratives impact, compliment and feed into social change, as parallel social movements create new co-constructed opportunities for stories to be told and heard, and for individuals to participate in democratic moments. Storytelling itself, especially sexual stories around intimacy and sex lives, such as those around HIV, can gather people together and lead to political action, as is testament to the narratives from feminist, LGBTQI+, disability and civil rights movements, which would not have flourished had the stories not been told nor heard (Plummer, 1995). Certain kinds of stories have currency within a specific historical and social context and develop their own significance, thus creating the space for a unique glimpse into the lives of people over periods of time.

Through narrative co-construction, the link between the individual narrative and its impact, both from and on wider social forces, underpins the research and guides its own epistemological approach, in order to interpret and analyse the respondents' social worlds. With this approach at the forefront and recognising where the researcher fits into the wider changing landscape as I approached the research, the following section will now reflect upon my positionality and reflexivity.

My own positionality, reflexivity and relationship building with respondents

I had to consider my positionality within this research project as my experiences were key to how they affected the research design and implementation. My positionality of personal and professional experiences, interactions, emotional involvement and reflections on what I have previously observed and analysed in society are vital to consider and reflect upon (Hammersley, 1992).

As part of my positionality and reflexivity, I need to declare my position in relation to the research question and the participants (Finlay and Gough, 2003). In their later work, Finlay and Gough (2008) acknowledge the blurred borders among the diverse forms of 'reflexivities,' where one can identify how reflexivity is practised and adopted: who practises 'it'; what the research is 'on'; and what the researcher's agenda 'is.' This, they argue, is an immediate and dynamic process which involves continuing self-awareness throughout the research. With Finlay and Gough (2003) at the forefront of my research practice, reflexivity was an important part of the process, and I had to consider how and what I learnt was informed and constructed, but also how my knowledge was challenged, and how I developed new knowledge from the research. Broadly, these strands come together to form what I will now call my ‘reflexive practice’ (Attia and Edge, 2017; Stevenson, et al, 2018) which was to position myself within my research and acknowledge the influences of my views, context, experiences and role in shaping all aspects of the research (Green and Thorogood, 2014).

In parallel to my research experience, Stevenson et al (2018) draw from an individual experience in a PhD project, which explored the experiences of older women living with HIV. This led to considerations of reflexive practice through background and present state of a researcher producing new knowledge, as well as being an advocate committed to supporting women living with HIV, as an ally and as a participant in a wider community of HIV practice. Similarly, to this, I also bring a number of dispositions to this work which cluster around four intertwined identities which I inhabit regarding HIV, which are that of a sociologist and academic researching HIV, an HIV practitioner, and an HIV activist and ally. Throughout this research, I recognise that these ‘multiple identities’ (Allan and Arber, 2014) also form who I am, and that I also come to this research not with a *tabula rasa* approach to what I know and what I brought with me, but with preconceptions that were enlightened, contested and confronted as the research took place, which will be discussed further in this section.

Greene (2014) reflects on her own positionality in her work doing research with graduate students as an academic within the establishment. Greene (2014) raises the concept of a researcher being an ‘insider’ and ‘outsider’ in the research process. Associating myself as being an insider/outsider with a researcher’s own position in relation to study participants and to the institutions under study. My reflexive practice and positionality are also a key part of this study, and they inform my reflexivity from when the study started and as it progressed. Through my background experience, I came to this research with ‘insider’ contacts (Green, 2014) and pre-existing networks within the HIV community, and I brought research, activist, ally, and practitioner experiences. I have been involved within the 'HIV community' and HIV Third Sector for over a decade, which has included volunteering and working within HIV organisations, including setting up an HIV organisation in North-East England, as well as actively leading support groups and of engaging in HIV activist marches, rallies, and events. This has affected my choice of topic for this research and as HIV has become central to my role as an academic and researcher, this in turn, has influenced and impacted my HIV activism. Therefore, consideration of my role as an HIV researcher, activist and practitioner means that it informs a self-conscious attempt to choose the narrative method over other interview and survey methods; to ensure that respondents' lives are not framed by only their *life with HIV* during the research process, as I had seen from past experience, which will be discussed below.

Stephenson et al (2018) discuss individual practitioner experiences of working for an HIV organisation. In this work Stephenson was often approached by researchers, undergraduate dissertation and masters-level thesis students, who frequently came 'blind' to the organisation often with the same research questions, leading to research fatigue amongst people living with HIV. This echoes much of my experience in the sector, whereby there is both a dual history of people living with HIV working with researchers (such as pharmaceutical industries), alongside a general mistrust of research being 'done to' the community. Telling your own story can be exhausting and it can deplete further when its currency is demanded often from other people (Stephenson, et al, 2018). Due to this, Stephenson found that this often led to an unwillingness amongst many people living with HIV (and staff and volunteers who work with them) to engage with yet 'another' research project, led by an unknown person from outside of the sector. Being, what she referred to as a "known quantity" (Stephenson, et al, 2018: 5) helped Stephenson and was also invaluable to me, not only for access to participants which will be discussed later, but in that my reflections and experience were similar to hers; which meant that I needed to consider my background and use of methods to gather data. This will be discussed next.

Reflexivity, positionality and the impact of my own experience on this research

My self-conscious choice of narrative methods was affected by two additional reasons based on my experiences to date: 1) experiences of researchers framing an HIV master narrative amongst service users, and 2) my background in conducting narrative methods. Firstly, experience of researchers framing an HIV master narrative in service users was informed by my experiences of observing (and hearing from service users about) the effects of existing quantitative and semi-structured interview studies on service users in HIV organisations where I have worked. In my lived experience of seeing HIV research taking place within institutions, I have seen more positivist survey approaches, whilst semi-structured interview methods can have an unintended side-effect in further deepening the service users' own HIV master narrative in defining them by their HIV status only. For example, previous clients for a North-East HIV organisation I worked and volunteered for, often remarked in support groups and discussions, that the range of frequent medical surveys, health surveys, and questionnaires, alongside interviews from students, researchers and professionals only asked about topics related to their HIV status. This research 'done to' people living with HIV, becomes disempowering to many service users, with them remarking that it pushes their own identities to the back, in favour of one identity of living with HIV. This had the effect of individuals often feeling that they had no control over the research process.

Through focusing on the process of living with HIV only such research approaches from my experience had led to people living with HIV to feel defined by an *HIV master status,* as researchers documented their information. This also led to a self-conscious culture change in the organisation I worked for at the time, about 'who' we let through the door, to consider the quality of the research on our service users, and becoming a gatekeeper ourselves as an organisation. This was not an organisational-led decision only, as it was a decision made in consultation with service users, who themselves found certain types of data gathering (in this case, most short interviews and surveys) draining and disempowering. In order to avoid a more oppressive-based practice and to not disempower respondents (or have access blocked to potential respondents), I reflected upon my experiences to date, recognising that the use of the narrative method would support a more empowering process. The choice of narrative method was as much a move to both relax respondents as well as to enable their voices to be heard, which have been silenced or have been limited by being framed in light of purely living with HIV (Plummer, 2006).

The second reason shaping my experience which I bring to this study emanates from my experience in leading narrative research, and the skills and learning points I could bring to this study as a result. I could lean on my strengths in this research, in that I have already completed a previous research project for a Third Sector organisation that I worked for, using narrative methods about people living with HIV. This peer and staff-led project documented the lived experiences of individuals living with HIV in the North-East of England by documenting the life narratives of service users who took part in it (Dalton, 2017). This project was developed as a participatory methods piece, whereby service users worked with me to design the project itself; they took part in interview and research methods training, engaged in peer-research interviews and co-constructed the research together with me. At the end of the research, positive feedback came from service users who felt that this method was more sensitive to their lives and that the life narrative method *did not define them by an HIV master status,* which much of their previous experience of research had done. That research was then presented at a number of conferences, seminars and workshops to professionals and people living which HIV, which reaffirmed my confidence in the method and reinforced me as the ‘known quantity’ within the sector (Unluer, 2012; Heslop, Burns and Lobo, 2016; Stevenson, et al, 2018). Due to this high level of success in using the narrative method, I felt I could bring this experience to this thesis, using my skillsets as a strength of the study.

However, a tension was also initially present in my early research interviews, as I felt that I wanted to get as close as I could to the respondents' lives by helping them with their own problems, as I would do as a practitioner in an organisation. It was often tempting to want to intervene at key points in the interviews and provide support for people living with HIV, rather than maintaining my perspective as a researcher and allowing the narratives to flow. In early interviews, in particular, I balanced the multiple identities of practitioner and researcher. I recognised that I had to negotiate and balance this by stepping back and reflecting upon what I brought to the study that may cloud my vision, so that an eye could be cast on how all of the respondents' everyday realities were experienced (Gubrium and Holstein, 1997). Not only from my professional experience, but also with having engaged in narrative research with people living with HIV, I had significant experience in terms of listening and responding to difficult conversations; hearing often traumatic life events and other life experiences relating to HIV allowed me to approach this and what I hoped for, was empathy with my participants.

My professional experience has been invaluable in this relationship building. I have run one-to-one meetings and have facilitated group sessions as part of my work within HIV organisations, with service users who were dealing with their HIV diagnosis, living with their HIV or who have other complex life issues. Drawing upon the knowledge and experience I have learnt from my professional background allows me to navigate discussions in interviews around HIV treatments, side-effects of medications and the effects of HIV-related stigma without being clumsy or showing a lack of knowledge which may have led to distrust from respondents. The benefits of this background work meant that it built strong relationships with my respondents, as I attempted to understand their lived experiences and use any 'insider terminology' specific to living with HIV. Due to this relationship-building approach, when asking if respondents had anything final to say at the end of the interview, respondents frequently remarked upon my background with comments such as, *"I trust you. You know what it is like for us"* (Amy), *"I just want to tell you, you are a very nice person. You understand what I am saying"* (Eva) and *"It is* *nice to just talk to someone who listens and gets it. I can tell you did this type of work. Thanks"* (Jessica). However, I want to note struggles with my background of practitioner and activist identity as this on occasion I felt limited the academic scope, which I will explore next.

'Messy' research realities – reflexivity and the changing nature of the research

I initially determined to have a focus on exploring intimacy and dating amongst older heterosexual people living with HIV. However, as the first interviews started to yield early themes, this focus changed as a result. My practitioner knowledge from working in the Third Sector assumed that stigma would be a limiting factor in all lives and that older people living with HIV would be unsuccessfully ageing with HIV and so this would affect their intimate and sex lives. I had also assumed that ageing with HIV would be a negative process overall, in all of its forms, but my position on this was contested with the initial findings challenging my assumptions and knowledge that I had brought to the research. After reflection, I recognised that simply focusing on sex and intimate lives amongst older people living with HIV was no longer suitable, as new unknown (to me) narratives and themes were emerging. Therefore, I decided to refocus on how people managed to live their lives, which was clearly coming through the stories of the respondents, also offering a unique and emerging lens in which to situate my work.

This shift in perception led me to consider the respondents' stories from their biographies, which were displaying examples of how they were living and thriving with HIV as an older person rather than simply a master narrative of ageing as a negative process, which I had originally been eager to avoid. This shift in focus and changes to research is what Allan and Arber (2014) describe as the 'messy research realities' that often go undocumented, undiscussed and undisclosed, but are vital for emotional reflexivity. With this in mind, the topic of this research pivoted toward examining sociological concepts of 'resilience' (see chapter three), in light of this recurring theme emerging from the data findings, challenging my preconceived thoughts as I continued the research. This enabled deeper, more reflexive thinking in myself. I was also surprised as my preconceptions from my experience had assumed that this ‘hard to reach’ group would be difficult to reach due to suspicions from previous research projects, as set out earlier in this section. However, I managed to collect rich and in-depth data from ten respondents by reaching out to them successfully and being known to them due to my background. This challenged my professional fixed notions of what ‘hard to reach’ means and how I needed to reconsider and reflect on my previous thinking about this (see the sampling strategy in this chapter for further information about this). However, to ensure that people could open up to discuss their lives, a variety of skills, methods and techniques were used, which will be explored next.

Engagement and building up relationships of trust became vital for the research to be successful. The process of building up these trusting relationships often rested on my status as an HIV activist and volunteer, as set out already. However, this enabled the building blocks of trust. Often in initial discussions, before the interview took place, my previous experience aided in making respondents feel at ease, as I was able to exercise empathy. This process of reflexivity has been called ‘empathic insight’ (Boden, et al, 2016) and it enhances the research process as a result. Both in exercising empathy and in nurturing levels of trust in the interview process on my part, and in my respondents’ levels of trust toward me as an interviewer. Whilst many qualitative researchers are imbued in their research projects, knowledge is still always partial and embodied with power in its production. The ‘God trick’ (Haraway, 1988) as a reflexive practitioner is not possible within any qualitative research. Rose (1997) argues that reflexivity does not equate to ‘transparent knowledge’ and so I could not be ‘all-seeing’ in my reflections on the dynamics of my research relationships. I recognise that my reflexivity comes with inherent limits rather than a ‘God eye view’ of the research and that my view, from a particular position and background, shapes my research (Rose, 1997).

Engaging with respondent interviews

Many of the interviews lasted for several hours, with an average of two hours (the maximum length being just over four hours – for more details about this, see the sample section of this chapter under each pen portrait). Maintaining interest and allowing people to speak freely allowed my respondents to talk about the subject in their own frames of reference (Silverman, 2011). To ensure success in interviews, I did not want to intimidate the people I interviewed by giving them a complete lack of structure, so I prepared a ‘topic guide’ (see appendix one) for myself, which listed in the broadest and vaguest terms, key life events, that could be used by myself to keep a discussion on track. This topic guide was often used by myself in interviews as a generic guide to keep my focus within the interview, whilst still allowing for an open-ended, flexible discussion of the respondents’ own lives, which were not inhibited by a strict agenda. This proved to be fruitful for helping respondents remember points where they were at in their lives, whilst also allowing for their narratives to come through, and in picking up details about their life stories as I took any additional notes. This topic guide worked well and proved to be a useful discussion tool. Upon contact, some respondents requested interview questions, of which the topic guide was sent in advance to them. This helped to alleviate any worries or fears about what a narrative interview would entail and was appreciated by the respondents who asked for this.

Throughout the interviews themselves, I also practiced ‘active listening’ (Silverman, 2011) where I would allow the respondent to have the freedom to talk and to consider their own meanings from what they discussed, with the intention of building deeper levels of trust as the interview was allowed to emerge as respondents felt comfortable telling their story. I aimed to not interrupt or jump into discussion points when interviews fell silent, or when a person was reflecting or thinking about what they were going to say next. This is a technique I have used professionally within my HIV work for many years. Placing the person at the front of the interview brought the interview process alive, as respondents told personal anecdotes, jokes about their family and friends, formulated thoughts about their own life events, and discussed their reflections and worries about growing older with HIV. There are stretches of the transcripts where I say little at all (or very often only make affirming noises), as in some cases the respondents raised and answered their own questions and it became clear that as these people living with HIV told their stories, they *were* the story. This process of story-making enabled the lives of the people in interview to emerge at the forefront of the research, as they should within narrative approaches.

In order to engage with my respondents, to open up to discuss their stories and life narratives and to keep them at the forefront of their stories, particularly with some of the interviews taking so long, I also become the ‘skilled helper’ (Egan, 1988). This is to, “help people become better at helping themselves in their everyday lives" (Egan, 1988: 8). Egan (1988) argues that this role needs an element of ‘wisdom,’ which is not something that is born with nor inherent within a person, but instead is, “an expertise in the conduct and meaning of life” (Egan, 1988: 122). This means that I could relate to their lived experience of HIV through my previous experiences, and so build trust and create a non-judgmental environment so as to talk about often difficult topics. Egan’s (1988) ‘SOLER method’ as part of the skilled helper was key to the process of building a trusting environment, which used the following techniques:

- **S**quarely facing the respondent;
- Maintaining **O**pen posture and body language;
- **L**eaning toward the respondent;
- Maintaining **E**ye contact;
- by being a **R**elaxed, skilled helper so the interview is comfortable for the respondent.

Deploying active listening skills, the repeating of what respondents said (when needed), the use of summaries to check agreement, as well as to challenge when clarification was needed over points of confusion, were all techniques used. These, added to drawing upon my professional background and skills, were all important to establish a high level of trust and an atmosphere where people could be open with me and stay connected during the interview process. Egan (1988: 176) argues that "effective helpers are not only understanders (listening, processing, sharing empathic highlights) and clarifiers (probing, summarising) but also reality testers (challenging)." People interviewed were encouraged to drive the discussion forward and this led to a relaxed environment where in all interviews, time was perceived to have passed quickly and was thus remarked upon by both myself and respondents. One of the pleasant, but unexpected, outcomes of this whole process was that a number of respondents remarked after their interviews that they found discussing their whole life narratives as being *"cathartic"* (Rachel) with another stating that *"It's not often I get a chance to think about my life like this, I got a lot from doing this"* (Dean). This is what Eike (2010) describes as the 'joy of interviewing' whereby the interview process itself can become therapeutic or cathartic (Eike, 2010; Hutchinson, Wilson and Wilson, 1994).

The research diary

An audio research diary on a Dictaphone was used to keep my record of initial thoughts, feelings, questions and queries after the interviews took place, becoming something of a cathartic tool for myself. I asked four questions in my research diary after each interview, which were:

- How do I feel about this? (My emotional state and reflections on the interview)
- What have I learnt? (What knowledge has been constructed from this interview)
- Next time, how can I do this better? (How to improve my practice as a researcher)
- What else do I need to document here?

These four questions allowed me to arrange my ideas and thoughts as the research progressed, yet this thought pattern was often a 'messy process' as the following excerpt shows:

"So I guess this commentary is a little bit all over the place, but at the moment I'm busy digesting initial thoughts, feelings and things coming from the interviews" (Myself. Research Diary Entry 6).

Whilst these initial thoughts were messy as I recorded them, they reflected my thoughts at the time and the four questions above gave structure to some of my thoughts. My research diary served as an anchor for my thoughts, feelings and decision-making process as each diary entry was completed after each interview and measured my emotional state post-interview. The 'reflexive closeness and distance' (Allen and Arber, 2014) of being both an academic and HIV practitioner was not only about my respondents' experiences and reflections, but it was also about *how I felt* and the emotions that were engendered after sometimes hearing painful stories. The "real inner drama of research" (Newbury, 2001: 2), which can appear through qualitative interviews and sensitive topics, emerged in places. Using the research diary method supported me as an initial outlet to reflect on any of my emotions that occurred after the interviews. As an example of this, one respondent discussed her own experience of being raped, which led to her own HIV transmission. Whilst the respondent felt strongly that she had dealt with it via counselling and therapy and was reassuring about this (stating that she needed no further support post-interview), I still felt compelled to use the research diary to document my feelings afterwards to be able to process this.

As a practitioner, I have heard stories like this within my professional experience, however, that does not take away from the shock of hearing it, as I reflect below after the interview:

"It's made me think that I've dealt with that very well, probably because of background experience with doing this before…which has helped me deal with similar issues around this, but

there were mentions of rape throughout the interview which were perhaps a little bit more difficult to process" (Myself. Research Diary 1).

As well as an outlet to reflect upon my emotional state, I also used the research diary to consider how my practice as a researcher was progressing, and how I could improve for future interviews. Also, the diary was a tool in which to analyse themes which were apparent within the interviews, as I reflect below:

"Definitely sharpened up [a] bit better this time. I just let the conversation flow and build it up together which was much more positive and led to more fruitful discussions. I can see now, that in this interview and the one before, that unknown issues around ageing of the body came through strongly and so did strong themes about a lack of HIV community for heterosexuals. I'll make a note of this to see if it pops up in the others" (Myself. Research Diary 2).

This process is what Gersti-Pepin and Patrizio (2009: 300) call "epistemological awareness" as I considered how knowledge emerged in the interviews and how I could make links between respondents' lives and their wider social world of living with HIV and ageing. The diary process also allowed for this knowledge to ferment, and for me to connect any themes both in and across, different interviews that had taken place (Robson and McCartan, 2016).

The sampling strategy

In terms of defining the sample population, I focused on self-defined heterosexual men and women. However, labelling men and women who acquired HIV via heterosexual sex as 'heterosexual women' or 'heterosexual men' oversimplifies sexuality and can alienate men and women who do not identify as heterosexual (Brown, et al, 2019). In the case of this research, I define participants as women and men who probably acquired their HIV infection through heterosexual sex and/or people who self-defined their sexual orientation as heterosexual (Brown, et al, 2019).

As Stephenson et al (2018) note in their work around recruitment and sampling with older people living with HIV, “being known and being trusted are huge assets. Staff in the voluntary sector are busy and overstretched and lack the time and resources to support everything” (2018: 5), noting that if you gain their support, it is invaluable. I was a ‘known quantity’ due to my previous experience, and I came to my research with pre-existing networks across the HIV-voluntary sector. This process is what Singh and Wassenaar (2016) describe as a ‘negotiated transaction’ between the researcher and the organisation, whereby I could use my professional background and a framework for access to the sample. A phased framework utilised in this research follows the work of Johl and Renganathan (2010), which provides a useful phased framework for a responsible engagement with organisations, my sample and their gatekeepers. Johl and Renganathan (2010) refer to the four access components in their work as ‘pre-entry’, ‘during fieldwork’, ‘after fieldwork’, and ‘getting back.’ This framework allowed me to use the pre-entry phase to negotiate an ‘informal process’ of initiating communication with potential gatekeepers who I knew in the sector so as to gain pre-entry, I then maintained contact with the organisation during the fieldwork process and thanked them after it had come to an end. This allowed the final ‘getting back’ stage to be initiated, to use the same organisations again if needed. This meant that recruitment doors could be opened up by established trust and my existing networks within the sector, though this was not in the way in which I originally envisaged, as I shall discuss next.

I had originally intended the research sampling process to build upon my networks and relationships of trust and so as to take a ‘purposive sampling’ approach, to reach out to pre-existing networks via staff within organisations within the HIV Third Sector. My aim through this approach was to utilise staff members of Terrance Higgins Trust, Positive East, and the National

AIDS Trust to help in finding respondents within HIV organisations to come forward. Unlike random sampling, which includes a diverse cross-section of ages, backgrounds and experiences, my idea behind purposive sampling was to concentrate on organisations and with people with particular characteristics, in this case older people (aged fifty and over) who define as heterosexual and living with HIV. This is similar to what Etikan et al (2016) describe as ‘homogenous sampling’, whereby the sample would focus on respondents who share similar life experiences, and in this case, growing older as a cohort living with HIV. To accomplish this purposive sampling approach, a blog site which explained more about the research was developed and emailed to my known staff contacts in HIV organisations so as to disseminate to their internal groups, as well as posting online. This was initially successful, as it spread through some HIV organisations via Twitter and to their internal groups, hoping that I could then encourage a ‘self-selection sample’ (Sarantakos, 2013). However, I ran into early problems with this approach, as my recruitment of the sample using this method dried up quickly and provided only one respondent within the first few months of recruitment. I later found out that this was due to pre-existing contacts at my chosen recruiting organisations leaving their places of employment.

Recognising that this would become an issue for recruitment, I made some key changes to my sampling approach after my first interview and so I decided to snowball sample. Being a ‘known quantity’ or having ‘insider status’ (Amundsen, Msoroka and Findsen, 2017; Stephenson, et al, 2018) worked to my advantage as a researcher, as throughout my time within the HIV voluntary sector I have worked heavily with people living with HIV across the UK, through facilitating workshops, participating in conferences and being known online as a practitioner and HIV activist. Throughout this, I have brought to my research relationships of trust with people living with HIV and having a positive reputation of already having done similar work through previous charity research. As Stephenson et al (2018: 5) reflect upon, about similar experiences when recruiting people living with HIV, the “difference between an invitation to participate in a research study that is received ‘blind’… from an unknown researcher, and a direct contact from one of these trusted people, who says this research and this researcher are worth participating with, is immense.” Being a known quantity certainly aided the sampling access, which will be discussed below.

Sampling and being a ‘known quantity’

This concept of the ‘known quantity’ to gain access to the sample was evidenced after the first (and only) interview using my initial purposive sampling approach took place. I asked the respondent whether they had any other contacts who would be interested in taking part. As a response to this, they passed on my University of Leeds email details to other candidates for interview, who then contacted me expressing an interest to take part. This then continued to rapidly snowball as word of the research spread from respondents via their own phone calls, WhatsApp chats and some respondents’ personal social media, and sharing the blog link.

This process meant that I was regarded as trusted and ‘known’ within the sector, as will be set out below. Whilst it is critical to ensure that participants are not influenced or pressured to take part, reassurance from a trusted contact is invaluable and can open doors to people taking part in research (Gurchathen and Suruchi, 2008; Siwale, 2015; Amundsen, Msoroka and Findsen, 2017). As examples of this in practice, one respondent (before their interview) remarked in correspondence that they had seen me speak at a conference and she thought I was *“very approachable”* (Lydia) and so would take part in the research due to this. Another respondent, again in correspondence, knew that I managed a small HIV organisation at that time and so took part in the research due to this. I recognise that access to people living with HIV can pose difficult challenges in recruitment for many researchers. People living with HIV may be difficult to engage with in research due to a number of reasons; such as stigma, feeling that they are ‘over-researched’ with regard to repeated topics or via requests for research being from unknown researchers, as I have already outlined in my professional experience in this chapter. However, bringing my multiple identities to the research of advocate, ally, professional and researcher, paved the way for recruitment to happen successfully. This allowed the research to gain a much wider audience and through this, the remaining nine respondents were recruited this way. In total, nine respondents were recruited overall (initially ten respondents responded, but one dropped out later in the research process).

Whilst this approach yielded many strengths, it also brought with it limitations. Due to this snowball sampling method, many of the respondents were connected together in 'loose ways' which meant that this came with limitations and issues (which will be further explored within the ethics section). It is also recognised that due to the connectedness of much of the sample, this thesis cannot claim to be representative of the wider population of older people living with HIV. Whilst this interconnectedness has an impact, in terms of any claims that can be made of the data and made in the recommendations of this research such as policy changes for older people living with HIV, the participants in this research *are still a sample of the older population living with HIV*. Their views can still contribute toward the recommendations for policy change, despite the sample limitations.

The sampling strategy was also prone to voluntary response bias. While subjectivity is commonly understood as inevitable and important by most qualitative researchers (Mehra, 2002) this can also be seen from two key vantage points in my research. Firstly, my professional background certainly influenced the nature of the study (as explored within the positionality and reflexivity section previously) and my 'personal connection' to HIV fuelled this research interest further (Mehra, 2002). Throughout the research process, I continuously had to ensure that I was aware of my positionality as an HIV activist and as an HIV researcher. Secondly, voluntary bias also came from the respondents themselves as they may have self-selected to participate in the research due to their own strong opinions or interest in the topic. All respondents noted a keen interest in the research topic and wanted to be updated after the research was written up. It is important to note that the views of the respondents in this research may not be representative of wider views of the general population of people growing older with HIV, due to how they were recruited and their connections to each other.

Interviews with respondents varied between one and four hours in terms of the length of interview (see the sample section pen portraits for the length of each interview). Most interviews were on average two hours in duration, using frequent breaks when needed. Some respondents gave much more focused and shorter answers, touching upon some aspects of their lives and not others, whilst other respondents talked at length about their lives. The entire interviews were transcribed, not just sections of them, to gain a sense of the respondents' lives and to immerse myself within the data as a researcher. I also used the transcriptions to develop individual timelines of each person's life as a reflection and reference tool (see coding and data analysis section). Only after an entire interview was transcribed, were they coded and then themes drawn from the transcripts, which will be discussed further in the data analysis section of this chapter.

Organisations which had support and social groups for older people living with HIV (both men and women) were targeted originally via email and through an existing range of staff contacts. Whilst the recruitment process hit difficulties with gatekeepers as discussed already, the research interviews themselves were still able to be held at National AIDS Trust (NAT) and Terrance Higgins Trust (THT) offices, which are the leading HIV organisations in the UK. These were well known to people living with HIV, were easy to access by respondents, and the environments were safe and confidential due to the nature of their work.

The sample pen portraits

A total of ten people responded to the call for respondents (one of whom dropped out due to personal reasons). Respondents were all based in the UK and research interviews were conducted between February and August 2017. All respondents self-identified as cisgender, heterosexual, and aged fifty or above. Further anonymised profile information can be found in their pen portraits below:

Lydia Lydia is White and was in her early fifties at the time of interview. She was born in Southern England and now lives in Southern England in a large city. Whilst at university studying in her early twenties, Lydia had a relationship with an exchange student from a nation-state in Sub-Saharan Africa, which she believes led to her HIV transmission. After decades of having unexplained illnesses and underlying health problems, she was finally diagnosed with HIV in 2014. This led to a change of life for Lydia, who then divorced her previous husband and decided to travel the world and to be open about her HIV status. She has since re-married, and she now works full-time in the Third Sector. This interview lasted for three hours.

Dean Dean is White and was in his mid-fifties at the time of interview. He was born in a coastal town in Southern England. Born with underlying health problems, Dean described his childhood as 'abusive' and 'difficult', and he moved geographically between different places and different forms of employment throughout his life. Dean was diagnosed in 2003 and believes that HIV transmission came from sex with a woman he had been in a short-term relationship with. At this time of diagnosis, his CD4 count was extremely low and as he was late in his diagnosis, which caused severe health issues. Dean has told his family about his diagnosis, and he started as a service user at an HIV organisation, where he then volunteered and now works. Dean still has long-term health issues which he is dealing with, but he welcomes the prospect of retirement, when he wants to retire to a coastal town in England. This interview lasted for two hours.

Rachel Rachel is Black-British and is in her late fifties. She was born in a large city in Southern England where she now lives. Due to the family atmosphere and an abusive father, she left home at the age of seventeen and married her then partner, having children. After a routine blood donation in 2001 she discovered her HIV status. Rachel believes she had HIV for decades and it was transmitted by her former husband, who has now passed away and who was her only sexual partner to that date. Rachel has a number of projects which she likes to work on, supported by her friendship group, describing herself as 'self-sufficient.' Her future plans are to live in another country once she retires. This interview lasted for two hours.

June June is White and at the time of interview was in her mid-late fifties, living in a large city in Southern England. Born to a 'middle-class' family in Northern Europe, June trained in medicine, and she met her husband at her workplace, whom she moved to a nation-state in sub-Saharan Africa to live with. During the marriage, her husband became an alcoholic, as well as increasingly violent and abusive. After a very violent incident in 2003, June left both her husband and the nation-state, taking her children with her back to her home country. June believes that her HIV status is linked to transmission from her ex-husband, who has now passed away. In 2004, June found out her HIV diagnosis when she was in her forties. June now works full-time within a healthcare setting after changing career roles later in life. She has some underlying health problems, but she travels frequently and is out about her status to her friends. June is a practising Christian and regards herself as religious, which she came to later in life, several years after her diagnosis. This interview lasted for three hours.

Rebecca Rebecca is Mixed Ethnicity and was in her mid-late fifties at the time of interview. Now living in a coastal town in Southern England, she was originally born in Southern Europe. After studying at a technical college, she worked in the tourism industry and travelled throughout Europe. In 2000, she met a partner whom she settled down with and eventually moved to the United Kingdom with. However, in the same year, Rebecca was later diagnosed with HIV in 2009. Due to this length of time between transmission and diagnosis, Rebecca has developed some serious long-term health difficulties and has not worked in a number of years. Instead, Rebecca previously volunteered and has been an HIV advocate for HIV organisations but has since given this up. She now describes herself as 'settled' and has her own home, living with her partner whom she describes as 'supportive.' This interview lasted for one hour.

James James is White and was in his early seventies at the time of interview. Born in Northamptonshire, James joined the Royal Army, travelling to several countries whilst on duty. After his second wife died, he described himself as a 'rebel' and he dated several women. He was diagnosed with HIV in 2007 after a period of severe illness as he was diagnosed late, which he believes came through sexual contact. Now, James describes himself as 'healthier than ever' due to ART, is open about his status and is active in seeking HIV support. He has joined HIV groups and is proactive in attending HIV seminars and talks. This interview lasted for two hours.

Olivia Olivia is White and she was in her early fifties at the time of interview. Olivia was born in Scotland but moved to a nation-state in sub-Saharan Africa where she worked in healthcare. In 1999, during a needle stick injury after taking blood, Olivia states that HIV transmission took place. She now lives in a large city in Southern England in a 'very, very middle-class area' and she described herself as 'scared' to tell friends about her HIV status. She has only told her immediate family and husband that she is living with HIV, but not her child. As a long-term survivor of living with HIV, Olivia has had several severe health problems throughout the years and continues to do so, partly she thinks due to the side-effects from participating in various medical trials for HIV drug treatments. As a result of this, she was not in employment. This interview lasted for two and a half hours.

Jessica Jessica is White and she was fifty at the time of interview. She was born in a coastal town in the South of England, where she still lives today. After a self-described 'dysfunctional' family background, Jessica left home at the age of sixteen to move to a large city and had children with her partner. She is currently married but separated from her partner. Jessica was diagnosed in 2008 with her HIV status being from an ex-partner she had been dating. During this time, she was studying for a degree but withdrew after finding out her status. Jessica discussed a 'turning point' in her life when she started as a service user at a local HIV organisation and attended an HIV women's conference which expanded her network and self-confidence. After this, she started full-time paid employment and is open about her HIV status to her friends and family. This interview lasted for four hours.

Brenda Brenda is White and she was fifty at the time of the interview. She was born in a large city in Southern England, where she still lives today. After attending university, she started to travel the world and she found employment in the tourism industry. In doing this, she met her ex-husband. Brenda stated that her

> HIV transmission came from her ex-husband, who had complex mental health problems and she tested positive for HIV in 2001. She now has two children, is partnered and she works in two different jobs. Brenda described herself as 'spiritual' and is a Buddhist. Brenda is open about her HIV status. This interview lasted for one and a half hours.
>
> Brenda was the only respondent recruited through purposeful sampling. All others were recruited via snowball sampling.

Figure one: Respondent sample information

Kholi's (1987) research divided the 'young-old' (65-74), the 'old old' (75-84) and the 'oldest old' (85+) and early in the research, I hoped that respondents would be representative of these demographics. In addition to these categories, I had also added a category of the 'youngest old' (50-64) to reflect guidelines currently used by Public Health England, Age UK, and the World Health Organisation's (WHO) definition of an 'older person' (see chapter one). As noted within the pen portraits above, the sample of respondents tended to fit into the 'youngest old' category and so did not fit neatly into the age categories as was originally hoped. This highlighted an initial flaw in my sampling process, in that it was not appropriate to lift quantitative sampling approaches and transport their logic over to qualitative methods (Emmel, 2013), especially when relying heavily on snowball sampling. It became evident to my research that qualitative sampling is not a single planning decision, but it is an iterative series of decisions throughout the process of research (Emmel, 2013). I adjusted and modified my sampling process as it became clear that it was not going to be a 'neat fit' to use a sampling frame, which was unsuitable for this research. In terms of the research methodological outlook, I aligned with Merriam (2009), who argues that "there is no answer" (Merriam, 2009: 80) in terms of the correct sample amounts and sizes within qualitative research.

Research ethics

All research comes with ethical risks when telling stories, and the social sciences have become increasingly concerned with the ethics of conducting research (Frankfort-Nachmias, Nachmias and DeWaard, 2015). To ensure ethical procedures were followed within my research, I followed the British Sociological Associations (BSA) Statement of Ethical Practice (2017) which was applied and rigorously referenced during this research. Not only this, other health and safety procedures were put into place and ethical constraints impacted the research, which I will discuss next.

Sociological research should be based on the freely given informed consent of those studied (BSA Statement of Ethical Practice, 2017). Participation in the research was voluntary and consensual. Each respondent was given an information sheet (see appendix two) outlining the purpose and plans for the research pre-interview. A consent form (see appendix three) was also given to all proposed participants to sign, to ensure that informed consent was at the heart of the research. It is vital that research, “should strive to protect the rights of those they study, their interests, sensitivities and privacy” (BSA Statement of Ethical Practice, 2017: 4) and confidentiality, anonymity, and sensitivity were guiding principles throughout my research. This was especially important to factors such as using pseudo-names for respondents. Also, in the use of personal details and locations, particularly as the topics of discussion were around stigma, ageism, sex, intimacy and HIV status, as well as other aspects of the life narrative which were deeply sensitive to the respondents interviewed.

After I was initially contacted by respondents via email and they were presented with the information above, they were then given up to two weeks to decide whether they wished to take part in the research, which was highlighted via the response email after initial contact. I did this to ensure that the respondents had a suitable length of time to reflect on their participation, and to ensure that they were comfortable with the research process and the information that was presented to them. Respondents were able to withdraw from the study before the results were written up into the thesis. To do this, all respondents were given a pseudo-name by which to both anonymise them and identify them should they wish to withdraw from the research.

Consent was built into the foundations of my research, and this was an ongoing and negotiated process as respondents were able to answer some questions during interviews and pass on others if they needed to do so. In one particular example of consent being a negotiated process, one participant who I had already interviewed, decided that they wanted to withdraw from the study due to their own personal reasons, and so their details were destroyed immediately.

All of the interviews were conducted on the sites of HIV organisations that agreed to the research taking place on their premises. To ensure safety for myself and the respondents, I had completed and had approved a University of Leeds risk assessment to minimise risk. This considered lone-working and specified appropriate signing-in and out procedures of host organisations. This was complemented by gaining the risk assessments of the HIV organisations where the research interviews were held, as, "social researchers face a range of potential risks to their safety. Safety issues need to be considered in the design and conduct of social research projects" (BSA Statement of Ethical Practice, 2017: 4). These procedures were adopted to reduce any risk to myself and my respondents. In case of distress or personal issues arising, I kept a list of support organisations for a range of personal issues, which could have presented themselves throughout the course of the life narrative interview, to be handed to participants during or after the interview. The staff of the HIV organisations were also on hand should any issues need further support before, during, or after the interview process. Due to these measures being in place, this study was guided by the University of Leeds' Research Ethics Policy, with ethical approval for this research granted on the 16th of May 2016 (ethics reference: AREA 15-106) by Education, Social Sciences, and Law (ESSL), Environment and LUBS (AREA) Faculty Research Ethics Committee at the University of Leeds (see appendix 4).

In terms of the respondents' data, all data was locked electronically on a password-protected computer in line with the Data Protection Act (2018), the General Data Protection Regulation (GDPR) guidelines and the University of Leeds Data Management Policy via the 'M-Drive.' After recording the interviews on an audio device, they were uploaded to the University M-Drive for secure storage and then deleted from the audio device. Upon transcription, all data was transcribed by the researcher, anonymised and given a pseudo-name for the coding process, whereby it was kept on a password-protected computer to ensure secure storage. Transcriptions were completed immediately, or as soon as possible, after the interview to ensure that the interview was fresh within my memory. In all cases, I transcribed the interview recordings. This allowed for deeper immersion in the data than an external transcription service would have allowed. In all interviews, transcriptions were a true record of the full interview, and this also allowed for complete respondent anonymity.

Ethical constraints and limitations in this study

However, there are ethical constraints and limitations within this study, reflected in the ways in which the data were presented. Due to using the snowball sampling method, all of the participants in this study were connected through ‘weak ties’ (Granovetter, 1973) with each other. Whilst this was a strength in terms of recruitment, through gaining access to their friendship groups, HIV community networks and acquaintance networks, this approach also presented me with limitations; in that the participants were loosely connected to each other. In particular, two of the respondents were friends and therefore should they be able to read this final thesis, it is highly likely they may be able to recognise each other’s lives in the data. I must stress that this is not to assume that all respondents were close friends and knew each other’s lives intimately. Other than the two close friends, most respondents explicitly stressed to me pre-interview that they only knew each other vaguely through HIV groups, HIV events and HIV networks. However, there is still a ‘clustering’ link via their connections, due to the sampling method used, and I could not assume that all people would not be recognised in the data.

Each respondent was fully aware that their friend or networked acquaintance had given them my details and that the respondent was aware of this when giving consent. This was also expressly addressed as a discussion point pre-interview. It was emphasised that there was a chance that some respondents may be recognisable to each other, due to being recommended through their social networks. In order to update all respondents after the research, and knowing the limitations of respondents knowing each other, I decided to put together a ‘key findings’ document instead of presenting the thesis, to be emailed to them after completing the thesis.

Nind (2017) in her work with people with disabilities stresses that an important feature of qualitative research is the ethical principle of ‘checking back’ with participants in a process of participant validation. I was eager to do this and stressed to respondents that data would not be included that respondents might later be uncomfortable with, or if they felt that it misrepresented them. I offered the opportunity for all respondents to be able to self-review and redact their entire interview transcripts before I started the process of writing up. My decision to fully transcribe each interview, despite the length of them, become a powerful tool of involvement and respondent empowerment. As set out earlier in this chapter, in my examination of my positionality and reflexivity, I was eager not to repeat some of the mistakes I had seen in my professional life, whereby I had seen research ‘done to’ people living with HIV. Having seen respondents feel that they had little, or no control, over the research process. I told each respondent that they would gain a copy of their own transcript within a one-month window time period, which was a realistic timeframe to transcribe and enough time for respondents to reflect on their interview, and to make any changes to their data that they had said in the ‘heat’ of the interview.

James, a respondent, brought this issue to the forefront, remarking that he had been interviewed by another unidentified researcher previously and had asked for a copy of the transcript. After several months, his transcript had not arrived (at the time of interview) despite emails to the researcher. This led to James feeling negative about his former research experience, stating: *"I am not happy. I haven't even got a copy yet. I wanted to see it and I've heard nothing back"* (James). I reassured James that I would send him the transcript and gave him a timescale of when this would be (the transcript was later sent on time), but this affirmed how disempowering the research process can be if checking back for participant validation does not take place. No respondents requested any additional changes from the transcripts sent to them and all confirmed that the transcript was an accurate reflection of the interview. However, another respondent, June, remarked in email correspondence after I sent her transcript, that seeing a culmination of her life events pulled together made her feel positive about what she had accomplished in her life.

The response above echoes other respondents who had also found the life narrative interview process 'cathartic' as mentioned earlier in the chapter, and I found that the conscious decision of checking back with participants and using the life narrative method, opened up a more empowering and ethical research process overall. Alongside other authors, I also feel strongly that the life narrative itself can also empower the respondent by enhancing their knowledge and understanding of the world and their place in it (Atkinson, 2004; Nind, 2008; Squire, et al, 2014) and by doing this, I could use narrative methods to enable my participants to recall, recount, and review their lives; valuing them as expert witnesses rather than mere sources of data (Atkinson, 2004). This kind of qualitative research, through being concerned with the person's unique identity and history, meant the participants could not be depersonalised, as it enabled them to emerge as *people not cases,* to reclaim *their lives as their own* and to provide counter-narratives where needed (Nind, 2008).

Meininger (2006: 184) explains that creating narrative stories "supposes mutuality and invites a dialogue" and enables a person to find a thread running through their life and give sense to it. In this way, the narrative approach can be transformational. I especially noticed this in interviews, as several respondents remarked that talking about their whole lives, and not just their HIV, *"was a refreshing change to talk about my whole life, my life with HIV, and more than just my diagnosis"* (June). While another respondent remarked that telling their life story was a *"clever way to talk about HIV cos I feel like I see more…I feel like I am listened too"* (Jessica). This more empowering, participatory and inclusive approach to the research process meant that my research was not simply research *on* people but was research *with them.* When used this way, the narrative method is a natural ally to self-advocacy (Nind, 2008). Encouraging this narrative storytelling and checking back process aided the research. Through doing this, I could bring together my respondents' insights, enabling them to make connections and take strength from their lived experiences (Nind, 2008).

In conclusion, the ethical constraints faced in this research were largely due to the clustering of respondents who were linked to each other via the sampling method. Ensuring that respondents could not be identified by others who took part in the research was a concern. However, I took key steps to prevent this from happening. The following section will now discuss the coding and data analysis of these narrative interviews.

The coding and data analysis process

The constructionist approach taken by my research, "treats interview data as accessing various stories or narratives through which people describe their world … the interview participants actively create meaning" (Silverman, 2017: 327-328). This opened up respondents' narratives as they discussed their own subjective lives, views, and experiences and created meaning through themes which emerged. After interviewing took place with respondents I then started to code and analyse the data, which will be discussed below.

Once an interview was transcribed, and as part of the initial coding process, I created a short digital research memo (Silverman, 2017) and linked this memo to the relevant transcript file. This research memo also included any hand-written notes taken during participant interviews and via transcription. Though this did create some duplication, it was a useful process to recap and recount the main points made in the interview, proving valuable in later stages of analysis when I was reviewing significant amounts of life narrative data.

Initially, all of the interview transcripts were coded and analysed using an 'open coding process' (Silverman, 2017); seeking to identify points of interest using what Miles, Huberman and Saldaña (2014) call 'first cycle coding.' I decided to use this first cycle coding approach to give me an overview of the data and to begin a very loose analysis of points of interest. This did mean that my first stage of coding was somewhat sporadic as I did this over the six-month timeframe of the data collection process whilst I interviewed different respondents. I spent a significant amount of time during this initial coding phase, with transcripts needing to be re-read a number of times to allow for a "close encounter with the data" (Corbin and Strauss, 2008: 163). Alongside the digital research memo and timeline for each respondent, this process allowed the data to come together and for me to gain an overview of each narrative. I initially coded each transcript as an individual entity, but I also recognised that certain codes would 'bleed' from transcripts analysed earlier in the research and may appear in other transcripts. I also recognised that the coding of data is a non-linear operation and would continue throughout the research, either as more insights were developed from a continued review of the literature, or as more data were collected (Sayer, 2010; Maxwell, 2013; Silverman, 2017).

I also plotted overall individual timelines of each respondent to examine their key life events as highlighted by respondents in their interviews (see appendix six). When doing this, I placed the events from each life narrative onto individual timelines about each respondent, which were then colour coordinated to show different codes using the same open coding method as the interview transcripts (Sarantakos, 2013). This meant that notes were written about each respondent's timeline which I fed into the coding process, and which led to me seeing larger emerging themes across all of the interviews. I found this process of plotting timelines useful as

I could transplant the main events from the transcripts onto a timeline. However, not only were major ‘life events’ documented via the timelines, but also overlapping ‘routine’ events and parts of conversations from the data transcripts, which helped to bring the everyday and taken for granted into consideration (Silverman, 2017). These timelines proved to be invaluable and acted as a useful supportive aide for coding and as an aide-memoir when transcripts were re-read in initial, and subsequent stages of coding.

Cresswell (2013) describes the data coding process of research as a ‘spiral’ process, and this was the case in this research. Whilst initially each transcript was coded in isolation, once this process had been completed each transcript was re-analysed in ‘second cycle coding’ (Miles, Huberman and Saldaña 2014), using all of the codes I had developed across the previous coding activity. I found that through coding one transcript, it often led to a recognition of a similar section of data in another transcript. Through doing this, I found that both cycles of coding created an extensive range of codes with similar themes being identified but named differently. Creswell (2014) also describes a systematic process for coding data in which specific statements can be analysed and categorised into themes that represent the phenomenon of interest. Other authors, such as King (2004) agree and have outlined a process of creating a provisional template to use on the full data set, arguing that using a template forces a researcher to justify the inclusion of each code, and to clearly define how it should be used. In my research, this became a valuable way in which to code the data and I used a ‘coding table’ to show this. This process of creating ‘code manuals’ (Crabtree and Miller, 1999) served as a data management tool for organising segments of similar or related text to assist in interpretation, and provided a clear trail of evidence for the credibility of the study. The coding table as shown below, condensed the number of separate codes into their ‘parent’ codes. Once this process had taken place, I then re-analysed all of the transcripts using these parent codes to begin to identify themes across the research.

This is what Crawford et al (2008) state is the most appropriate approach, when the researcher aims to examine the data in order to discover common themes and thoughts from more than one participant. This allowed for an overview of all of the lives and across all of the lives of the respondents. I did not use NVivo for the coding process. Although computer programmes such as NVivo may be helpful to organise and examine large amounts of data, they are not capable of the intellectual and conceptualising processes required to transform data, nor can they make any kind of judgment (King, 2004). Instead, I preferred the approach of Ryan and Bernard (2003) when they argue that during coding, "we highly recommend pawing through texts and marking them up with different coloured highlighter pens" (Ryan and Bernard, 2003: 11). This allowed me to personally become closer to the data and the process was more immersive as a result.

In my coding table below, I display some of the codes which emerged during the coding process. In this approach, sub-codes often moulded into each other and so the parent codes are also displayed. Through doing this, I show how these codes generated a parent code and thereby emerging research theme, in the following table:

Codes	**Parent code**	**Theme which emerged across all of the data**
• Ageing • Ageing and the body (uncertain) • Interaction of HIV and ageing • Unpredictable bodily changes • Comorbidities and HIV • Medications and the body • Healthcare professionals • Changing medical care for people with HIV • Bodies as a medical puzzle	Uncertain how both the body and ageing responds to HIV	Changing bodies
• Heterosexual HIV community (lack of)	Existing 'communities' not useful enough – new types of community formed	Changing communities

• Heterosexual HIV community (emerging) • Engagement within HIV services • Disclosure • HIV support • Disengagement • Use of technologies to communicate • New HIV community types for older people		
• Future possibilities • Relationships • Future plans and ventures • Religion and identity • ART as life-changing • Changes (positive) to life goals • Stigma management • Future concerns	Positive attitudes, plans for the future, and resilience in their approach	Changing mindsets and futures

Figure two: Coding table

This process of generating themes which emerged across all of the interviews was broader than the codes themselves. Initial codes identified, which rarely appeared in the data, were discarded (and are not shown above) as the overall themes then emerged. I will now expand upon the thematic analysis method I used in this research.

Thematic analysis

A theme, "is used as attribute, descriptor, element, and concept and it is an implicit topic that organizes a group of repeating ideas, it enables researchers to answer the study question" (Vaismoradi, et al, 2016: 101). In their work, DeSantis and Ugarriza (2000: 362) argue that themes are an abstract entity which bring "meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole." As shown in the coding process, themes emerged from doing this and once identified, appeared to be significant concepts that linked substantial portions of the data together (DeSantis and Ugarriza, 2000). I chose a 'thematic analysis' approach to my research and data analysis (Squire, et al, 2014), as a useful method for examining the perspectives of different research participants, highlighting similarities and differences, and generating unanticipated insights (King, 2004). This thematic analysis is an effective way in which to show common themes over the respondents' lived experiences of ageing and HIV.

This method of thematic analysis was inductive in nature, focusing on themes which share patterns of meanings and where the theme development was directed by the data itself (Ryan and Bernard, 2003). This meant that the coding and analysis was a 'bottom-up' emergent approach, where the themes were driven by what was present in the data and derived from the narrative content and the coding process. King (2004) argues that this is a way in which to increase the probability of 'credible theme finding' within the coding process; themes should not be considered final until all of the data have been read through and the coding scrutinised at least twice. Due to this, I invested significant amounts of time in my first and second cycle coding process (as outlined previously in the coding section) and from doing this, I identified patterns of meaning via three key themes across my data which made sense of the respondents' collective meanings and shared experiences. The three themes of: *changing bodies, changing communities* and *changing mindsets* that emerged from within my respondents' stories were then pulled together to form a comprehensive picture of their collective experiences, and the coding approach I used helped to strengthen the bringing together of these three themes.

During this phase of drawing out these three emerging themes, I wrote a detailed analysis for each individual theme which came from the coding, identifying the story that each theme told. Whilst also considering how each theme fitted into the overall story about the entire data set in relation to the research questions. The themes were not considered final until all of the data had been read through and the coding scrutinised. Throughout my research, data were collected, transcribed, coded and conceptually organised as the qualitative process moved forward, and data collection and coding were merged with data analysis. This allowed an establishment of connections between interviews and of linking these themes together (Sarantakos, 2013; Silverman, 2017). I kept my research diary, as discussed earlier, not only to reflect upon my positionality and reflexivity during the research process, but also to consider points of analysis directly after an interview and to see where themes were potentially emerging and connecting.

Whilst I recognise from my positionality in this research that I am not bringing a 'tabula rasa' approach to this process. I worked to ensure that the themes which emerged from the data were not pre-constructed or hypothesised beforehand, aiming to ensure that the three themes that emerged from respondents were not my personal or professional beliefs being mirrored onto them. I used Vaismoradi et al's (2016) concept of 'immersion and distancing' for this, whereby I both immersed myself in the data and then distanced myself from the data for several weeks. This distancing approach after my intense immersion ensured that I could take stock, re-appraise the analysis process and 'distance' myself from the data for a period of time to reduce any premature, incorrect, and incomplete analysis of the themes. Doing this aided my data analysis and helped me "to reveal themes correctly, and to assess and examine the accuracy of the coding process" (Vaismoradi, et al, 2016: 106). After a number of weeks away from full data immersion and thematic analysis, I began the process of then revisiting the data analysis and following this stage, I felt assured that there was a relative certainty about the themes that had emerged.

I will now examine the three themes of *changing bodies, changing communities* and *changing mindsets and futures*, which will be discussed and analysed in chapters five, six, and seven.

Chapter Five: Changing bodies

This chapter will outline the first core theme which emerged of 'changing bodies.' A number of related issues emerged under this theme, which will be expanded upon through the findings from respondents. Despite respondents facing significant changes in ageing with HIV, such as comorbidities, the changing nature of HIV healthcare, heterosexual populations being ignored or overlooked by medical systems, or providing respondents with few answers as they grew older with the virus, many found ways to control their lives with HIV medication. Yet, in controlling their bodies with this HIV medication, respondents faced three key tensions in their lives, which left their bodies both 'controlled but uncontrolled.' This chapter will aim to unpack what all of this means for heterosexual people growing older with HIV in the UK.

Late HIV testing, comorbidities, and comparisons to peer groups. Overlooked?

Several respondents had concerns about how growing older with HIV was going to affect other aspects of their health, yet most were happy with their current HIV treatment regime. Four respondents highlighted particular problems with their bodies that they felt were impacting alongside other comorbidities or were emerging as a result of living and growing older with HIV. These health problems were exacerbated by their late diagnosis, and associated health problems due to this, which many felt were partly through being overlooked by medical practitioners for HIV testing earlier in life due to their heterosexual demographic. Ageing and its interactions with HIV presented anxieties to some respondents, as it represented an unknown facet to them in terms of comorbidities. Furthermore, respondents felt that their bodies ageing with HIV were being overlooked by practitioners and increasingly framed as a 'medical puzzle' (Rosenfeld et al, 2014). It was not just a case of simply growing older with HIV and the effects of HIV medications on their bodies which caused alarm for respondents, but a combination with additional factors, which will be discussed further in this section.

Dean was diagnosed later in life, and he was not previously tested for HIV, attributing this to not *"having that information to hand. As a heterosexual man, it was never anything that I thought would affect me and nobody ever offered me one"* (Dean). Dean felt he was overlooked by medical experts, who failed to pick up on his HIV diagnosis because he was heterosexual, leading to late-stage HIV infection and poor health problems due to this. When Dean initially presented himself to HIV services after his first HIV test with a very low CD4 count of 137 he was in poor health, and he did not expect to live long. His account outlines how he never expected a long life expectancy when he first found out his HIV diagnosis, and how the combination of the effects of his low CD4 count, and reaction to initially taking ART, affected him:

> *R:* *"The way medication has been refined over time is good. I was diagnosed the day before my forty-third birthday, but I never expected to see fifty. The medication when I first started was horrendous. Vomiting, diarrhoea, nausea, you know, you name it. But now, we are the ones to look at now, people are realising that things have changed. Obviously, medication has helped, the NHS has done wonders with the research and all that" (Dean).*

Dean presented an optimistic view of his HIV treatment at the time of interview, which he put down to how the medication for HIV has developed, and how he found a combination of drugs which kept him healthy and his immune system in better shape. At the time of interview, Dean's CD4 had increased to 397, ensuring a healthier immune system which he now attributed to him *"living well, I've got a better mental outlook now thanks to the HIV treatment I am on these days – I am on meds which suit me better and my CD4 count has gone up"* (Dean). Dean talked about the current side effects of the treatment, seeing them as a counterbalance to living successfully on ART as *"putting on weight"* and how the *"medication has led to fat concentration around my stomach, but that is a small price to pay for getting better"* (Dean). However, in addition to his HIV diagnosis, which he felt he managed well as a condition, Dean also lived with a rare neurological disorder which he had also discovered later in life, stating that it *"is getting worse"* (Dean). He had also recently discovered that he had developed diabetes. Due to this, Dean expressed uncertainties about his body growing older and whether his neurological condition, and his diabetes, were linked to his HIV diagnosis, including how they interacted with his body. This will be discussed below.

Research suggests that older people living with HIV report more general chronic medical conditions and comorbidities and lower levels of wellbeing and health, however, this is not yet fully understood in medical terms (Population Reference Bureau, 2009; THT, 2017; THT, 2021). Dean discussed his development of diabetes, which he thought was a result of living with HIV, and how the two present significant challenges together:

> *I* *"How do those two work together?*
>
> *R* *Well I've always said really, they don't, they don't seem to sit too well" (Dean).*

Dean had questioned several medical practitioners about whether both the impact of his neurological condition and diabetes was linked to his HIV, but *"never got a firm answer about this, I keep asking but they do not know either really. I guess you can't put toothpaste back in the tube. There are times when I get anxious about it, I know I can deal with the HIV, but I am worried about how it interacts with the other things"* (Dean). Dean's account, whilst positive about his HIV drug management and growing older with HIV, were reflected in his previous comment about older people living with HIV being *"the ones to look at now, people are realising that things have changed"* (Dean). However, the interaction with other health ongoing comorbidities provided less certainty to him.

Similar concerns highlighted by Dean, were also reflected upon by Olivia who compared her physical ailments in comparison to that of her peer and friendship group. Olivia used *"getting* *older"* (Olivia) to explain away her symptoms to herself, but had grown increasingly concerned with symptoms of ageing, such as painful joints, which emerged earlier in life for her, but were not present in her similarly aged friendship group. Olivia was a long-term survivor of HIV, being diagnosed in 1999 due to a needle-stick injury. Throughout her life, she had taken part in numerous drug trials for new HIV treatments over the years. Similarly, to Dean, she was *"happy"* (Olivia) with her HIV treatment, but she was concerned that both growing older with HIV and that the effects of drug trials had longer-term effects on her body, potentially producing new symptoms which would not have emerged otherwise. She goes on to say:

> *R* *"Um I think it's more, I think we experience a lot more [inaudible: 18:41], but we, and we put it down, a lot of it down to 'oh well but I'm getting older'.*
>
> *I* *Right.*
>
> *R* *And it's not really, you know, I look at my girlfriends and, you know, the same age as me, and they haven't got all the aches and pains and, you know, all that other stuff that goes with it" (Olivia).*

Olivia's concerns were also about other potential comorbidities, not just her HIV, stating that she felt that there was *"something else. It is not just my HIV as I am on treatment for that. I feel happy with the, um, the medication I'm on. It's the other stuff"* (Olivia). When asked about what she meant by the 'other stuff,' Olivia used a comparison with her peers, stating:

> *R:* *"Well I know my friends are okay. The trouble is, I can feel pains in my joints, okay? I get headaches, I had cancer, so many operations. I know I am not fully well. I asked about this at the hospital. They said I am reacting well to my HIV medication most of the time, but they cannot find out why I am this way. I mean, I have been a guinea pig for treatments over the years and always put my hand*

> *up. I think I am developing things due to this. Nobody can tell me anything about this because they don't know. It's very frustrating, but what can I do?" (Olivia).*

Olivia, like Dean, found her HIV medications to be *"a lifesaver. I am pleased to have them. That's one thing I can control"* (Olivia), however, she was anxious about other 'unknown' and uncontrollable aspects of growing older with HIV, which she measured against her peers who she viewed as HIV negative and in better condition to her physical state. This comparison to peers in terms of measuring health was also reflected by June, who showed similar levels of concern compared to others she deemed similar to herself in terms of age. June had known her HIV diagnosis since 2004 and as a regular churchgoer, she often compared herself to her friends in the congregation, their age, and their health:

> *R "People are really not as healthy as, if I look, people my age in church, HIV-positive people, definitely there's a difference.*
>
> *I Yeah. Yeah, yeah. Interesting that.*
>
> *R And a lot is like painful limbs, and I'm sure it's neuropathy in most cases. Or the high cholesterol and, I mean then come all the other things. If your cholesterol has been high for too long, then you are more prone to heart attacks and stuff like that" (June).*

When June initially sought medical help for clear symptoms of late-stage HIV she felt overlooked by medical professionals who did not offer her an HIV test. She stated that she was *"ignored by doctors like when I wanted an HIV test. They never, they never thought of it because I then had a male partner"* (June). June similarly felt overlooked when presenting current additional problems to medical experts, and in asking whether they were linked to her HIV. Although June had other underlying health problems, *"these aren't taken into account. They tell me it's ageing or not serious, or they don't know yet, and to wait to see if I show more symptoms. I don't want* *to see, my friends aren't the same as me, I want to know what's going on with my body"* (June). Similar to Dean's and Olivia's accounts whereby medical experts did not seem to provide suitable answers to them, June like Olivia, used a mindset in which to reflect on both the perceived wellness of her peer group to measure her own state of health, as well as the growing development of *"all the other things… we don't really know what is happening to our bodies"* (June). Similar identifications of the unknown nature of ageing, the body, and the impact of HIV, were also highlighted by Rebecca who was also overlooked for an HIV test, which will be discussed next.

Despite being *"very active",* Rebecca stated that her ageing had *"brought some changes in my physical way, body"* (Rebecca). Rebecca had faced significant health problems in her recent past through kidney failure and cancer where she was previously taking *"nineteen tablets a day,"* stating that *"I risk my life by being brink of death for at least two or three times"* (Rebecca). Rebecca estimated that she had gained HIV in 2000 after a sexual assault, but she did not find out her HIV status until she was offered a test in 2009. During this period of nine years, Rebecca had presented various symptoms and had been misdiagnosed with Chron's Disease by her doctors, and despite later being *"in and out of the hospital for one year"* (Rebecca) with a mix of warts, tuberculosis, and her kidney malfunctioning, she was not tested for HIV by doctors until 2009. Mirroring Dean's and June's account about late HIV testing due to her demographic of being heterosexual, Rebecca states:

> *R "I was not tested for nine years. I was with my [male] partner, but they did not test me for HIV. I think they think I was with my partner, so no need. I am frustrated. I am straight so they never test me" (Rebecca).*

Rebecca also expressed problems with her joints, and she discussed a *"complete breakdown of the muscles of the legs. So much so that I could not walk. For one month I could not walk"*

(Rebecca). Adding to her confusion about these unpredictable incidents with her body, she recently had problems with her weight and eyesight. She had had a number of operations on her eyes. She was unsure as to whether these was due to her HIV, or medication for the tuberculous she was taking:

R *“I had six operations on my eyes. It affects my eyes”*

I *“Right, okay”*

R *“I don’t know if it was HIV or the tablets that I took for TB”*

I *“How do you feel about this?”*

R: *“I am confused by it all. I think I ah I am very active, but I am slowed by these things with my body. I think it took so long to test for HIV, so I develop these things now. I do not know about the future”*

I *I see*

R *“Then ah gaining weight, ah that is a battle. Ah, I am thirty kilos overweight. I know that you can be ah slimmer when you were, actually when you were eighteen, but all these people that I know of my age and my, you know, ah friends of same age, they didn’t have this change” (Rebecca).*

Similar to other accounts mentioned, Rebecca stressed being overlooked as a person who is heterosexual for HIV testing earlier in life, which has caused later problems in life with additional health issues and comorbidities. After undergoing significant life events with her poor physical health, she discussed her anxieties with her body as being a site of the unknown, as she does *“not know about the future”* (Rebecca). As with the other respondents outlined, Rebecca reflected on comparisons with her peers of a similar age (perceived by her as HIV negative) who she viewed as ageing differently from her, in terms of fewer health problems.

Dean, Olivia, June, and Rebecca, in all four accounts outlined so far, highlighted their anxieties, worries, and questions about growing older with HIV. They also layered this with comparisons to their perceived healthier peers, and the unknown nature of their bodies. They saw their bodies as presenting unpredictable symptoms that they felt were either overlooked initially by medical experts for HIV testing, and again, as they grow older with HIV. As discussed in chapter two, the invisibility and marginalisation of many heterosexuals throughout much of the historical development of HIV and AIDS in the UK comes to the forefront of some of the respondents' accounts here. As evidence of this, heterosexual respondents spoke about being neglected for HIV testing despite showing signs of late-stage HIV infection, and as a result, forming additional comorbidities due to a lack of immediate treatment. This also points to a downward placement of individuals or groups within a status hierarchy of testing and needs provision, indirectly stigmatising heterosexuals as a group not needing support (Links and Phelan, 2001; Balfe, et al, 2010). Added to this, respondents in this survey who are now living with HIV and growing older with it, found their concerns about additional health issues similarly being overlooked. This left them with little frame of reference to go on, in terms of ageing, other than measurement against their perceived HIV-negative peers. The following section will go into further detail about the body being framed as unpredictable and the framing of older people as a 'medical puzzle' (Rosenfeld, et al, 2014).

The body as unknown

As early research and public dialogue on growing older with HIV emerges - and what this means for the physical body whilst it ages (Wallach, et al, 2019; Kall, et al, 2020; Rosenfeld, 2021) - older people living with HIV see and hear these messages, and internalise them, as Jessica points out:

R *"I think, well the only thing that probably really worries me is that obviously they talk about, you know, HIV accelerating or accentuating your HIV.*

I *Mmm.*

R Or the ageing process. And I think to a certain point that is true" (Jessica).

Jessica was fifty years old at the time of interview and was diagnosed in 2008. Since her diagnosis, she had volunteered or worked in the HIV sector, which gave her immediate access to materials and early research discussing the effects of HIV on ageing. This gave her concerns about the implications for her own body as she aged. Despite this, she stated that she was *"comfortable with my HIV medication as it keeps me stable, and I don't think I get too many side effects with that now… I am now unsure what I am going to be like when I am an old woman. I have no real idea what problems I'm going to face, or if the HIV will accelerate my own ageing. Will I get dementia earlier?"* (Jessica).

In relation to Jessica's concerns, there is some emerging evidence to show that HIV is linked to premature ageing (AVERT, 2018). In a medical survey from the Terrance Higgins Trust (THT) (2017), 22% of people living with HIV rated their current wellbeing as 'bad' or 'very bad', with an additional 39% stating that it was 'fair.' Furthermore, people in their fifties living with HIV, had on average three times as many long-term health conditions when compared with the general population, especially around memory loss (THT, 2017). The concern with memory loss appears in this thesis, in that respondents discussed their own experiences of memory loss, which they blamed on their HIV status, leading to concerns about the future. Whilst noting moments where her memory had gotten worse as she aged, Rachel stated that, "I *don't know, I think I forget a lot. I think it affects your memory as well" (Rachel).* This concern with memory was also raised by other respondents, with eight out of the ten respondents all expressing worries now and for the future about accelerated memory loss, decreased cognitive ability, and memory impairment.

Similar to Rachel's anxieties about memory and accelerated ageing, June also showed concern in her interview about her own memory loss. She highlighted concerns of this being explained away by healthcare professionals earlier in her diagnosis when she was only aged forty years old as something that was related to only her age, and not from the effects of HIV. She discussed a routine appointment with a doctor for an osteoporosis check, caused by the effects of her HIV medication. At this meeting she mentioned recent episodes of memory loss:

> *R* *"For example memory loss, big one I think. The healthcare professionals, they always dismiss memory loss, 'it's related to age'. Um, but they are so dismissive. I am sure it is related somehow. Why should somebody at age forty, when I first turned up, have age-related memory loss, you know?... The doctor told me I was not to worry, and this is common in a woman in her mid-fifties…I don't think that's good enough" (June).*

As well as memory loss, other unexplained symptoms in the body emerged in the data from all respondents, things that created uncertainty about whether it was a general ageing symptom, or whether being that of HIV's interaction with the ageing process, or the effects of their medication. Compounding this anxiety further was that the healthcare staff they came into contact with often seemed unsure themselves (Rosenfeld, et al, 2015). Rebecca highlighted in her interview that for *"one full month"* (Rebecca) she struggled to get out of bed due to her legs giving way from extreme weight gain and swelling which she linked to her status, stating that *"having HIV brought some changes in my physical way"* (Rebecca). Rebecca expanded upon this further as she saw dramatic changes to her body, particularly her legs:

> *R* *"No knees, no muscles at all. So much so that I could not walk. I could not wear socks, shoes, and then one night, believe me, one night I lose nine kilos. And nine kilos of air or nothing. I was just so swollen. And in this period, it happens to me but basically they had to [inaudible] to start to learn to walk basically. And ah*

something my left ankle happened, but now my left ankle is like a little slack" (Rebecca).

Rebecca found that the medical teams who treated her as *"not knowing, they had no answer for what I went through. I want answers but they cannot give them – how do they know? We are new people to them"* (Rebecca). By 'new people' Rebecca meant the 'new generational cohort' of people growing older with HIV, being on medication, and living longer. Jessica, June, and Rachel also reflected on their own experiences with healthcare experts, and they felt the same. The body represented a site of unpredictability for the respondents as they aged and for their healthcare professionals.

James was the oldest respondent in this study, being in his early seventies, and though he felt *"healthier than ever"* (James) with his HIV, he echoed a similar issue around the lack of knowledge of healthcare professionals with his ongoing heart and breathing issues. He said:

R "You know? I mean like last year for instance I was in hospital on and off for a month because of my heart.

I Mmm.

R Now whether it was through HIV or just a general run of the mill thing. They don't know, and as it happened now I've, I've still got an irregular heartbeat, so it hasn't gone away. Out of breath.

I Yeah.

R So, you know, is that because of the HIV or is it because it's just part and parcel of getting old, you know?

I Mmm, mmm.

R You can't, you can't say, you know?" (James).

James felt healthier now than when he was first diagnosed, and he was comforted by his own faith in taking medication regularly. He felt that this would increase his life expectancy and would enable him to be able to see his grandchildren grow up. James gained some ontological security and control through his regular medical regime, and so felt better for it. As he stated:

> *R* *"And um, and that was it, and we have this doctor who we see occasionally who comes and talks to us, you know, about different HIV medications and all that. And his words are, he says 'you know, you'll all live to see your grandchildren.' But because I look after my body. I do what I'm told to do. Which is what you should do. There's no reason for me not to live longer, you know? Okay um I have to take these pills, but that's life, you know? Because, you know, as far as I'm concerned if I wake up it's a bonus" (James).*

The body as a site of unpredictability was a theme in all of the interviews. Despite this, all respondents found that their medical regime of HIV treatment was helping to provide some stability in living with the virus. Nevertheless, some mentioned side effects related to their ageing process. Reproduced within this 'unpredictable body' narrative were the views of healthcare experts, whom respondents considered felt similarly. The impact of the unpredictability of the ageing body with HIV, the lack of knowledge by medical experts, and the respondents' own anxieties about this, had the potentiality for the long shadow of social death to emerge. Compounding this further, respondents highlighted their own experience of historical invisibility of testing offered to them, which led to poorer health outcomes later in life, as well as their current concerns about their HIV and ageing being overlooked. This long shadow of social death has been conceptualised in chapter three as respondents having a clear sense of their agency, in the sense of knowing their bodies are impacted by ageing and HIV. However, they face a series of health-related resilience losses, which cumulatively, have the potential to result in older heterosexual people living with HIV being further disconnected from social life

(Norwood, 2009; Borgstorm, 2017). In light of this, the following section will examine the respondents, their interactions with healthcare professionals, HIV austerity cuts, and the changing nature of medical care.

Healthcare professionals, HIV medication, and changing medical care

The anxiety reported by respondents regarding healthcare professionals and their lack of knowledge about ageing and HIV was elaborated upon by June in her interview. As someone who used specialist HIV support often, June worried about the impact of external factors such as government austerity cuts to HIV funding. She questioned what this meant for future treatment which had now shifted to primary care from GPs, whom she felt knew less than her previous specialist HIV consultants. Worrying about GPs' lack of expertise, she also expressed worries that older people living with HIV are becoming more invisible in HIV treatment:

R *"And then I think something which is worrying me a little bit is that there's talk that they want to shift care from the consultant to the GPs.*

I *Right okay.*

R *I spoke to my GP, she thinks it's a bad idea, because they don't have the expertise. How do they want to gain that, you know? And then maybe they've got one or two people and how do you want to, you can't, GPs can't look after us. You know that everywhere in the HIV sector or area money is being cut and services are being cut. It actually encourages healthcare provider to just, you know, like, you know, say ah, you know, 'that's part of ageing' or whatever. Ah that's disappointing me a little bit. I find it disturbing that there's not much more effort being done, because the older we get the more likely it is that we end up with these comorbidities, maybe one or two more, and if they are denying it that means we don't get the best of care" (June).*

Concerns shared by respondents surrounded whether or not GPs are sufficiently educated and informed to lead on the delivery of care and treatment of HIV. Both GPs and HIV specialist services appear to share a desire to see awareness and education of HIV increase in general practice and primary care. The House of Lords Select Committee Report on HIV and AIDS in the UK (2011) strongly recommended that GPs become more involved in the care of their HIV-positive patients. Yet, many people living with HIV have fears around and experiences of receiving poor treatment in primary and generalist healthcare settings (Beer, James and Summers, 2014). James, as the oldest respondent interviewed, had further concerns that new drug trials and medications were being tested on younger populations only. This mirrored concerns expressed by June about the neglect and invisibility of older people with HIV in medical care terms. Similar to June, James also expressed deep concerns with funding cuts as well as feeling that ageing was ignored in clinical trials:

> *R* *"Because most of the clinical trials that are taking place are on the younger generation. None are taken on the over fifties, you know, to actually find out how your body will react. Because you as well as I know, and you know that as you get older your body changes. You know? What was good for you when you was twenty-five could be bad for you when you're fifty. But [pause] since the medication is improving all the time. So, people are living longer and the thing that [pause] they haven't really looked at is how will these anti-retrovirals affect you at later life, you know? And nobo-, and because the government are like stopping the funding or cutting the funding down" (James).*

Brenda was similarly concerned about HIV funding cuts, the changing nature of healthcare, and the lack of knowledge amongst healthcare staff, though she took this further:

R *“My worry is that we [heterosexuals] have been so poorly represented within HIV studies and literature. My specialist I have now can provide me with advice and support that a GP could never do. I worry about the cuts to HIV services.*

I *And what does that mean for you?*

R *Worry. I am worried that I will slip through the net in terms of specialist care. I mean, I am fifty now. I’m thinking about my future with this bloody virus. Don’t get me wrong, HIV medication has been a blessing, but I so often feel invisible anyway in HIV services anyway so will they know my needs? I just really, really worry, you know?” (Brenda).*

As seen with June, James and Brenda, a real anxiety about the future of HIV, ageing, and medical care appeared in all respondents’ interviews. Interrelated factors also played a significant feature, including external issues such as lack of awareness from key medical staff, poor visibility of the heterosexual HIV population within HIV treatment, and further austerity cuts to HIV funding. Those who worked or volunteered in the HIV sector, such as Dean and Jessica, felt that people living with HIV were often *“left to get on with it as the cuts sink in deeper”* (Jessica), and that they had *“been sidelined for HIV support. The services have gone, and you have to make your own way with things these days. The charities are closing”* (Dean). As stated in chapter three, in her work on Stigma, Tyler (2021) discusses the rise of twenty-first century ‘stigma politics’ whereby a ‘stigma machine’ made of interconnected parts comes together to maintain external stigma, which is beyond that of the personal lived experience. Whilst previously stigma politics devalued individuals living with HIV, new forms of the stigma machine have now developed through government austerity cuts, which have impacted heavily on disability services, devaluing HIV services by removing specialist support (Dalton, 2016).

Living a 'normal' life with a changing and unpredictable body?

Advances in effective HIV treatment mean that more people than ever before are living into older age with HIV, and the UK Collaborative HIV Cohort (UK CHIC) study found that life expectancy for people living with HIV on successful treatment in the UK is now considered 'normal' (May, et al, 2012, 2014). However, some respondents using their own experiences as framing expressed criticism about the overarching HIV narrative, propagated by the medical world, that a 'normal' life expectancy is now typical.

Olivia was diagnosed in the late nineties and was 53 at the time of interview. As a longer-term survivor of HIV, she regarded herself as having, *"VIP tickets"* (Olivia) to both HIV and ageing, meaning that she has lived with it for so long. This has presented her with numerous health problems due to her long-term use of ART medication, as well as being involved in drug trials throughout her life. Although expressing happiness with her current family life, her previous poor health outcomes impacted her own resilience and her mental health, to the extent that she had previously considered stopping her HIV treatment. At one stage in her treatment she found herself in a hospice due to kidney problems and it was only due to her seeing her son that she decided to carry on with the treatment. At the time of interview, she was facing yet another kidney transplant in the very near future, as Olivia states:

> *R* *"Um, at one stage I took very, very ill and I actually thought, I don't want to live any more, I don't want to fight this thing anymore. I landed up in a hospice and pretty much said to them 'stop everything.' You know? I just, and I mean he was four, five. And then at that stage, with the portal vein I had varices and they burst. So, I started bleeding from every orifice, and they still walked in and said to me 'do we just leave you here and let, you know, let, and this is how you're going to go?'*
>
> *I* *Yeah.*

R *And I don’t know what it is, and I just thought, no, no, he’s not ready. You know, he’s not ready to lose me.*

I *Yeah, yeah, yeah.*

R *I said ‘no, get me to wherever’” (Olivia).*

Olivia, as a long-term survivor living with HIV, stated that *“I was one of those guinea pigs way back when”* (Olivia) and the kidney problems she faces now, *“are a result of long-term DDI treatment for HIV”* (Olivia). This caused Olivia anxieties that her body was highly resistant to certain types of medication and reacted badly to others. Due to this, Olivia had concerns with future medication changes and wondered whether there would be new drugs available that she could move on to. She expressed worries about whether she would be resilient enough to carry on, after spending a number of years changing and shifting medications:

R *“And then it’s also the other complications that we’re having from living with it for so long…and now I’ve got the, you know, I’ve got the liver disease. I have chronic osteoporosis, you know? Which is due to, again, the drugs that I took when I, you know, bones getting so thin…and that these are things that I’m going to have to actually just live with. And that can be quite daunting in itself, because you want to be like fifty or, fifty’s not old. And then it’s getting more and more difficult because you’re getting older, and it’s all, you know, you’ve got to go on anti-rejection drugs and, you know, that interferes again with your HIV meds, because that’s already changing. And I must admit every time my drugs get changed, I get very anxious, and I’m not normally an anxious person, but because I’ve lived through years of side effects I just think, oh I can’t do it” (Olivia).*

Due to the ageing body being a site of change and unpredictability, this formed key concerns for some respondents such as Olivia. Echoing earlier respondents' lack of HIV diagnosis due to their heterosexual demographic, Lydia said she had unknowingly lived with HIV for decades, contracting it she suspected from her days at university. Now in her early fifties, Lydia's HIV diagnosis was recent at the time of this interview (within only the previous two years), and it significantly changed her outlook on life. This led her to leave an unhappy marriage, travel regularly, and making of new friends across the globe. Despite this, Lydia still expressed some concerns around ageing with HIV, stating:

> *R* *"You see, I am outgoing and all that. I love my life. Since my diagnosis I have done more things as an older me, than my younger me would ever have thought. I was so ill for many years before being diagnosed, lying in bed all the time being unhappy. Never once did anyone think that it would be HIV or did anyone think about testing me for it. Now I am doing everything I can to enjoy life, but I still have that niggle in my head, like, like I might one day be elderly and unable to do anything due to my HIV" (Lydia).*

Lydia echoed concerns expressed by Olivia and Brenda about their capacity to engage with the active ageing process whilst they faced potential, or actual, issues with their bodies, ageing, and ill-health. As well as discussing two people who had HIV she knew who recently died of throat cancer, and about other friends with the virus becoming affected by pneumonia, June stated:

> *R* *"Then I always have that feeling I'm going to be seventy and that's it, and I think it's, they are trying to tell us that with HIV you can lead a long life just as if you don't have it because it's controlled by medication. I think you can't tell me that the medication we take has no effect on our body, you know? You can't tell me that. And I can see with people with their different ailments they have.*

I *Right.*

R *It's not true that you live, you might live a fairly long life as well and are fairly healthy, but I don't think as if you are HIV-negative. I don't believe that. And I don't understand why they are trying to tell us that. I mean whom are you trying to tell that? You know? If you are affected you feel it for yourself, you know?" (June).*

Contemporary approaches to resilience in healthcare and policy have revealed that an inherently conservative and neoliberal approach, in which personal 'topped up' resilience is used as an outcome for patients and health strategies, especially in regard to the lack of knowledge about and treatment of people ageing with HIV (Leach, 2008). This discourse reinforces personal responsibility and the need to foster personal resilience by those living with the virus, for 'waiting for answers' and 'living a normal life with HIV.' This absence of knowledge about growing older for those living with HIV generated anxieties amongst the respondents. Olivia, for example, felt a sense of abandonment by experts around their poor level of knowledge of HIV and ageing. Yet, ART was seen as a crucial way to be able to gain a sense of mastery over the unknown factors in their lives, which will be discussed next.

Control over the body?

All respondents stressed that they felt some control over their changing bodies, as all positively valued the impact of ART in keeping their viral loads and HIV controlled, despite some having more serious longer-term health impacts, and comorbidities than others. ART had presented a significant sea change in all ten respondents' lives, as expressed below:

R *"It's been as life changer for me, so has my diagnosis, I have changed my outlook on everything for the better. Without the drugs, I would be just like how I was, lying in bed, feeling ill, and feeling sorry for myself" (Lydia).*

R *“I take tablets. I am active and I get on with my life. It is important to me. HIV treatment is getting better all the time” (Rebecca).*

R *“I know I have a load of underlying health problems, but, um, I know my life without my medication wouldn’t be the same” (Dean).*

R *“I thank God for the medical progress that’s been made. Ah, I can live a normal life. I have aches and pains, I know, and I know I talk about not being healthy later in my life, but at least I can control my viral load” (June).*

R *“They [medication] keep me healthy. They keep me on track. I am in my seventies and still going. I mean, I could be better, but it’s progress isn’t it? [Laughs]” (James).*

R *“I have been through hell and back with this [HIV], but I tell you that I am better than I was when I was first diagnosed. My body has bounced back into life thanks to meds, and I am doing so much more with this life than I did. I mean, look around, look what I am doing now to help other people with HIV” (Jessica).*

R *“I plan to live abroad in the future, I know I’ll be taking these for life, but if it means I have better quality of life by doing it, then I will take them forever” (Rachel).*

R *“I reckon out of all of the people you will talk to in this research, I am probably one who has had the most physical shit happen to them [laughs]. Listen, it’s shit what has happened to me, but I’ve got my husband and son, I am still here, still going. In my low days, I remember these things, take my pills and get out there again” (Olivia).*

Respondents faced three key tensions in their lives. Firstly, all felt some sense of control over their lives, bodies, and a personal sense of agency through their HIV medication which had enabled them to manage their HIV on a daily basis. Despite there being a tension around this medication interacting and causing issues with the ageing process. Secondly, as *“new people”*

(Rebecca), or the first large cohort now growing old with HIV in the UK, they also felt that they were dealing with the tension of the unknown in their lives. Many presented problems with their own health outcomes, and so they naturally had worries, fears, and concerns with how ageing would interact with their living with HIV. To measure this, some respondents used comparisons with their own peers to examine their own changing bodies compared to where they felt they should be at that point in the ageing process. The final tension faced by the respondents surrounded their concerns with new and unpredictable health issues that had emerged. In that they sought answers from medical experts but felt they either overlooked their concerns, or didn't have the answers to their questions, leading some respondents to become sceptical over the 'normal life narrative' propagated by the medical establishment. These three tensions led to a paradox within the respondents' lives, of their bodies being both controlled through HIV medication, yet feeling uncontrolled in terms of what the future had to offer.

Conclusion

A multitude of factors are at play within this chapter, such as the problematic nature of changing bodies, the invisibility of heterosexual needs, the impact of changing healthcare and cuts, the interaction of HIV and ageing facilitation, and the lack of knowledge from experts about HIV and ageing. All would appear to impact whether active ageing and Aranda et al's (2012) concept of unfinished resilience can be realised in older heterosexual people living with HIV, as set out in chapter three. Similarly, in relation to the invisibilisation of heterosexuals, as set out in chapter two, HIV testing was not offered to respondents, despite displaying late-stage symptoms, compounded by perceptions of medical experts over-looking their living with HIV and ageing concerns. The socio-historical framing of who has been deemed to need HIV support and testing hints at aspects of the long shadow of social death in operation, and the stigmatisation of this group in terms of a devaluing of their needs.

Furthermore, the tensions of both ‘control and uncontrolled’ bodies ran throughout all respondents’ interviews and is a notable theme within the research. These tensions had the potential to negatively affect their levels of unfinished resilience and their engagement with the active ageing process, while the potential of the effects of the shadow of social death, led ultimately to social withdrawal. Yet despite the historical invisibility of many of the respondents in HIV services and the current challenges that they faced, respondents navigated their lives and decisions with both agency and a sense of optimism, pulling upon sources of comfort where needed. Respondents questioned and critiqued medical experts and wider narratives of ‘growing older normally’ given to them by actors and institutions and were not passive in their decision-making. Whilst wider social structures threatened flux and change, as shown by the changes due to government austerity cuts, and the uncertainty of medicine as an institution to offer answers around ageing with HIV, the respondents’ own sense of identity enabled navigation around change. Respondents did this through feeling a sense of control via their medication, which helped to control their HIV to mitigate against some of the unknown changes to their bodies as they aged, yet represented a tension in that it caused potential harm to their bodies. A deeper analysis of these findings will be discussed further in chapter eight.

In light of respondents feeling medical support is lacking and that questions were overlooked, as well as being affected by their own changing bodies, where did they seek support from others? The following chapter will explore the role of HIV support groups and the accessibility and usefulness of them, which appeared prominently in respondents’ interviews. All respondents actively engaged with HIV support groups at different points within their life course. To what extent were respondents represented in HIV support services and the wider ‘HIV community’? Might these HIV support groups and networks support the process of active ageing and offer resilience, or do they facilitate social withdrawal and the long shadow of social death? Support systems are the second theme of this research, which will be unpacked in the following chapter.

Chapter Six: Changing Communities

HIV support services, groups, and organisations, developed alongside the early stages of the HIV epidemic, played a significant role in easing feelings of social isolation, combating stigma, providing social support, and poverty alleviation, as well as a range of other services. In the early stages of the HIV epidemic, a sense of a wider 'HIV community' formed (initially) through informal groups, which then developed to counteract the unwillingness of the UK government to provide frontline HIV support; many of which have now evolved into larger, professional organisations (Weeks, 2000). However, the socio-historical invisibilisation of heterosexuals and becoming marginalised in terms of the wider HIV community in the UK, as set out in chapter two, was a second key theme from the interview data. This chapter will now outline whether the respondents felt that they had access to the wider HIV community, and if not, what issues and problems they might face in trying to? Without access, how do older heterosexual people living with HIV, find their own support, and a sense of community? Or, is a sense of community found in unique and different ways to that provided by mainstream HIV services and support? Overall, many respondents felt that they lacked a firm, organised, and well-resourced HIV community that listened to their needs. They also noticed there being a lack of a heterosexual community of people living with HIV compared to that of MSM. This will now be discussed.

Lack of a heterosexual HIV community

As outlined already in chapter two, much of the HIV epidemic saw the invisibility and marginalisation of heterosexuals due to a number of factors. These factors took several forms, such as the dominance of MSM and their needs being elevated within HIV social movements (Power, 2010). Also, the framing of other 'high-risk groups', the side-lining of heterosexual groups to the periphery of the epidemic in the UK (Persson, et al, 2006), as well as the distinct lack of strong bonds through a minority community based on ethnicity or sexual orientation

(Sophia Forum and Terrence Higgins Trust, 2018). The impact of these key factors means that HIV has not spread into the language of community and relationships among heterosexuals in the same way that it has with MSM (Persson and Barton, 2006; Millard, 2009). This was strongly noted by several respondents, who argued that there was a lack of a general 'heterosexual community' in terms of HIV community activism, support, and organising. This lack of a heterosexual community of people living with HIV will now be discussed in the proceeding section, beginning with Rachel's account.

Rachel, now a longer-term survivor of HIV, originally attended a number of support groups when she first found out about her HIV status, and from this, she *"admired the activism of gay men… their sense of community"* (Rachel). However, her interview highlighted a lack of HIV community and solidarity amongst heterosexuals living with HIV. She goes on to state:

> *R* *"HIV predominantly, back in the day it was gay men…I feel that if it wasn't for gay men we wouldn't have come this far. We would, you know, the research and everything. So, I applaud them really.*
>
> *I* *Yeah.*
>
> *R* *Because they, they've helped so much. And as you say they do stick together, they are stronger" (Rachel).*

Rachel's point about the community of MSM living with HIV being 'stronger' reflects two concerns of her own, with her first concern reflected on the socio-historical rise of the HIV movement where *"gay men led the way. They knew what they want. And I don't think we did the same, we were never really part of the movement like they were. We helped, we were there, but didn't get the same light on us. I can't explain why"* (Rachel). Her second concern highlights the growth of HIV activism by MSM which she perceived as strong, however, it had a side effect of isolating heterosexuals within the movement by not getting the ‘same light on us.’ Rachel goes on to say:

R *“today we [heterosexuals] still can’t organise a piss-up in a brewery [laughs].*

I Why is this the case do you think?

R We just can’t seem to do it. I mean, I used to go to HIV groups and stuff, especially after my husband died, but when we tried to set up our own, they didn’t last. There wasn’t the community like the gay men had, they were able to organise. We were scattered across the UK. Maybe it’s because they have had to fight harder for their rights, and we didn’t. Maybe that’s it?” (Rachel)

June had similar thoughts to Rachel, in that she also felt that MSM with HIV were more organised, had access to wider social capital, and that the heterosexual community living with HIV was more fragmented:

R “I wouldn’t know an activist from the heterosexual community. They are the ones [gay men] with the information, they are the ones who want to find out things. The heterosexuals, they like pfft I don’t know” (June).

Rachel and June’s accounts touch upon a lack of in-group solidarity with the wider heterosexual population living with HIV, and her discussion of ‘gay men’ forming more in-group solidarity reflects wider LGBTQI+ rights movements and fighting for legal change, which emerged onto the public stage during the high point in the epidemic. Due to heteronormative privilege, legal rights for heterosexuals were already in place, ensuring that mobilisation of heterosexuals living with HIV was made more difficult. However, some of this privilege only holds so much power in that heterosexuals like Rachel were living with HIV, which is still stigmatising and a stigma which is carried, marking her as different to others of her wider demographic, whether or not that stigma was known or not by others (Goffman, 1963).

Research on HIV and ageing has highlighted that White heterosexuals, in particular, know very little about HIV before their diagnosis. They often feel particularly isolated from other people who are living with HIV and their knowledge of HIV is poorer. This has also led to stigmatisation from family members, partners and friends (who also know little about HIV); more so than other groups living with HIV such as MSM (Rosenfeld, 2015). The sense of isolation as a heterosexual within the wider HIV 'community' also became apparent in June's interview. June talked at length about this topic as she pulled apart the distinction between LGBTQI+ and heterosexual solidarity, and how the socio-historical background to HIV, and earlier deviant labels attached to MSM, appear in her view to unite those of the LGBTQI+ community living with HIV:

> *R* *"I mean I went to heterosexual groups I think there's a lot who, ah a lot less activism. I think it's also our own fault because I think whereby the gay community, they, there are a lot of activists in there and they take things in their own hands. They set up themselves, whereby the heterosexual community, they can't get their act together somehow, or we can't, you know?*
>
> *I* *Why do you think that's the case?*
>
> *R* *I think a lot of us can't be, there is, you know, I think with the gay community because gay was like (shocked noise) 'you are gay?' you know? Um and the bonding is a lot better than with the heterosexual community because you are all in the same situation that people looked at it as abnormal or whatever. Look at Pride for example, you know, like you can, I mean there, heterosexuals, they would never get a parade like that together for any topic, you know?" (June).*

Echoing Rachel’s account of strong in-group bonding with the LGBTQI+ community, June felt that when it came to heterosexual people with HIV mobilising *“everybody thinks: ah, it’s for others to do”* (June), pointing toward a wider complacency by heterosexuals to mobilise within the HIV community. Dean similarly found this problematic and advanced the discussion further, by stating:

R *“The problem is, is that we thought it would never happen to us. When it did, we didn’t know what to do, in my opinion. I searched high and low for a group to join but there were only groups for gay men that I could find. I guess until I came to work here [HIV service]. There were one-to-one drop-in’s, but I wanted, wanted to meet other blokes, you know, like me who I could talk to about it.*

I When you say blokes like you, what do you mean?

R Straight blokes really. Blokes I could talk to about girlfriends, my ex-wife, how I tell women about my HIV in the future. Erm, I mean now I work for an HIV organisation, so I meet many people, but even we don’t have a group for straight people despite trying, they just don’t come to the service often. When they do they keep a low profile.

I Why do you think they keep a low profile?

R I was the same at first. I didn’t want anyone to know, and I was a bit ashamed. I thought it was something that only affected gay men. If you’d asked me to take part in wearing a red ribbon or attend a march, I’d have told you where to go. It was stigma. Now life’s changed, I obviously think differently” (Dean).

Dean, whilst currently working for an HIV organisation, found reaching out to other heterosexual people difficult. While he acknowledged that *“the ones I’ve met just access their individual HIV health checks and counselling, as they are ashamed or don’t feel that our support services are for them, erm, they think it’s just for gay men. We struggle with this”* (Dean). Dean’s account points toward a wider stigma which is felt by many heterosexual people in HIV engagement support, preferring to keep a ‘low profile’ due to being ‘ashamed,’ and yet engaging in their own stigma practices themselves, seeing HIV organisations as a place for MSM and not themselves. Yet through this practice, Norwood (2009) argues that this forms a series of losses, in this case the loss of community, which casts a shade from the long shadow of death (see chapter three). This brings forward some of the earlier socio-historical baggage and stigmas around HIV and AIDS, which had been internalised by the heterosexuals that Dean came into contact with. Other respondents, such as James, perceived a similar development, highlighting another aspect contributing to the lack of engagement with heterosexuals within the HIV community and support groups, which will be discussed next.

James saw the lack of support for heterosexuals as a structural problem, seeing something of an invisibility of resources representing him, highlighting the invisibility of older White heterosexual people in mainstream HIV organisations. Due to the socio-historical framing of MSM and BAME (Black, Asian, Minority, Ethnic) groups as ‘high risk’ groups of contracting HIV, this has had unintended side effects for some of the White respondents. Whilst James welcomed groups for BAME groups in his interview and recognised their importance in needing and accessing HIV services, he also felt that the groups he attended, and the materials presented by organisations, did not represent him. James thought that this may lead other people to not ‘see’ themselves in HIV support services and thereby not commit to building a sense of community. James’ observation that HIV support promotional materials did not represent him left him (and potentially others) feeling more isolated, in terms of older heterosexual people:

R *“And when you look at the statistics. You’re not mentioned. You know? You don’t exist. Because, um, they would seem to think you’re either Afro-Caribbean. You’re gay. Or you’re MSMs. Or pregnant women that breastfeed, do you know what I mean? So, you, you’re not actually on the list. And I find that rather* *strange in this day and age. That there isn't enough done about the older generation. As regards literature regarding white heterosexuals I would say that there isn't a lot about, unfortunately. Um, because we're a minority anyway, so, you know, they aren't going to produce a lot of leaflets if there's not a lot of white heterosexuals accessing the group, you know? They're predominantly Afro-Caribbean. So, you know? I feel the odd one out.*

I *Mmm.*

R *It could be, it could actually be [pause] a flyer or a pamphlet. About fifty-plus living with HIV and giving them a general rundown. I mean, I think where heterosexuals are concerned, I think they need to be, need to be signposted because when you think most of the groups or drop-in centres are very um Afro-Caribbean orientated, you know? They're there for them.*

I *Yeah.*

R *You know? And the majority of white heterosexuals, we feel out of place, do you know what I mean?" (James).*

James, as a man in his early seventies, stated that he was a *"rare find in HIV services. You don't see old men like me in them [laughs]"* (James). Whilst he gained a lot of comfort from the support services he attended, he thought he understood why other heterosexual men did not want to attend support groups, from his conversations with other older men who had attended previously. When asked why this was the case, he replied:

I *"The older heterosexual men?*

R *They come to one meeting, maybe two. Most don't stay. They look out of place usually, you know what I mean? Uncomfortable. I hang around because I am stubborn [laughs]. They pick up leaflets and see gay men on them. The*

> *representation of heterosexuals, and older people, just isn't there, so they don't come back, you know?"* (James).

There has been a dearth of HIV research produced on White, older heterosexual men and their specific barriers to accessing HIV support services. There is a wider reluctance for heterosexual men to use HIV services due to fears of others labelling them as MSM or in the closet (Djiometio, et al, 2017). Heterosexual men living with HIV can feel excluded from HIV clinics that brand their sites as safe and inclusive spaces for MSM, which may be less about homophobia and more about wanting a safe space for connection with, and support from, their own community (Djiometio, et al, 2017). As stated in chapter two, heterosexual men in HIV prevention were historically portrayed as a 'bridge' to female infection, and as having acquired HIV through other practices such as sex with other men or drug use, and so heterosexual men were sidelined both by interventions and by trials on HIV and AIDS medications (Leal, Knauth and Couto, 2015). The perception of heterosexual men living with HIV was often one of active HIV transmitters, but not as active agents in prevention. This means that the framing of heterosexual men has often seen them presented as spreading HIV, but not in literature around safe sex prevention (Leal, Knauth and Couto, 2015). Perhaps as a result of this, heterosexual men (and especially older heterosexual men) have largely remained invisible in HIV support literature due to the stigma around this, which reflected the frustrations felt by James in his interview.

The accounts from Dean, James, Rachel and June all point toward a perceived lack of heterosexual HIV community to engage and organise with, mobilise behind, or support. Many found that MSM living with HIV were more organised, motivated and able to provide a community for their members, but this sense of purpose was lacking amongst heterosexuals living with HIV. This appears to be down to several factors, as highlighted so far, such as poor historical mobilisation, a lack of representation within HIV support literature and in services, stigma perceived by heterosexuals in using mixed services they felt were for MSM, and as Rachel stated, a ‘scattered’ HIV community of heterosexuals.

Heterosexual women, HIV support groups and networks

There was also a general frustration around traditional HIV services being perceived to be run predominantly by MSM from some of the respondents. Whilst many expressed the ability of MSM to mobilise and provide support groups as a community, such as June, others felt a tension with this, such as Brenda and Rachel. They both felt that women’s needs were side-lined in terms of not having their own support services, or that their funding for groups was actively being cut or redirected. Brenda suggested that this is due to *“a bias in people at the top of organisations”* (Brenda), arguing that organisational priorities lie elsewhere, particularly in the HIV support needs of MSM, *“which is in the services offered. It all seems to be about gay men”* (Brenda).

Furthermore, Brenda felt that traditional HIV support services and groups tended to lack direction and presented few answers, or support, to women ageing with the virus. She discussed her expectations of a group she had attended, where she aimed to gain some certainty about how to find future strategies to age successfully with HIV:

> *R* *“And I wanted to go there for like, ‘so this is how it’s going to work.’ ‘This is what’s going to work, and this is a strategy’. Do you know? It was service providers, ‘so you’re a service provider. What service are you providing?’ ‘Oh, we don’t know’ (laughs), you know?...‘Social interaction is important in a group. Doing fun things is great’. Yeah good, okay, so how can we do that?” (Brenda).*

Having withdrawn from the support group, Brenda stated that *“they didn’t have a clue what to do with me, they were focused on gay men mainly and chem sex. I know that’s important, but like, I had questions, and I wanted action for women like me. I don’t go now”* (Brenda). Rachel reiterated this in her interview, reflecting upon an HIV organisation that had changed its original focus from women to including men within their services, most of whom are now mainly MSM.

As a reflection of changing funding priorities, Rachel states that:

> *R* *"And now they call it [organisation name]. Because funds are short they've had to incorporate men in the group. And, um, it's sort of more or less run by gay men now.*
>
> *I* *How has that changed things, would you say?*
>
> *R* *It's changed the dynamics. Within, I mean we used to have our [heterosexual group] meetings there. So that's been cut back. I think it's once a month now. Yeah. Um [pause] as far as I can tell there's not much help for heterosexuals" (Rachel).*

This lack of support for older heterosexual women was reflected in several accounts, particularly among people involved in HIV work and advocacy, such as Rebecca and Lydia, who both had similar concerns with many traditional HIV support services:

> *R* *"I was an HIV advocate for many years. Not now. I was trying to get support for women within my groups. I spoke to many people about our needs such as menopause, but it fell on deaf ears.*
>
> *I* *Why do you think this?*
>
> *R* *I think because we are not seen as important. Not, erm, part of the community" (Rebecca).*

Lydia also felt similar, stating that:

> I *"I run a group for women now [living with HIV]. They are powerful, beautiful, and affirming women. I get so much from them myself, even though I run the group. But it's mainly younger women. I am the oldest there and I'm not that old. Older women don't seem to want to come, which is a shame, as they'd get so much from it. I had to fight hard to set this group up with my own resources as there just isn't the support there" (Lydia).*

Brenda, Rebecca, and Lydia's accounts highlight a scarcity of resources for older women in dealing with topics such as older women living with HIV, and associated issues such as HIV and its interaction with the menopause. Lydia (who works in the Third Sector) mobilised her own resources to provide a space for women, yet still found this group lacking in engagement from older women. A felt process of marginalisation, and the shifting priorities of organisations, meant these respondents felt that existing services were skewed to the needs of MSM, which left older people not feeling 'part of the community', as Rebecca had pointed out.

Brenda voiced some of the outcomes of this process of marginalisation as she stated that she had been called 'stable well' and therefore not in need of engaging with support from HIV organisations. Brenda had concerns over this category of 'stable well' which is often used in HIV treatment and HIV support groups. She stated that the reason for her lack of engagement in HIV services was that *"I think that there's a lot of us who are just getting on with our lives, if we are called this"* (Brenda). As a result, she concluded:

> R *"So don't access support. And I think that's a really interesting, you know, when I did the [inaudible] thing 'stable and well'. 'Stable and well' is a category. And I don't, I don't get that at all. So just because you're on medication and you're hanging, you know, you've got a full-time job, you're not on any benefits. You've got a family. You're a care provider, you're looking after your elderly parents. Or*

> *you're looking after your kids. Doesn't mean that you don't need something. Yeah, because what is stable? I don't know what the future is, but I think the future has to be a lot more about psychological care, not just medical care" (Brenda).*

HIV support services are an opportunity to engage with older women living with HIV and the needs of this group, however, for some female respondents in this research, they felt that they were inaccessible, or focused on only medical support, as already stated by Brenda. There was a feeling amongst some respondents that traditional HIV groups did not cater to them and so many of them experienced a process of withdrawal from their services. The HIV support groups that were actually run by heterosexual women were also facing issues in recruiting other heterosexual people to come to them for support. Jessica works within the HIV Third Sector and has also struggled to get people who identify as heterosexual to her services, despite her being open and out about her status as an older, heterosexual woman in the HIV community:

> *R "Yeah, I think so, because I don't really, saying that though, you know, here in [location], here, we don't actually get that many heterosexuals walk through the door.*
>
> *I I see.*
>
> *R Weirdly enough. Again, I don't know where they are.*
>
> *I Yeah.*
>
> *R You know, we know they are there" (Jessica).*

For respondents who had attended traditional support groups, there was a clear trend of support groups not fulfilling their needs or not being set up for them, especially felt by most of the women interviewed. The invisibility of heterosexuals in HIV literature was a contributing barrier for some respondents, not aided by the social history of HIV, which is largely still framed as something that impacts mainly MSM and BAME communities, as high-risk groups. Spaces for both the voice of activists and catering for the needs of older heterosexuals have not emerged as strongly as a result. This is not helped in part, that HIV services were seen as over-represented and run by MSM, which led to many of the female respondents disengaging. Interestingly, a majority of women in this research reported negativity in traditional HIV groups which also increased their anxiety, and added to negative thoughts about using them, dissuading many of the women from engaging, which will be explored below.

Not 'fitting in' and it is all 'doom and gloom' – issues for women living with HIV

All respondents had attended either traditional support groups, workshops, or conferences provided by HIV support services previously. Whereas a majority of female respondents reported negative views of the more traditional support groups, the two men in the sample tended to use them and found them useful.

Lydia found traditional support groups for older people living with HIV as *"doom and gloom"* (Lydia) which led her to withdraw from attending. Lydia found the focus on topics in the previous groups she attended to be "*terribly depressing"* (Lydia). Lydia ran an affirmative, creative, and artistic support group for women. Whereas she found the more traditional support groups, with an onus on medical care and – as she perceived them – to be tackling only the negative features of living with HIV, to be problematic. She referenced the group organisers and their choices of topics:

> *R* *They just seem to be, there aren't many sort of positive people, bad pun (short laugh), positive people. It all seems to be such doom and gloom, you know? And I'm not a doom and gloom person. It seems to be this sort of feeling that you're different from everybody else. They don't seem to celebrate the kind of*

possibilities and opportunities that this brings, and for me, it's about making the best of everything, you know?

I *Yeah.*

R *Um, it's also all a bit of a kind of (short laugh), I struggled to find in the groups anybody that was like me. And it's not that I can't get on with gay men or African women or, you know, anybody. Of course, I can. But you're kind of thrown together (short laugh) with nothing else in common except that you've got HIV, and it's like, you kind of think, well what am I doing here, you know?*

I *Is the HIV not enough of a bond in a group like that would you say?*

R *It can certainly be, but not when you all have to sit through depressing topics every week about how the HIV is terrible, gives you aches and pains, what drugs to try to combat this. It becomes depressing. I need more affirmative ideas about living well with my HIV, to make me jump off my seat and say 'yes,' because we have heard all of these things before" (Lydia).*

Lydia's comment about 'being like me,' whilst initially sounding problematic, was meant in the interview in terms of her tiredness with traditional topics that she had sat through several times, of group facilitators lacking engagement with a diverse group of people bonded by their HIV. Lydia's own support group for women living with HIV, of which she was the facilitator, *"uses the arts to engage with living positively and we focus on positive self-reinforcement and not just the medical narrative. We build up the confidence of women, not knock them down. We all know we have HIV, but that isn't our main focus"* (Lydia). As such, Lydia could not see herself represented in the support groups she had previously attended as a user, leading to her own withdrawal. Interestingly, this was also found by Rosenfeld (2018) in their study of older people living with HIV, where people may have found groups helpful for a period after diagnosis they did not want to endlessly focus on the issue of HIV (Rosenfeld, 2018).

When attending HIV services for a week-long set of workshops, Olivia found the sessions that she attended triggering to her mental health, and unsafe. The workshops she attended left her feeling uncomfortable as she was still dealing with her own internal issues of living with HIV. This was in addition to dealing with an uncomfortable situation whereby a man who also attended the workshops made sexual advances toward her. On top of this discomfort, the topics discussed in the workshops further added to her feelings of anxiety, which led to a complete self-protective withdrawal from services:

> *R* *"They were talking about issues that I hadn't experienced and was hoping probably not ever to experience, so it was like, almost like if I don't talk about it and I don't see it I don't have to deal with it. Then there was, you know, the hormonal side of it as well, you know, they were going, you're going through change of life a lot earlier than lots of other people, you know? And so, they were discussing things like that, and I was just thinking, this isn't me, I don't want to be talking about this. I don't want to face it yet, so I don't want to be in a group where it's all being actually discussed and it's okay. I didn't feel I belonged there. So no, not in a million years will I ever go back to any of that" (Olivia).*

Reflecting the experience mentioned by Olivia, Rachel also withdrew from other support groups due to the advances toward her from men in the group:

> *R* *"But you do find a lot of people were sort of pairing up, and um [pause] I think, I'm not being arrogant or snobby, it's like some of the guys there think that because you are then you have to be with them, you've got no option… It's really off-putting and creepy" (Rachel).*

Many respondents not only chose to avoid HIV groups because they wanted to minimise the role of the medical narrative of living with HIV, but also due to the perceived negativity of traditional HIV support groups, alongside their feelings of safety around other heterosexual male group members. Rachel's attendance at an HIV support group after her initial diagnosis led to a personal shock and withdrawal, in that she met people older than her, and saw the illnesses that they presented within the group that she had attended. This affected her mood, as expressed here:

> *R* *"You know, all the illnesses that accompany it, and then you're seeing other people who are maybe stages ahead of you and they don't look very good. You know? It's like, oh my god I'm going to be in that position, you know, maybe in a couple of years. You know, it's not a good environment really (short laugh). So, if I surround myself in all that negativity, that illness, that 'oh woe is me'. Then it's going to bring me down as well, and I, I don't want that.*
>
> *I* *Why do you think this?*
>
> *R* *I don't want the negativity. It is nothing to do with the other group members. You know? It's just that I wasn't in a place to deal with that in my head, and I, couldn't deal with men at the group coming onto me. Then seeing people look ill, just made me worse" (Rachel).*

Rachel's own ontological security in living with her HIV was shaken after attendance at this group. Due to her recent diagnosis, and the anxieties that came with this, these factors compiled to make her mental health worse. Rachel, like Olivia, felt the need to withdraw as a form of self-protection, stating "*I want something more than this. I get that people get ill and growing older with it affects our bodies, but I want us to unite around something better than this. You know?"* (Rachel).

This is not to state that all respondents were not problematic in their own attitudes toward others who attended support groups. Seven of the ten respondents were White, and one account, in particular, stigmatised other group members in support services with their own privilege. This was clear in June's account, where June found that people who attended groups that she had attended were not, *"my kind of people"* (June) and recounts the story of a group event that she had attended, which had made her feel uncomfortable:

> *R* *"There are still, like there is [organisation name] also, but they are just not my kind of people. I'm not a snob at all but I once went there to a Christmas party and I, it was just horrible. It was, to me it seemed as if they are all drunks to be honest. Or coke addicts or something like that. That's how it seemed to me. I didn't have anything in common with anybody, I just wanted to get out quickly again" (June).*

Whilst feeling like something of a *"minority within a minority"* (June) within support groups, June voiced some problematic statements about other younger group members, BAME and MSM, enacting stigma practices on people who attended the Christmas party as 'drunks' or drug users, or not her 'kind' of people. Though these comments were rare among the respondents' interviews, June's self-confessed 'middle-class' upbringing led her to have social privileges which were not necessarily afforded by the other members of the support group. Whilst June was the only respondent who enacted stigma and prejudiced attitudes against other group members in such an overt way, it did problematise her comment about being a 'minority within a minority,' revealing it for the privileged position it was.

It has been suggested that the growing population of older adults living with HIV face considerable psychosocial challenges with social engagement and interaction, as well as important issues around the effectiveness and adequacy of social support and community-based services to their growing and changing needs. Due to this, isolation results from a variety of reasons, including internalised HIV stigma and self-protective withdrawal (Shippy and Karpiak, 2005) which negatively impacts an active engagement in life amongst older people living with HIV (Nichols, et al, 2002; Emlet, 2006). Some secondary HIV services, as highlighted by many of the respondents, have not yet adapted to the growing needs of some older people, and so this acted as a barrier to many respondents engaging in them, leading to withdrawal.

Engagement in HIV services: What about the men?

Existing research suggests that heterosexual women are more likely to use traditional HIV support groups more regularly, and heterosexual men are seen as more difficult to reach out to; when they do engage with support groups, they do not do so for any length of time (O'Brien, et al, 2005; Men's Health Forum, 2009). The findings from this research, albeit with only two men in the sample, tentatively show the reverse of this. Both men were engaged in using HIV organisations, networks, and to an extent, traditional support groups at the time of their interviews taking place, though these ranged between the formal and informal.

Dean now works for an HIV charity, after starting initially as a service user. He hoped that the organisation would close down in the future in, *"the hope that one day it won't be here because people will be aware and take care of themselves"* (Dean). Dean spoke highly of the HIV service he worked at and that he would occasionally *"go along to other support groups just to meet up with people, for the craic"* (Dean). However, for his own personal support, he often reached out to others online for advice around his own HIV and its interactions with diabetes. Dean used online Facebook groups to reach out to others in similar positions to himself for information gathering about how his diabetes interacts with HIV, citing a knowledgeable member in a Facebook group he is part of:

> *R* *"I went to see him, and I said to, and I did say to him, I said 'have you got anything coming up?' 'Because I could do with someone to talk to about it all'. He talks quite openly about that online. I've seen quite a lot of his posts on Facebook and things like that, and the groups that I'm in, the HIV groups I'm part of" (Dean).*

James discussed the need for connections and to remove isolation as an older man living with HIV. He discussed his previous isolation in terms of not being able to disclose his status to people who he previously worked or socialised with, stating that, *"you've got no other connection with them"* (James). James had found a sense of community of people, bonded through HIV, who met at more traditional face-to-face HIV support groups, which stands in contrast to most of the female respondents. He went on to say:

> *R* *"Well, um, I'm glad they're there. Because you don't feel isolated, you know what I mean? Because [pause], okay if you've got nobody to talk to then you can't get what's on your chest off it. Met a lot of people I would never have met. And I think people with HIV are more friendly than people who ain't. Where with being HIV you go to different, go to seminars and you meet, see the same people. But they know you so you're friendly and you exchange what's been going on and, you know, and things like that. And you don't feel so [pause] isolated" (James).*

James and Dean did not talk heavily about their use of traditional HIV support groups, other than to state the need for them and how they have been invaluable to their coping with living with HIV; in terms of reaching out for advice and in combating loneliness. However, Dean had engaged more heavily with online support through more informal networks such as Facebook, and information groups for people living with HIV, whilst James preferred a support group.

All of the respondents, at some point within their life course, had accessed a form of traditional support group, organisation, or network, to cope with growing older whilst living with HIV. What was unexpected in the research, was that the majority of respondents at the time of interview did not attend traditional face-to-face HIV groups often, or at all. As outlined so far, some of the barriers faced by older heterosexual people in mobilising access to a wider HIV community, and yet simultaneously withdrawing from traditional support services, would initially seem to support the theoretical premises of the withdrawal seen in the long shadow of social death on their lives. In turn, this problematises the active ageing model whereby many people withdraw from society as they age, impeding their activity and engagement within the changing social structures around them.

However, as glimpses of the respondents' lives have shown so far, many were engaged within their own support systems and they formed a sense of community away from 'mainstream' HIV support. This is represented by examples such as Dean's Facebook outreach and Lydia's affirmative HIV women's group, which she ran outside of work hours. Respondents were not merely passive actors within their social worlds or victims of wider social stigma through their marginalisation as a demographic, many used their own social capital to reach out to others or engaged with creating their own (often informal) systems of support (Marsillas, et al, 2017). Within this, they were actively ageing and engaged, developing their unfinished resilience between their individual agency and in interaction with the social structures around them. As chapter three states, unfinished resilience is something in which an agent nurtures and uses their available resources in negotiation with their personal sense of identity, resources and the resilience offered (and restrained) from the social world around them (Aranda, et al, 2012). This is reflected by respondents slowing down or stopping the process of social withdrawal as they aged with HIV, and avoided more limiting aspects of the long shadow of social death. The following section of this chapter will outline how they did this.

Mobilising to create HIV support for the heterosexual community

Respondents used their agency to employ various tools, techniques, and methods to reach out to others and to seek support, despite not always feeling part of a larger 'HIV community.' This was most prevalent in June's account, where she had used her own available capital, resources, and agency to create informal meeting systems, to provide support to other older heterosexual people living with HIV. This was via a virtual WhatsApp group uniting the participants of a face-to-face group which she once attended. The original group was designed for heterosexual people living with HIV, but due to funding cuts, it had since ceased operation. June had helped to reconfigure this group, as stated below:

R *"I would like to do, like what we've been doing, like my, I've got one, two, four girlfriends who I met via [organisation] we used to once in a while; we've got a WhatsApp group, ah we used to meet once in a while and then we started, like often it was a birthday or something like that, and then we thought, ah we should meet like every two months and meet for dinner.*

I *Yeah.*

R *And then we invited other people, and now we were twenty people… So we invite who we think might be interested in coming and we just have a meal together. Ah, last time we went to [location] afterwards, a few of us. Um, that's more my cup of tea, you know, like than like I would like a formal meeting if it's got an agenda. I don't have to sit in a meeting to hear the same story. That really put me off, that it was the same every time. You're just waiting for the meeting to finish when everybody goes on to the pub, that's when you speak to different people and that's when you get to know them" (June).*

June also discussed private party evenings for heterosexuals living with HIV provided by another woman living with HIV, which worked on a rolling basis in different locations each month, but which ended due to being too expensive to manage:

> *R* *"Or most of us, ah, or socialising and I don't know where she got her e-mail list from, there were hundreds, um, and she had people who were or knew people who gave her, like once they were in the [names central city location], for a very reduced rate. I think she knows a lot of them from [online website] actually. She used to do that but then, ah, I think in the end, ah, with the costs involved she couldn't do it. I mean, it was her only, if it was an organisation it would have maybe been better" (June).*

These groups were often online and temporal, but they were significant as they offered informal spaces for heterosexual people to meet, with many of the respondents gaining a sense of purpose from these informal networks, in that they could meet others and find common ground. However, these were referenced by respondents as fractured and sporadic and so it appears upon first sight that opportunities for collective or community resilience were limited. June goes on to state that:

> *R* *"We ah might not have had a formal group as such, but ah, we found ways around it. It's amazing these days that modern tech-technologies can bring us together now. You don't have to sit in a drab meeting room. We lead the agenda, not the other way round. I know the party evenings didn't work out, but we have our WhatsApp group" (June).*

June had a clear sense of agency and used her sources of capital to instigate her own group that was suitable for her needs and others. However, she recognised wider structures such as funding cuts and the temporal nature of these groups, as not helping these groups to continue to thrive. Yet, whilst her own unfinished resilience allowed her to reconfigure groups to provide support, her decisions were also constrained by larger social forces.

A number of other (particularly female) respondents expressed a desire for traditional HIV groups to be run differently, to fit with their changing needs as older people living with HIV. As older people are more likely to use emerging technologies, such as social media, apps, and websites there has been a cultural shift in how support services are accessed (Czaja, 2016). Most respondents used online technologies to engage with others, as June did with her WhatsApp group, such as online dating as an alternative to other ways of meeting people. As stated already, Lydia did not find traditional support groups useful, but did with online groups on social media. Working in therapeutic services herself, she recognised their value for support and connecting herself to a bigger sense of community as a tool to reduce the isolation:

> *R* *"Well I joined, um, some groups on Facebook, so it was private, secret groups or whatever. You know? It's mostly rubbish, but for people in my position because there aren't that many people with HIV and it's hard to meet other people [and] that is a brilliant platform. And there's a lot of support on there. And um it's really, you know, and it's, you know, worldwide… I just think it's great" (Lydia).*

Similar to Dean using online tools for his support, Lydia used informal online groups to mobilise and meet other older heterosexual people living with HIV (though open to all), yielding positive results:

> *R* *"We have a core group from Facebook who have started to meet and um, it's great. Others sometimes join. We have lunch, discuss whatever we need to discuss, and we all come away reinvigorated. I mean, having that space. It's*

> *empowering and we don't feel so widespread and spread out, here, there and everywhere" (Lydia).*

Rachel engaged with a *"ladies who lunch group…"* (Rachel) which she stated:

> *R "… sounds more glamorous than what it really is [laughs]. None of us have much money but a group of us with HIV meet up, some men come along too. We are open to all really.*
>
> *I How did you all meet?*
>
> *R We are mainly all women of colour. We met through support groups originally but got bored with them.*
>
> *I How so?*
>
> *R They were so negative, we thought. We made this lovely lunch group, and we have a Facebook chat, erm, we arrange dates, days and things like that. I think as African women we face our own stigma with HIV in our community. I mean, I erm, never told my friends or my parents, or people at church. My late husband never talked about it even though he had it and gave it to me. I just feel like I have space to breathe there, and I can talk about my menopause symptoms without sounding silly as we are all going through it [laughs]" (Rachel).*

Lydia and Rachel, like others so far, found new and innovative ways to mobilise a sense of HIV community for heterosexual older people, and despite these networks being more informal and without significant structural support, they offered a different 'recipe' of the support service to the respondents which resonated with their needs. Informal support like these, whether face to face or online, provided respondents with the opportunities to form their own version of a community, despite larger structural resources from HIV organisations being perceived as unavailable, or suitable for them.

However, not all used informal methods and networks to meet with other heterosexual communities living with HIV. When she was first diagnosed, Jessica used the HIV organisation that she now works at as a place of support where she *“moped about”* (Jessica) for three years *“feeling sorry for myself, being isolated from everyone. Not engaging at all, I lost contact with people, gave up my studies. I felt that everyone knew I had HIV, even though they didn’t. I felt dirty”* (Jessica). Jessica was later presented with an opportunity to attend a conference for women living with HIV by the HIV organisation where she sought support. After attending, the positivity of the women’s conference resonated with her and presented an opportunity for her to change her biographical journey, which led her to then work in the Third Sector with people living with HIV. She recounts how it affected her:

> *R* *“And there was all these women. You know, we’re not talking like two women. We’re talking a group of women, sort of like thirty women. You know, from all over the UK, all different ages, all different nationalities, cultures, colours, sizes, whatever you want, do you know what I mean? Of women living with HIV. And some of them having children, living normal lives, studying, working, partying, whatever, do you know what I mean? Whatever they were doing individually to themselves. You know, just seeing these people and thinking, blimey, okay, you know? Well okay I’m not going to die. I think one of the women there had like been living with HIV twenty-five years or something and I just thought, woah, you know? It just totally changed my life and …*
>
> *I* *Yeah.*
>
> *R* *I remember coming back from it and feeling so empowered” (Jessica).*

At the end of the HIV women’s conference the women were told to do something positive, and Jessica used this opportunity to come out about her HIV status on her personal social media. This ultimately led her to take part in a photography awareness campaign highlighting women living with HIV, which then allowed her to write articles in the national and international press about her story. Jessica, whilst using more structured mechanisms such as a national HIV conference, followed a similar trajectory to many of the respondents with their informal services, where they used their agency to then build resilience, actively age, and in the case of Jessica, re-engage, manage her felt stigma, and pull back from the long shadow of social death.

After having negative experiences in traditional HIV support groups, Olivia had withdrawn from all traditional HIV services other than her regular healthcare. In her interview, she presented ideas about how HIV support groups could be run, using techniques that move away from the 'doom and gloom' narrative. In many respects, Olivia was the least public in terms of her HIV status amongst the respondents, and she feared the stigma around her. As a long-term survivor with significant health problems, she was critical about engagement with HIV groups. However, she did recognise the potential for re-engagement with HIV services if they were to be reconfigured:

> *R* *"I think if we're older we're a little bit more mature. We've been there, we've done it, we've been through it… it's getting to be with like-minded people as well, you know? You know you can talk about things that are interesting, they've travelled and wonderful plays or whatever it is that interests them, that you might not know a lot about. But, you know, you're interested in finding out, you want to learn from. I don't want to just be going to a group and sitting discussing, you know, which doctor I saw this week and what meds I'm on. I don't want to. You want to get away from that" (Olivia).*

Olivia wanted a very active ageing approach to how she saw group dynamics being set up, with well-being and resilience at its core, but not so medically controlled and focused. She said that she wanted people with a *"zest for life"* (Olivia) to present at groups about the process of ageing, and with less of a focus on the medical problems of ageing bodies and, *"not what HIV has done to them"* (Olivia). Her thoughts were as follows:

R *"I want to be, you know, with people that are like-minded and have got a little bit of zest for life, because then that's going to give you more hope for the future. I want to see a seventy-year-old that is still globe-trotting and has a fantastic social life and I haven't heard anybody say it's a 'this is actually a great thing'. It's not talked about, and actually, you know, I've done this, I've done that, things that I thought I could never have done I've actually been able to do. So yeah if I could find a group like that I would be there like a shot. My life wouldn't be so secretive, so there would be a place where I could actually be comfortable, be with people my age that share, you know, some sort of, you know, excitement about getting old" (Olivia).*

Whilst Olivia from her account could be seen as disengaging into the long shadow of social death due to her felt stigma, numerous health issues, and previous negative experiences of HIV support groups, she remained hopeful about re-engagement. When asked how she engages now with any sense of a wider heterosexual HIV community, she responded:

R *"My community is my family. My son. My husband. They don't have HIV like me, but they're everything to me. My husband knows though, like I said. I have left behind a lot of HIV stuff now, but I still read a lot about it. I'm still engaged with websites, social media, and I even politely corrected a friend of mine the other month when she spoke of 'people with AIDS.' I said '[name] we should say HIV these days you know.' You know the best bit? She said, 'oh I am sorry, I didn't know!'*

I *Ahhh, brilliant.*

R *Yup, she doesn’t even know I have HIV. That is my contribution then, I correct other straight people [laughs]” (Olivia).*

Olivia worried about stigma, and especially courtesy stigma placed on her family if people found out that she was living with HIV. To correct a friend's language was a significant step for Olivia, and despite not engaging with a wider heterosexual HIV community, she remained active on social media and online, reading about HIV and keeping abreast of issues.

All respondents found new and different ways to build community and resilience which aided their active ageing positively. In some senses, then, the narrative often framed by HIV services around heterosexuals not attending traditional HIV services, and having a weaker sense of community, could be contested. All respondents interviewed used *different* techniques to engage their own sense of community and learnt to use tools to find HIV support as older people which fitted their own needs, despite facing larger structural challenges. This complex interplay ensured that they were not withdrawing from social networks and into the long shadow of social death but were active in their own (often) informal networks.

Conclusion

Upon first glance, the invisibilisation and marginalisation of older heterosexual people living with HIV have emerged in socio-historical terms. This has led to a fragmented sense of an ‘HIV community’ for this group to draw resilience. Yet, it would be overly simplistic to argue that respondents had withdrawn from society simply due to not attending traditional HIV services, and therefore facing the long shadow of death. Instead, respondents still found new ways in which to engage with their own sense of community, supporting their own process of active ageing and growing older with the virus. Since heterosexuals in the UK have often been ‘outsiders’ in the HIV community, they have withstood resilient adaption to living and growing older with HIV. Furthermore, despite lacking a “’community of experienced elders,’ as it were, to whom ageing with HIV can turn for evidence-based guidance or advice" (Rosenfeld, et al, 2014: 29), they found their own unfinished resilience as something that was formed when systems were changed to adapt toward their needs, using their own (sometimes limited) resources at hand (Ecclestone and Lewis, 2014). As such, all respondents engaged in new, creative, and unique ways to find a sense of support, and their own place in a wider (albeit more fragmented) HIV community. This will be further analysed in light of theories brought forward in this study in chapter eight, yet this theme with respondents opens up an important question. Despite the limitations of their bodies that were faced, as outlined in chapter five, and their non-traditional and more fragmented (though important) sense of community, what did this mean for their future goals and mindsets? The following results chapter will outline this final theme and its findings found in this research.

Chapter Seven: Changing Mindsets and Futures

This chapter will outline the third, and final, key theme from the data in this study. Respondents talked in-depth about their 'changing mindsets and futures' from their HIV diagnosis and process of getting older with HIV, with many presenting optimistic plans and strategies for their current and future lives. Whilst ART had played a significant factor in these changing mindsets, respondents found resilience in their process of ageing in different, creative, and complex ways. Wider social factors such as stigma and the uncertainty of the body were 'ever present' yet were mitigated by a range of strategies. Whilst the effects of ageing, the body, and stigma were not felt evenly (and wholly optimistically) by the sample, respondents had all engaged and mobilised resources to plan and prepared for their own future goal setting as the 'final frontier' of a cohort of people now growing older and ageing with HIV.

Ageing with HIV – the final frontier?

Many saw the process of ageing with HIV as having the potential to be not only a positive force in their lives and an opportunity to engage with new experiences, but also as an opportunity to lay foundations for younger generations who would grow older with HIV. Many recognised that other than some long-term survivors of HIV, they constituted the first generational cohort to grow old with HIV. Rebecca reflected upon this, stating that *"we are the final frontier"* (Rebecca), as did other respondents such as Brenda, stating "*Where is the precedent? We are the precedent"* (Brenda). Rebecca and Brenda were reflexive in that they recognised that they were part of a generational 'first' and so felt that they could "*help to pave the way, to make it easier for other people of a younger generation with HIV, to grow old with it"* (Brenda). Not only had some respondents viewed themselves as having a trailblazer approach such as this, but others recognised that there had also been a generational shift in social attitudes which enabled them to age differently.

Rachel had considered this and had delineated herself from previous generational age cohorts through her actions, seeing changes in societal views of ageing. Rachel summarised her thoughts about this below:

> *R* *"It's different now because, I mean I'm going to be sixty. I think sixty's the new forty (laughs). Not the new fifty, the new forty (I short laugh)… And [pause] things have changed so much through the generations. We're not behaving the way that sixty-year-olds used to behave maybe thirty years ago. You know? We're out doing things. Yeah. I think it's all changed now. I don't think it's a problem at this time. I think we're healthier now, we're living longer. I think we're more open to doing things that weren't expected of people of our age back in the day" (Rachel).*

Similar to this, Jessica and Brenda saw ageing as either a site of empowerment or playful eccentricity, both of which hinted at strong levels of independence. Jessica viewed her status of living with HIV as *"empowering"* (Jessica). This was especially felt after attending a conference for women living with HIV, which altered her mindset and led her to work with people living with HIV. She had support networks around her due to working in the Third Sector and was proud to be independent from a series of *"mistaken relationships in the past"* (Jessica), stating that *"I'm probably going to progress being a fiercely independent old woman wearing funny sports socks"* (Jessica).

Brenda, upon diagnosis in 2001 was given fifteen years to live, but refuted this in her story, stating that her ageing process was going to be one of empowerment:

> *R* *"I'm going to be a wise woman, I'm going to be a crone, I like this, I can do this, you know? I've got to an age now where I just don't give a fuck and I like that. I*

> *spent too long trying to have people show me that I'm worthy and get acceptance, and I kind of like being fifty. I'm going for a hundred" (Brenda).*

Whilst a number of respondents saw ageing as empowerment, change, and independence overall, which will be highlighted in this chapter, a small minority of respondents in this research did highlight some problematic elements of ageing and HIV. June found the process of ageing an issue in terms of her body feeling disassociated from her own mind, which felt younger than that of her body which was showing signs of ageing, leading to concerns about what this meant for her living with HIV. Similar to 'old age mask' theory, which highlights a contradiction between a stable youthful 'inner' self and a negatively perceived physical decline, or, 'the body as a cage' (Rapoliene, 2015: 4) June felt this increasingly. She stated:

> *R "Lately I dislike the idea of ageing because I'm more aware that I'm ageing.*
>
> *I Right.*
>
> *R It started showing or it started to come up when you really see the lines are not going away anymore with the cream and yeah, I, you tend to get, you know like when you start getting little aches and pains and you have to do your stretching exercises in the morning before you do anything much. So, I feel that I am ageing, and I really dislike it because in my head and in my heart I don't, I haven't aged, you know? And it's like the body is a different thing to the rest of me, you know?" (June).*

Whilst it could be argued that this happens to all older people, respondents such as June, who expressed these concerns linked it to their uncertainty around ageing with HIV and the uncertainties that it brings for them, making the unknown more pronounced. Echoing this, Olivia had internalised some negative ideas about the future ageing process which caused some anxiety and distress on her part and made her question what she would be like growing older with HIV. As a long-term survivor of HIV, she questioned what this means for her future bodily self. Ageing, HIV, and her uncertainties about the body, intersected often in her story and have resulted in anxieties about growing older:

> *R* *"It's because it scares us, of what we're going to become. That's what we're going to look like, and we don't want to face that reality. I mean I don't like to think about getting old… We don't want to see old people with HIV, because they're not meant to be there. I'm not meant to be here. I should've gone years ago and somehow I think it might've been easier because I wouldn't have all the other complications which are partly HIV and partly just getting older, you know? But we never, we never did see older HIV, never, because we never ever got to these ages that we're getting to now" (Olivia).*

Yet despite this, Olivia recognised that her mindset is *"positively changing"* (Olivia) toward growing older with HIV, which she viewed as a mental state that she did not previously feel. However, these mixed emotional states were able to make her feel more vulnerable on occasion, which she discussed below:

> *R* *"I mean I do get scared sitting in the clinic and see some of them coming in, and I think, oh god that could be me in ten, fifteen years. I do, it does scare me because I can see how they're struggling and I think, I didn't want this, I didn't want this, and in one bizarre, horrible way I thought, oh it's maybe a good thing that I've got this because I'm not going to get to that age. Now I'm having to face the fact that I may very well get to the grand old age of seventy or eighty" (Olivia).*

She describes the people ageing with HIV as something she sees in the clinics she attends, “*like they’ve lost all their sort of personality, their spark. They’ve become old people” (Olivia).* Similar to other research findings (Rosenfeld, et al, 2018) and old age mask theory, older people very often use techniques to measure themselves against other older people (as highlighted in chapter three). This is an engagement with an ‘othering’ process to set themselves apart from visible signs of ageing, stating that they are not like that/will not become that (Rosenfeld, et al, 2018). Though within this research, only a minority of respondents raised this, and Olivia most strongly, it is important to highlight these respondents were acutely aware of their *potential* frailty. This could create barriers to their active ageing in future, reducing their feelings of resilience and increasing their social isolation. However, this was not simply due to the normal ageing process, but it was due to the uncertainty of ageing with HIV, which represented potential concerns for the future.

Respondents professed complex relationships with their ageing bodies and ART medication, as seen in June and Olivia’s accounts and highlighted in chapter five. Whilst this had formed a tension in their lives, with many recognising that the body was a site of unpredictability and uncertainty, it was simultaneously a source of liberation through taking ART, despite it causing complications with their health and potential ageing. ART represented an opportunity for new beginnings and changing mindsets, which will be discussed next.

Changing mindsets – ageing and the impact of Antiretroviral Therapy (ART) in offering a ‘new life’

Most respondents viewed their life after their HIV diagnosis as offering valuable hope for their futures, aided by the development of ART in offering a *“new life ahead of us”* (Lydia). The impact of ART was expressed optimistically as they actively aged, leading many to feel that they had changed and grown resilience as a result of their diagnosis, and subsequent treatment. Several respondents expressed this viewpoint, stating:

R *"I really do have a genuinely good outlook that there is a life for us head. You know? Rather than just keeping your fingers crossed and hoping. The drugs helped that. I never thought I'd make fifty. Old age could be achieved" (Dean).*

R *"For me it's [HIV] now a bit of a non-issue. It's broadened my horizons, it's made me so much less judgmental, more empathic. But it's made me appreciate things more, you know? There was one guy at an HIV workshop who said, 'what skills have been honed with HIV?' and I thought that was great. It has empowered us, it has awoken us, it has made us better people" (Brenda).*

R *"To me, the world's my oyster at the moment as I get older. Frankly, now I feel stronger within myself. I think it's important to keep going, looking at new things, new adventures. Yeah, it's an adventure" (Rachel).*

R *"It's definitely given us hope." (James).*

Psaros et al (2015), in their study of women aged over fifty living with HIV in Boston, found that upon diagnosis, women described a sense of hopelessness which developed as they grew older, re-evaluating their beliefs, which resulted in a greater acceptance of their diagnosis. The women in the sample, from a range of ethnicities, described the importance of relationships and finding meaning in their everyday lives via support groups and volunteering. Psaros et al (2015) found that growing older with HIV meant a re-evaluation of beliefs and resulted in a greater acceptance of the diagnosis through engagement with networks and volunteering. Jessica held similar views, echoing the notion that the HIV diagnosis had changed her positively, which she reflected upon in her interview as she spoke at length about her initial volunteering and then working in the HIV Third Sector. Due to her HIV diagnosis, she moved her life direction toward working in the HIV sector after initially starting as a service user, which then led her to attend conferences and feelings of empowerment by meeting other women with HIV. This had a significant effect on her own resilience in dealing with HIV as she aged. How this changed her life course is expressed here:

R *"It doesn't make me glad that I became HIV-positive, but … it makes me realise that I'm glad that despite the fact that it changed my life completely" (Jessica).*

Other respondents echoed similar thoughts and did not see ageing with HIV as an issue which concerned them. Olivia was engaged in a number of activities, despite being a long-term survivor of HIV. Despite facing several health problems, however, she did not fear HIV and what this meant for her:

R *"It's not something that worries me, no. I mean I'm frightened of dying like everybody else is, but I don't see this HIV as a reason to be more frightened" (Olivia).*

Respondents largely spoke positively about their future, and of a shift in their own mindset, recognising the notion that there is a future and ageing with HIV. This was found particularly in Dean's account, who is a long-term survivor living with HIV. Dean likened dealing with the future of ageing with HIV to his strong work ethic, stating that:

R *"Because, I'm going to be honest, I've got a lot to now look forward to. I can look forward basically to getting old… I can look forward to old age. That, that there is a life for us ahead. Rather than just keeping your fingers crossed and hoping… I had to do something because otherwise we were going to basically sit around and vegetate. Which, I've never been one, because like I said I done sixteen-hour days. I cycled there, sixteen hours' work, cycled back and all that" (Dean).*

Dean continued about his ‘work ethic’ approach when speaking with excitement about ageing, despite the uncertainty of bodily changes. Dean recognised that there was a future ahead for those who are living with HIV due to the development of medical advances:

> *R* *“I didn’t know anything different. They just said, ‘take those tablets and get on with things.’ Which I think is all they could do. That is my, that is actually my default, what I call my default, is just keep going. That’s literally what I’ll [have] on my headstone if I was buried. Because there’s nothing else you can do. You know, you’ve just got to keep going. Or you just give up, and some time you would die” (Dean).*

This sentiment was also backed up by Olivia who spoke of a change in her own attitudes due to ART, enabling her to plan future goals as she was originally certain that she would not see a time when she would be able to grow older with HIV:

> *R* *“Yeah, well we’re not meant to get older are we? We were meant to die, and that, it has impacted. Well, what’s the point? I’m not going to make fifty. Never mind thinking now I actually might make sixty. So yeah, our mindsets had to change” (Olivia).*

Whilst the effects of ageing and HIV were not felt evenly, what was clear across the range of interviews was that all respondents had made significant plans for the future and had considered what their futures may look like for them as they move throughout the life course. Lydia spoke at length about her accomplishments and her active ageing as she described years of unknown health problems which were finally addressed upon her HIV diagnosis, and as such, was living healthier than ever, stating that *“It was like huge, it was so liberating” (Lydia).* In support of this, an HIV diagnosis has been found to allow older adults to achieve late-life stage goals and aspirations (McAdams, 2006) and this was certainly present in Lydia's interview as she achieved more after her diagnosis, which made her re-evaluate her life positively. As she stated:

> *R* *"I mean even though that consultant said that sentence to me, which has stuck in my mind, that 'this won't affect your life expectancy' she doesn't know whether that's true or not.*
>
> *I* *Yeah.*
>
> *R* *You know, she doesn't know. Obviously living with that untreated for thirty-one years has probably done some damage. Um, but what's the point in thinking about that? I could get hit by a bus. I could get, they could've told me 'you've got incurable cancer', you know? That would've been so much worse. So, I've just got to make the best of it" (Lydia).*

Lydia went on to state that doctors had informed her that she would have a near-normal life expectancy due to rapidly getting better and this led her to make some fundamental life changes to her marriage with her husband:

> *R* *"About two or three weeks after that I realised that I wasn't going to die, that I was actually, I'd got a future ahead of me, and that I actually didn't want to be with my husband (short laugh), which was how I'd felt before" (Lydia).*

The HIV diagnosis, and the thought of a longer future with ART as she grew older, were a source of great comfort and led to radical changes in her life and her identity. She went on to state that ageing with HIV does not worry her, as she had accomplishments to achieve and had learnt to appreciate life much more, including getting a tattoo, which was part of her 'bucket list':

R *“I mean, I went and got a tattoo, I was like doing my bucket list as quickly as possible. Having been faced with what I thought was certain imminent death, and I mean I really believed that because I was so ignorant about HIV, now that I’ve been given my life back, you know, that’s how I feel, I’m going to bloody make the most of it. So, no I don’t think it does worry me that I’m one of the ageing people with HIV. I mean, the fact that I’m so much, physically I’m so much healthier now than I was when I was thirty, you know, is encouraging” (Lydia).*

ART had a significant, but complex effect on respondents, as something which offered opportunities to live and age with HIV, but simultaneously being an ever-present threat with their changing and ageing bodies. Nonetheless, all of the respondents in this research felt that HIV had allowed them another chance to grasp opportunities to counteract the potential shadow of social death and the social isolation that was found less vibrantly in the experiences of older MSM ageing with HIV (in chapter three). This significant change in the respondents was thoughtfully summarised by Rebecca when asked about what ageing and HIV looked like to her in the post-ART era, Rebecca stated that *“we go parallel but not, we go in the same direction but not on the same track”* (Rebecca). ART had allowed respondents to make plans for the future, despite facing limitations of the body and access to a wider mainstream HIV community, which will be discussed next.

‘Possibilities’ – making plans and goals for the future

All respondents were involved in new transformative ventures and a range of activities in their lives which had emerged as a result of their ageing, status, and agency to seek out new challenges in a social world where they were not anchored to traditional HIV communities, as outlined in chapter two. To do this, many respondents pulled upon a wealth of social capital and available resources to develop their resilience to enable transformative and future-orientated experiences. These experiences were varied in their approaches, such as travel, investments, new projects, starting charities, creative pursuits, and political engagement, which will be discussed next. Amongst this, some respondents saw their HIV diagnosis as nothing to fear or worry about, and others ventured into new challenges as a *result* of their status.

Rachel discussed hopeful *"possibilities"* (Rachel) for the future, as well as taking on challenges and activities within the present to prepare a future for herself. Rachel discussed living abroad in the future, had involved herself with accumulating crypto-currency, and had attended a number of property training courses. She was looking for a property to invest in abroad, as she explained:

R *"I think that's what I've been looking for all these years. Not necessarily a partner but just having a purpose and feeling fulfilled.*

I *Yeah.*

R *I've done property training courses, I've attended a course on, on trading, and I, speaker training and it's crazy. I mean I talk about living abroad and I watch these programmes like A Place in the Sun, Home or Away. And it's always, the majority are partners. You know, looking for that place in the sun or whatever. And I think, how am I going to do it on my own? I, I don't like living on my own. But some people do it. Maybe I can. It's possible. Possibilities. Like going to the property training. Initially, I did that on my own. You know? So that's something years ago I wouldn't have done. I think it's important to keep going, looking at new things, new adventures. Yeah, it's an adventure.*

I *That sounds like it has been exciting.*

R *It has been. I did have some money. Um, I had an investment where I was making maybe two thousand, I got up to two thousand euro a week. I am not rich, so this was huge to me. Getting out of my comfort zone will allow me to travel and live abroad" (Rachel).*

As explained, Rachel had found a sense of personal resilience due to her identity as living with HIV through beginning to weigh up her possibilities, which were mental outlooks which were not previously available to her. Rachel saw the process of ageing as goal setting, having dreams and visions for the future and continuous reassessment of her identity, which led her to several activities to enhance her personal development and plan goals for the future.

Lydia, who described her HIV diagnosis as *"liberating"* (Lydia) also sought opportunities to travel widely with her friends and recent husband, aiming to go to a different destination each year. This was made possible due to her health improving after being diagnosed late, after decades of illness. This allowed for a new mindset and outlook on life, which she described as far removed from her previous existence of sleeping often, not getting out, and feeling ill and tired all of the time due to her *"mystery illness"* (Lydia) which was later discovered to be HIV:

> *R "What do I want to do? I want to travel. Travelling is my joy in life, seeing the world. So, you know, there are a lot of places still to see (short laugh). So, I usually try and make sure I go to somewhere I haven't been before in the world once a year as a minimum. So, I'm off to Norway in September. Because Norway I think is one of the only European countries I haven't visited" (Lydia).*

Due to engagement with online technologies and support groups online such as social media, Lydia had met five women on Facebook living with HIV in the USA (whom she had not met before) and she undertook a road trip with them across the USA. Travel and staying active allowed for a new change in attitude to increase her own goal setting, as she says below:

> *R "And the other thing that I really want to get across is that this has enriched my life so much. Having HIV. It's broadened my horizons, it's made me so much less judgemental, more empathic. I mean I was pretty empathic anyway, being a [job*

> *disclosed] but it's made me appreciate things more, you know? It's, I feel like I've had wonderful experience and met wonderful people. I had a fantastic trip to the States at the end of 2015 where I met up with five women there living with HIV. We had this road trip and we drove for thousands of miles and went to the beach. And went parasailing and all sorts. We did everything, you know? I wouldn't have had that without having this disease" (Lydia).*

For Lydia, as an older woman having HIV has enriched her life and due to this she saw new potentialities for not only travelling herself, but also in helping others through altruistic acts. One of these acts was to send HIV medication to a man living with HIV in Syria during the civil war after connecting with him on Facebook, stating *"I can start to think about others now I am back on track. I'd spent so many years feeling sorry for myself. This was the least I could do, and you know what? He was an older person too and I thought 'you can't just enjoy your own life now you've changed, help other people to do theirs"* (Lydia). With similar feelings of altruism to Lydia, June was also mobilised by her former experiences in a nation-state in Sub-Saharan Africa where she had originally lived and met her late husband. Due to her frequent travels to that nation-state and seeing the effects of HIV on others, she felt she was *"finally ready to give back"* (June) becoming inspired to form her own charity to help other people living with HIV. At the time of interview June was putting together the formal constitution and charity website, and learning website development skills to do this.

Not all respondents were able to plan foreign travel due to financial circumstances, and so others found different ways in which to spend their time pursuing active tasks and various pursuits. Rebecca looked after her partner as a career, but also found ways in which to fit in a busy lifestyle of volunteering:

R *"I'm very active. I do DIY. And then after a while I start to say 'mmm, looking for volunteers?' I go and to volunteer. Ah as I said I was, until last week, an equality opportunity officer, I was always meeting with [local authority], with the NHS, mentoring, training" (Rebecca).*

Some respondents also wanted to stay closer to home rather than travel abroad, and so chose to actively plan to find an ideal place of retirement in the UK, such as Dean, as he states:

R *"Because I'm, well the funny thing was actually we had our honeymoon in [seaside resort]. Because I love it. I'm hoping to retire there one day. So, one day I can move to [seaside resort] to enjoy my retirement" (Dean).*

Other respondents were engaged in creative and musical activities, such as Jessica who had published articles as a voice of a woman living with HIV, stating *"I've started writing things. I find it quite a release. I am planning to write a book, which is very exciting"* (Jessica). Similarly, James used his own creative energy to join a choir, had met his partner through it, and had recorded an album of their songs which were released online:

R *"Because I'm singing in a choir, well decided to join a choir and sing, not that I'm any good, but it just gets you out of the house. For like, you know, for a couple of nights a week. But we did a recording. And it's being, it's being released next Monday week" (James).*

Brenda was also working on the campaign trail for a politician, alongside her full-time work and volunteering:

R *"I've been politically active for [politician] and supported him, I've been talking to people, getting them politically active. I am not sitting indoors and withering away, I am out and about, always keeping busy. I've a future to think about these days [laughs]" (Brenda).*

Similarly, to June, Lydia and Rachel, further examples of respondents who were active in their goal-setting and activities were Jessica, James, and Brenda. With a 'future to think about' as Brenda put it, all understood that their support may not come from the traditional HIV community, as discussed in chapter six. However, this had led many to mobilise their agency and resources at hand to engage with ageing and their resilience building, despite a lack of a wider HIV community with which to draw on resources-wise. Alongside changing mindsets and future goal setting, some respondents also found space in their lives for relationships and sexual intimacy now that they felt more secure through ART, as well as their increasing self-confidence.

Connections - relationships and intimacy

Most respondents only briefly touched upon their current and future thoughts about relationships and intimacy. Six of the nine respondents were in either new or long-term relationships or marriages, at the time of interview. For Olivia, she felt a source of empowerment from her close and tight-knit family, being the only respondent who was not out about her status to anyone else, other than her husband:

R *"Yes, I've got the illness and yes, probably I've got a lot more complications than most. But I've got a lovely husband. I've got a lovely child. I've got a good life" (Olivia).*

After finding out her status and leaving an unhappy marriage of many years, Lydia discussed chatting to a man on an HIV-positive dating site as being something which boosted her confidence in starting to find intimacy in others:

> R *"I hooked up with some guy from [location], we are both positive. I drove so fast as I could, met him and within five minutes we were shagging [laughs]. It was like confirmation of being alive and that you can still have sex. It made me realise that my life's not over" (Lydia).*

This moment led to a reinvigoration for Lydia who *"starting dating again. It was wonderful. I met a man in a local pub one night, we got talking, connected about everything and he was great about my status"* (Lydia). Lydia had since married the man from the pub and the marriage was still intact at the time of her interview. Rachel felt a level of comfort in dating as well, though it was not a priority for her, stating that as an older woman she had gained confidence through learning her status after the death of her late husband. But Rachel had started to consider dating as an option now:

> R *"I have met some men for nice dates and meals, but I am too busy [laughs]. Reaching my goals are more important to me right now, but you know, having someone to share them with later on would be lovely. I don't live very well alone, and so if I move abroad I erm, I would like to share that with a man" (Rachel).*

Brenda goes on to say that without feeling empowerment from her HIV status she would not have met her now long-term partner by approaching him at his place of work in a local market, adding: *"So now I'm in a kind of proper-grown up relationship I call it, at fifty, finally. Complete honesty, just respect. He is the one so, you know, there's a future there"* (Brenda). Being at ease with her HIV led her to reflect on her growing confidence to initially approach her now partner, as well as it impacting on her wider life choices, as she states:

> *R* *"In a way, I've reached an element of gratitude for my HIV, which can sound really weird to some people. Because it's directed me to a better lifestyle. I don't think I would've gone for this [occupation] man in the market if I wasn't HIV. So, you know, I think, I don't think that would've happened. I don't know, I don't know how I would've aged without it, but it's helped me grow up. It's helped me be responsible for my choices, it's helped me take responsibility for my health, like not smoking. I'm grateful for that… because that's definitely changed my relationship with my children as well" (Brenda).*

Amongst the male respondents, James had met his partner through the new choir, and he hoped she would be his fourth wife: *"I'm hoping we will grow old together. I mean, I'm in my seventies now [laughs] but it's never too late, you know?"* (James). Dean had also used a popular dating app for people living with HIV, feeling that he was not *"too old to date"* (Dean):

> *R* *"Now I am in a better place and ready to retire, I want to settle down. I can look forward to basically getting old… because the medication will keep me going and, ah, therefore it's worth looking at relationships, you know?" (Dean).*

For some respondents, connection for them was represented not only by relationships and intimacy, but also through a more spiritual or religious connection. This was further framed in some respondents' accounts as being about religion and belief, which will now be discussed.

Connections - religion and spirituality

The benefit of religious practice has been positively highlighted by some authors as something which enables those living with HIV to improve their mood levels and depression, which are commonly linked to their own HIV status and HIV medication (Vance, et al, 2011; Chaudoir, et al, 2012). Participants in this thesis, who were anxious at times about their HIV status, often sought solace in religion and belief, with three of the nine respondents professing active spiritual or religious leanings. These respondents saw it as a site of identity transformation and support.

Research has evidenced that older people living with HIV have also been found to draw upon renewed spirituality to cope with their HIV diagnosis as spirituality and prayer can be powerful coping mechanisms for people living with chronic illnesses. Due to this, people have the capacity to develop ‘protective factors’. That is, conditions that buffer, interrupt or prevent problems from occurring, improving the resilience of people. This resilience is both internal such as personal religious practices and prayer, but also external such as neighbourhoods and community; very often these can be religious support communities (Siegal and Schrimshaw, 2002; Greene, Galambos and Lee, 2003). This was highlighted by June, in particular, who had a transformational experience with finding faith later in life, stating that *“It made a huge impact on me. It has changed me now that I can plan for my own future. And then for the first time I felt I belonged to a community”* (June).

June had *“never really seen myself as particularly religious”* (June) until the previous two years leading up to our interview, where she had recently used religion to help her cope with her HIV status, and to engage with a new community of people. She explained a powerful moment in her life when she went to church:

> *R* *“I had passed this church when I was going into [city] and they advertised an alpha course. So, I always thought, maybe one day I’ll do an alpha course, but I*

> *never really set foot in a church. And then one Sunday I just went, and I was just going in there saying (tearfully) 'oh I need somebody to pray for me', you know, crying, and then the guy at the door, he called somebody. They were praying with me. When I left he remembered my name and I was really impressed that, you know, they care so much. And then the woman who prayed with me, we were in contact continuously, you know? She kept an eye on me, you know? How I'm doing, trying to build me up. She's one of my best friends now. They really helped me out to have hope again and not to let this, you know, that my life is not at the end because of this. They empowered me so much, you know?... I've got strength. It made a huge impact on me" (June).*

Rachel attended a Black majority church in her city where she was not open about her HIV status due to *"stigma in the African community"* (Rachel), but she used it as an opportunity to reflect and pray. *"It's not something that I go to all the time [church], but I get what I need from it. My husband is now dead, my kids have moved out, and though I've got my friends, I need a bit extra"* (Rachel). Rachel found the church provided comfort:

> *R* *"It's like it offers me that extra, like I said. I can't tell people there about my status except the Bishop who is kind, but that doesn't matter to me, it really doesn't. I go for myself, for me, it builds me up when I face tough times, have aches and pains, or feel a bit low. I get that boost and start planning all of my things again [laughs]" (Rachel).*

Brenda also discussed a developing spirituality as she regularly attended a local Buddhist monastery, initially to deal with her diagnosis. This had developed in her reflecting on her life and given added meaning. She goes on to say:

R *“I mean I was always a bit of a hippy [short laugh], but the Buddhist monastery is nearby, and I started going. My life has been chaotic in many ways, you know, dealing with my HIV, the kids, all the restless movement I’ve had in my life. This grounded me and I’m accepted there. So, I go, I sit down and meditate. I have a lot more to be thankful for now than I ever did. Karma has been a bitch, but now I feel I have some meaning from all of this” (Brenda).*

Spirituality and religion allow individuals living with HIV to actively engage with social rituals which serve as buffers to life stressors by allowing individuals to interpret life experiences in the context of their beliefs (Grodensky et al, 2015). These can then provide meaning and purpose to older people living with HIV. Siegel and Scrimshaw (2002) in their interviews with older adults living with HIV revealed that religion and spirituality influenced the regulation of emotions. Drawing upon religion and spirituality enabled them to make sense of their diagnosis and lives, which increased feelings of control over their HIV status by providing emotional strength, building resilience, and negating feelings of helplessness and isolation. Religious networks used by Brenda, Rachel and June provided them with a sense of resilience and control and enabled access to wider communities and support networks.

Stigma as ‘ever-present’ and stigma management strategies

Whilst the accounts so far present respondents in a largely optimistic framework as they negotiated their lives, ageing and resilience, they were aware that HIV-related stigma was a factor in their current and future lives. Whilst the respondents faced complex interactions with their changing bodies, and most felt either marginalised or withdrawn from traditional HIV support services, they all had stigma management strategies to stay engaged and not to withdraw because of it, which this section will explore.

June, amongst other respondents, recognised HIV-related stigma as *"ever-present I guess. I know it is there. I am aware of it, but I don't let it get to me. I live my life and don't get bogged down with it"* (June). June's refusal to 'not get bogged down with it' was her self-management strategy of not defining herself by stigma. She felt that her HIV status actively self-perpetuated internalised stigma, stating:

R *"I have had HIV since 2004 now. I used to go to groups and talk about stigma this, stigma that, until one day I thought 'hang on a minute' it's me doing this, not erm, the people around me. I'm not saying it doesn't exist, it does, and some people are affected by it badly, erm, but the way my life is now if I were to dwell on it, I would see stigma everywhere. Why would I do that?*

I *Yeah.*

R *I mean, it becomes something that you will constantly do, you'll see it everywhere. I mean, I refuse, I won't let that happen to me now. I'm happier with myself. Yes, stigma is important, but if we erm, define ah ourselves with it, then we're headed to nothing" (June).*

Similar thoughts about internalised stigma and self-perpetuation were echoed by Rebecca who felt that stigma became a form of self-labelling: *"I want to underline that the stigma is related to, ah, first how you deal with it, because the first person who gives stigma is yourself"* (Rebecca). When asked if she faced stigma, Rebecca simply said *"no"* (Rebecca) and when asked why she responded:

R *"It is something we put on ourselves. We need to stop this. If we read all the research then we would be depressed. Yes, it's bad but I don't have stigma. I am at a stage now where I don't care" (Rebecca).*

The ‘I don’t care approach’ was echoed by Lydia’s account. Lydia was unapologetic and she was out about her HIV status to work colleagues, friends and wider family. She also managed stigma by rejecting any external or internalised stigma, stating: *“It’s the stigma that gets people. I don’t feel stigma because I don’t give a shit, you know?”* (Lydia). When asked what this means, she responded:

> *R* *“It means I don’t give a shit; people can think what the hell they like. I’m happy with myself. I’m a decent person. I care about other people. I work hard and I live my life. I don’t think having HIV is my fault. I also don’t think it’s the fault of the guy that gave it to me” (Lydia).*

Brenda was also very open about her status, as her stigma defence strategy which she operationalised by altering people’s opinions through social media. Part of this involved Brenda posting ‘positive’ posts about HIV on her social media pages, which she explained:

> *R* *“If I repost anything [on social media] on HIV it’s always a positive. It’s never a negative. It’s always a good story and a way to tackle stigma. So I kind of surround myself with the good stories. I think that’s important as it’s not shared, these are the good stories. It’s much easier for people to be like, ‘well we’re all going to die and we’re going to live in these care homes and no one’s going to love us.’ Good news is like Teflon, bad news is like Velcro, sadly, so I make it my aim to make good news into Velcro” (Brenda).*

Other respondents, such as James and Dean, saw hope for the future in what they perceived to be altering social attitudes around HIV and stigma, which were their coping strategies to seek comfort in changing public attitudes toward HIV. They felt that these changing attitudes were reflected in what they saw and experienced around them:

R *“I feel the younger generation are more equipped to deal with HIV than the older generation. Older people look down their nose at you [clears throat]. All my daughter’s friends know, and they are younger, and they say hi, we talk about it like we should be doing. I don’t let it [stigma] get to me, live and let live” (James).*

R *“I don’t see there being too much stigma around now. The ordinary person in the street, they know things have got a lot better. I feel free from stigma” (Dean).*

Many of the respondents were able to motivate various strategies for managing stigma, which was interesting in the analysis of this thesis’s findings as much of the research into older MSM shows stigma to be a felt and pressing issue. For the long shadow of social death to lead to withdrawal and limited opportunities, stigma is a key part of this process, however, this was not widely felt in the sample of respondents interviewed for this thesis. There is space here for reflection on heteronormative privilege, however, as the process of marginalisation of heterosexuals from the socio-historical impact of HIV somewhat isolated heterosexuals from a lot of wider (and harmful) HIV narratives. Conversely, this also often means that some heterosexuals today do not face some of the unique stigma which still impacts MSM. Due to this, it could further be argued that the self-management strategies of stigma management as outlined in this thesis, were easier to accomplish by the heterosexuals in this study.

Conclusion

Overall, this research found significant support to show that respondents were actively ageing, despite some occasional reservations about their bodies declining. As part of the process of unfinished resilience, they recognised their own agency in driving their lives forward and managing stigma, but they were similarly bound by the wider social world and the limitations of medical science to address questions about HIV, ageing, and their bodies. Nonetheless, networking, planning, goal setting and finding identity through activities and changing mindsets is a core theme in this research, emerging strongly from all respondents. To different degrees, all respondents used their diagnosis to develop more positive present and future mindsets through engagement with religion, relationships, travel, and personal and career goals, which reflected an unfinished and continuous process of developing resilience. This seemed to rebut the effects of stigma and the long shadow of social death and impacted the potential for respondents to feel systematic losses and withdrawal. Now all three themes and their findings have been presented, it is important to analyse these more deeply in light of the theoretical approaches brought forward from chapters five and six. These important points of analysis will be examined in the next chapter.

Chapter Eight: Analysis of the Findings

Introduction

In the previous findings chapters (see chapters five, six, and seven), three themes were outlined from the data, of 'changing bodies,' 'changing communities,' and 'changing mindsets and futures'. Although some of the theoretical and conceptual ideas which will be analysed in this chapter were touched upon briefly within these former chapters, it is now important to critically examine a deeper analysis of the theories, concepts, and research brought forward. This chapter will be split into three conceptual parts in light of the data from respondents. Part one focuses on active ageing, part two on unfinished resilience, and part three on the socio-historical invisibilisation of heterosexuals within the wider HIV narrative, its links to stigma, and the long shadow of social death. This will then all be brought together to attend to the data as a whole. However, it is important to first situate the findings in light of active ageing and what this means for older heterosexuals, which will be discussed below.

Part 1: Are older heterosexuals living with HIV, actively ageing?

In chapter three, some key questions were asked about active ageing to take forward in this study, they were:

- Do older heterosexual people living with HIV actively age, or do they disengage?
- What barriers, issues, and threats do they face in light of active ageing?
- When they face structural problems, how might they overcome them?

Before these questions are addressed, it is important to re-cap on active ageing as an approach. As discussed in chapter three, the active ageing approach advocates a more active part in the ageing process rather than traditional disengagement theories. This active ageing approach regards an individual's experience of ageing as subjective and unique, and so individuals can pursue desirable goals by choosing interests and activities that suit their abilities. Therefore, they can compensate for their limitations (Baltes and Baltes, 1990). This theory assumes that the older person’s desire for social interaction is balanced against society’s need for active citizens, and this is evidenced in that older people form relationships, maintain personal interests, set future goals, and sustain their well-being (Tanner and Harris, 2007). This approach recognises that deterioration within the biological body will still occur, yet the individual who is ageing will attain chosen goals desirable to them, rather than a social withdrawal as represented by disengagement theory. Indeed, there is evidence which highlights that a majority of active persons in later life are as satisfied as younger people; due to increased emotional satisfaction, they tend to become more satisfied with personal relationships and are more likely to feel increased control over their emotions (Butcher, 2003).

In short, the active theory of ageing proposes that older adults are happiest when they stay active and maintain social interactions. These activities, especially when meaningful, help older people resist the social pressures that limit an older person’s world. It assumes a positive relationship between activity and life satisfaction and predicts that older adults that face role loss will substitute former roles with alternatives. This active ageing approach examines how individual agency is not lost, as older people make life choices and decisions, despite wider social structures around them shifting or potentially limiting aspects of their lives. As such, active ageing encapsulates the complex interplay between structure and agency, allowing for both (Marsillas, et al, 2017). Active ageing situates the findings within the themes discovered in the research and as a concept is used to ask to what extent the respondents in this research were engaged in what could be constituted as active ageing. One of the key issues raised as a barrier to active ageing was the uncertainty of the ageing process and HIV on respondents' bodies, which will be discussed below in light of this theoretical grounding.

The body as a threat to active ageing?

There were a number of threats posed to the respondents' active ageing process, which were found notably in the two themes around the changing nature of their bodies, and their access to a wider HIV community. However, respondents found ways in which to counteract the threats they faced. With this in mind, the changing and uncertain nature of the body growing older with HIV will be discussed first.

Increasingly, medical research points to the fact that the interaction between HIV and ageing presents highly complex clinical challenges, and the diseases and conditions of ageing present earlier or more severely in people who also have HIV (Power, et al, 2010). Furthermore, data also suggests that older patients are more likely to experience side effects from antiretroviral therapy (May, et al, 2011; May, Gompels and Sabin, 2012). Also, even when the immune system is stabilised by the use of ART, HIV can accelerate the effects of ageing, especially in relation to cognition (Effros, et al, 2008; Desai and Landay, 2010; Deeks, 2011; Roger, Migliardi and Mognone, 2012). These factors are more likely to lead to early onset of frailty and diminished functional performance. Ageing with HIV has been framed as ‘unchartered territory’ (THT, 2017) and as the first and diverse generation starts growing older with HIV, HIV will present its own issues regarding the physical body and its interaction with the ageing process. Therefore, older people may face a range of new and unique physical experiences and challenges as they age which have yet to be identified and explained by research (Rosenfeld, et al, 2012).

A majority of the respondents in this research saw HIV and ageing as either a problem they face now, or something that they foresee happening in the future with their bodies. Initially, it could be argued that a mix of HIV, ageing, and the body would be diminishing for an active ageing process, facilitated by certain enablers such as poorer health outcomes, which would aid this diminishment. Three key factors did emerge, which represented threats to active ageing for respondents, which will now be discussed.

The first threat highlighted by the respondents' lived experiences was that of late HIV testing due to their heterosexual demographic. This was partly due to the respondents themselves not testing for HIV, seeing it as not applicable to them, but also due to interactions with medical experts not offering HIV-specific advice and support when individuals presented with symptoms. This feeling of being 'overlooked' was prominent in the data from several respondents, such as Dean, Olivia, June, and Rebecca, who felt that their needs were not acknowledged, and that their ageing with HIV had led to a range of comorbidities later in life. Within their ageing process, they had no community of experienced elders (Rosenfeld, et al, 2014) in which to draw on comparisons of ageing with HIV, and so used a process of reflection on their peers, which they viewed as physically healthier than themselves. Due to uncertainties with ageing being accelerated by the HIV, and the development of additional health issues, many faced a series of health-related losses which had the potential to lead to disengagement from their social life (Norwood, 2009).

The second threat could be found in factors such as a lack of knowledge about HIV and ageing from medical staff, viewing them as a medical puzzle, in which respondents faced anxieties due to the unknown nature of growing older with the virus. This was seen powerfully in the accounts of June, James and Brenda where they felt anxiety, which was also shaped by wider social factors such as cuts to HIV specialist support, leading to more generic services by GPs. From respondents' accounts, it was felt the GPs did not have the specialist knowledge needed. This had the potential to affect respondents' active ageing in a number of ways. Firstly, this shift represented poorer health care for the respondents and a sense of growing older into the 'unknown'. It also raises issues about whether GPs, who do not have specialist knowledge about HIV, will continue to recycle the pattern of overlooking heterosexuals who display symptoms of HIV. Ageing and HIV were viewed by respondents as complex and incompletely understood and this also accounted for their own uncertainties. As Rosenfeld et al (2014) argue, the global gap in knowledge around ageing and HIV has produced what they call 'experiments in living,' as respondents involved in this phenomenon navigate ‘uncharted territory’ with medical science. However, the often poorly understood nature of ageing is often framed by clinicians and scientists as only a temporary gap in technical knowledge, showing the current limitations of medicine. Something which is in contrast to those living with the virus, which provoked chronic uncertainties which permeated their everyday lives and ideas about the future. This gulf between medical experts and the respondents was clearly at play within the findings of this research. Whilst the formal medical services may not be providing the support and information needed by many older people living with HIV, the role of HIV support services external to medicine, becomes crucial.

The third threat to respondents, felt strongly by Olivia, June, and Lydia, surrounded narratives given to them by medical and healthcare experts when seeking HIV support. Intertwining with the medical puzzle narrative presented to the respondents as already discussed, they also felt that they were often given a glib response by institutions as to what to do next in light of their uncertain bodies, which was presented to them via a ‘living a normal life with HIV’ narrative. This narrative led to a scepticism by some respondents, as they reflected upon their peers' health and compared it to their own, seeing a rise of additional health factors framing their own ageing, but their poorer health outcomes being overlooked by the medical world.

There is considerable evidence that shows that the body is significant in terms of moral or ethical concerns over what makes a ‘good life’, in relation to health and illness (Butler, 1993; Shilling, 2003; Turner, 2008). The concept of embodiment draws attention to the relationship between the physical body and its centrality to our sense of self, our experiences and relationships which are shaped by our bodily engagement with the world. This fusion of mind and body, or embodied experience of the world, means that bodies are never neutral and are imbued with meanings of difference, whereby the body is monitored and controlled inside and outside of medicine (Rose, 2007). This embodied experience of HIV, its management and its conflict with other illnesses has led to McGrath et al (2014) defining chronic HIV as a new ‘social space’; with the unpredictable body taking centre stage in social spaces (such as hospitals and healthcare spaces) and causing anxiety on the part of the person living with it. Official institutional responses to the constantly fluctuating condition of the body are not relieved by the unknowns of ageing with HIV, and the lack of knowledge amongst healthcare professionals. McGrath et al’s (2014) notion of HIV as a new ‘social space’ within medicine was clear in the research. Respondents expressed concerns and anxieties about their physical bodies and embodied experience of living with HIV, whilst navigating changing social structures whereby medicine showed its own limitations, which increased their anxiety as a result. This did present tensions in their lives, however, in that respondents felt a sense of agency through ART which enabled them to manage their bodies on a day-to-day basis, but this led to a paradox as highlighted in chapter five, in which respondents felt that their bodies were both ‘controlled’ through HIV medication, yet ‘uncontrolled’ in what the future had to offer.

However, whilst respondents faced these threats, they found ways in which to mitigate against their effects. As stated in chapter two, a number of studies have shown older people living with HIV as being more resilient in coping with life with the virus and have shown positive effects of growing older with HIV (Shippy, 2004; Ribeiro, Kylma and Kirsi, 2012; Wallach, et al, 2019). One way the respondents did this was to feel a sense of control over their lives due to the advancement of HIV medication through ART. This alleviated the stresses of the unknown changes to their bodies as they age with HIV. Many used ART as a ‘narrative anchor’ (Rosenfeld, et al, 2021) to evaluate their quality of life and the impact of ART on it, whilst also recognising that elements of growing older were problematic. The respondents also used a technique of ‘pros and cons’ as a key feature in their active ageing and a balancing method in which to mediate and balance out an uncertain future in terms of their bodies, yet remaining cognisant that their lives and futures were also significantly enhanced by ART. This narrative anchor of ART offered to balance, mediate, or compensate for the wider personal health challenges that they faced. Respondents weighed significance to ART as a positive factor, and they were able to use their own conscious effort to focus on the factors that gave them opportunities to actively age. Additional support for respondents came from their own sense of community, which aided their active ageing, which will be discussed next.

Active ageing and engagement with community support

In terms of active ageing, the theory contains a set of domains; such as the low probability of illness and disability, high physical fitness, high cognitive functioning, positive mood and coping with stress, and being engaged with life (Rowe and Kahn, 1987; Fernandez-Ballesteros, 2008). These definitions are coincident with what lay older adults consider as the same thing, such as remaining in good health, feeling satisfied with life, having support networks, taking care of oneself, and adapting to changes related to ageing (Fernandez-Ballesteros, et al, 2008). Regarding the respondents interviewed, whilst the body represented a site of unpredictability, this did not affect the active ageing of respondents in the study, in terms of engaging in support networks in which to actively age. Whilst this may have created barriers in terms of a lack of a wider heterosexual HIV support community, felt sharply by the female respondents from a structural point of view, it also allowed them to use their own agency and active ageing to find unique ways to navigate and reconfigure their own social support. This enabled them to build up a sense of community where they felt one was absent.

What emerged from this theme in the research, is that a heterosexual HIV community was felt to be lacking for many of the women and so they sought their own community elsewhere in structures of their own making. Due to HIV support services seeming to be too medically driven, poorly represented, unequal in their power relations, or led by a perceived ‘doom and gloom’ narrative, respondents had framed them as sites for resilience depletion and so largely avoided them. In lacking a clear heterosexual HIV community in which to seek support, most of the older women had formed their own communities through online technologies and less formal support services to more network-based models. They navigated with agency, a largely (for heterosexuals) absent or unsuitable social structure in terms of the traditional HIV support groups and community, in order to network with others with similar needs.

The more traditional-led HIV group support services were not used regularly by most respondents, especially female respondents, as they represented a site where they felt isolated, uncomfortable, were unequal in terms of power regimes, and were put off by the perceived negativity of others. Many female respondents had ideas about how the groups should operate in terms of presenting a more positive, resilient image of HIV and ageing. As stated, some women had taken it into their own hands to run, or be part of, often short-lived or creative groups for older heterosexual people living with HIV. In this way, they challenged what they saw as an overwhelmingly negative narrative in organisations. Due to the observed lack of will from the HIV heterosexual community to mobilise, and the perceived dominance of MSM leading organisations (around their own needs), this led many respondents to stop using traditional methods of support. Added to these factors was a perceived invisibility of heterosexual literature from organisations, and a lack of identification with other members in groups. This led many of the respondents to withdraw from traditional services and move to online, to WhatsApp and social media groups instead, as part of a renewed active ageing response.

As discussed in chapter six, online support groups for people living with HIV were mentioned by many respondents, especially social media groups. Davison et al (2000) investigated the pattern of online support group activity for different health conditions and reported that individuals with HIV and AIDS were 250 times more likely to participate in an online support group compared to those with other illnesses, such as hypertension. Some findings evidence such online support reduces the sense of loneliness experienced by members (Sillence, 2013), and allows some control over their life (Mok and Martinson, 2000). Members reported that participation in online groups reduced their fears and anxieties associated with HIV, with the emotional support reducing any emotional discomfort and negative effects of other stressors (Pheonix and Coulson, 2014). However, little attention has been given to understanding how participation in HIV-related online support groups may empower group members and in what ways (Pheonix and Coulson, 2014). In the case of both the male and female respondents in this thesis, their experience of such was very positive.

“When networks became diminished or untrustworthy, these respondents constructed a different network that could sustain them” (Poindexter and Shippy, 2008: 730). Poindexter and Shippy (2008) state that these HIV networks are usually ‘fragile,’ yet in contrast, all respondents viewed living with HIV as empowering and a form of inspiration, connection, and an opportunity to make changes in their lives and plot future goals. Having been forced into a fragile circumstance, participants refined and reidentified themselves in light of growing older and living with a stigmatised condition. They increased the use of support mechanisms and their own social support to create new networks where previous ones did not fit their needs, forming alternative ones. However, whilst these were ‘fragile’, in the sense that everyone felt that they were at risk of bodily insecurity, instability, and uncertainty (to varying degrees from respondents), their networks were resilient; in that they presented opportunities for non-traditional support methods, which led to transformative experiences for respondents. Many of the older people who are now living with HIV in the research were also using online social networks to plot life decisions and goals, going against the narrative of age as fragility and disengagement, finding identity construction both as a process of unfinished resilience and therefore actively ageing as an outcome.

To some extent, it could initially be viewed that the uncertain nature of the future of their bodies, or a lack of traditional HIV support, were factors which are symptomatic of social withdrawal due to a reduction in forms of being able to engage with society as older people, and therefore evidence of disengagement theory. However, this was not the case, as most respondents were *actively ageing* and were involved in forms of HIV support that were *different* to that of traditional HIV support mechanisms and groups (except for one male respondent, who still used traditional groups, but also used other non-traditional support mechanisms such as a choir, outside of this). These were not fragile or unstable social networks as evidenced by Shippy and Karpiak (2005) but instead, *were changed and reformed to suit their own needs and as a reaction to the marginalisation that they felt from the larger HIV community.* Respondents presented their lives as engaging readily in firm, supportive, and rewarding networks within their sense of new community. Furthermore, they used tactics to avoid the negativity around HIV and used their own agency to withdraw from services which they viewed as supporting negative narratives. Disengagement theory can be refuted amongst the lives of the older people in this research, as respondents reported HIV as something which changed their mindsets toward ageing during the life course. This instead became a site to develop and navigate their active ageing support networks.

Actively ageing, changing mindsets, and future goal setting

From some of the evidence presented, it would be reasonable to assume that if respondents felt that their present and future bodies were uncertain, and prone to ill-health, then deteriorating mental health would accompany this. Yet feeling part of a ‘final frontier’ as Rebecca called it, older heterosexual people living with HIV were setting clear goals and direction in their lives, as shown by the respondents’ interviews, showing an engagement with the active ageing process, which was leading to better mental health outcomes.

All respondents had plotted future goals and saw a positive future overall, which evidenced resilience as they moved throughout the life course, albeit facing uncertainty along the way. The work of Oshri et al (2018) highlights this further, as they argue that active ageing, and therefore resilience, are linked to positive expectations for the future, which they identify as ‘future orientation.’ Future orientation serves as a tool in which individuals who can facilitate positive expectations for the future are likely to use problem-focused coping skills to persist in pursuing life goals. Future orientation involves setting goals and having intentions to achieve these goals, which sets it apart from optimism, which is simply a personality trait in which individuals are pre-disposed to believe that they will gain favourable outcomes (Oshri, et al, 2018).

Upon first glance, it could be argued that continuity theory is key to this active ageing. This approach claims that people aged the most successfully when they retain their, “habits, preferences, life-styles and relationships from mid to later life and when they continue to use their skills, coping strategies and learning to navigate any new challenges” (Lodge, Carnell and Coleman, 2016: 33). Core characteristics and values may become more pronounced as people age and older roles become replaced with previous ones (for example, paid work may become substituted with volunteering). People remain satisfied with their lives as there is a clear consistency between activities engaged with as people get older, and previous ones (Lodge, Carnell and Coleman, 2016). Though this was apparent among all of the respondents, there are clear limitations associated with this theoretical approach. It does not account for the impact of social institutions, structural stigma, and socio-historical invisibilisation, and it takes a ‘more of the same’ approach (Novak, 2011). Therefore, active ageing was clearer in the lives of the respondents as they used the ageing process to reinvent themselves in different ways. This included plans for living in a new country or taking on a different role, as seen in the respondents’ lives, for example, political engagement or writing. Active ageing theory presents a view that physical and mental health decline can be cultivated, and the quality of an older person’s life can be enhanced, when older people remain physically and socially active (UNDP, 2016), which was prevalent in the lives of all of the respondents.

To summarise, all respondents showed clear active ageing within their lives, and across all three themes, despite their bodies and external barriers faced. Within their lives, they actively engaged with their needs and found ways in which to mitigate against their limitations. They recognised wider social problems such as a lack of wider HIV community support, HIV funding cuts, changing healthcare regimes, and uncertainty about their unknown ageing bodies. Yet, despite this, respondents used their own agency to engage in an ageing process with HIV which did not lead to withdrawal and disengagement. Much of this active ageing was also linked to the process of resilience in part two, which will now be examined in light of the findings.

Part 2: Unfinished resilience

In chapter three, some key questions were also raised about unfinished resilience to take forward in this study, they were:

- How are active ageing and unfinished resilience intertwined within the respondents' lives?
- Are respondents living and ageing with HIV able to develop a sense of unfinished resilience, and what does this currently look like?
- How do older heterosexual people growing older with HIV envisage and shape their own future sense of unfinished resilience?

To frame this discussion, it is important to re-cap on what is meant by the term ‘unfinished resilience’ as a theoretical model, as set out in chapter three. This theoretical concept set out by Aranda et al (2012) argues that the concept of unfinished resilience is something that is both relational between the individual agent and the social structures which can offer opportunities or limit those opportunities around them. This approach rejects the ‘bounce back’ and ‘ordinary magic’ neoliberal approach ‘found’ within a person, who is able to simply ‘find’ resilience within themselves. Similarly, it rejects the narrative where resilience is ‘topped up’ or ‘made’, whereby resilience can be gained by an external source. They emphasise that the biological approach to resilience, with a focus on individual behaviour, has often been too narrow, with an emphasis on the neoliberal view that the sick or imperfect individual is ultimately responsible for their own health outcomes (Aranda, et al, 2012; Walker and Peterson, 2017). The American

Psychological Association, for example, defines resilience as how well trauma, adversity threats and tragedy (as well as other personal stressors) affect personal resilience. However, this does not adequately explain how complex responses that compromise resilience, including cultural and social factors, interact with stressful situations. A health system, for example, is not isolated from political, economic, social, and ideological structures though it is often treated as such.

Developing on the work of Bury (1982), who described the impact of chronic illness on an individual's self and their sense of identity, leading to a biographical disruption, which then forces people to construct a new fixed sense of self and identity, or strengthens their existing identity (biographical reinforcement) (Bury, 1991), Charmaz (2000) argued that the rise of chronic illness and the development of life-long conditions is part of a process of *transformational experiences* into new and dynamic identities. This continuity and development see chronic illness as part of a life's journey, seeking to develop a never-ending cycle of biographical appraisals and revisions, rather than a biographical disruption in need of repair.

Unfinished resilience takes this theoretical development further and bridges the micro-macro divide, forming a complex interplay between the individual and the society (Aranda, et al, 2012). Unfinished resilience sees a social actor as not 'complete' with resilience, but it is developed beyond that of biographical disruption (though this may play a part). Unfinished resilience is when an individual uses their available resources in negotiation with their changing sense of self and identity, whilst using opportunities to access resilience (and see it restrained from them) from the wider social world. This location of resilience inhabits a unique, and in-flux space between the agent and society, allowing individuals to resist powerful social forces (such as stigma for example), but also recognises that agents are not entirely separate from their social world.

This approach to resilience by Aranda et al (2021) also shares parallels with Wright (2021) in that it shifts an understanding of resilience as less of a behaviour that is ‘found’ or ‘made,’ to instead understanding resilience as something in which people work hard to develop individually, and as something in which people use to secure safety and well-being when facing wider structural adversity, potential threats, and vulnerability (Wright, 2021). With this in mind, this part of the analysis will reflect on how unfinished resilience was present within respondents’ lives, and how they used this to plot future goals, despite the limitations around them. Within this theoretical framework, a picture emerges of not only unsuitable support systems for many respondents but a lack of heterosexual cohesion as a ‘community,’ as well as problematic HIV support services for women. This could be seen as indicative of a decline in active ageing and resilience for older heterosexuals living with HIV, as many of the support systems in place were unsuitable, not utilised, or withdrawn from. However, this was not the case, which will be analysed further below.

The body as a threat to unfinished resilience?

ART saw a sea change in all respondents' attitudes, offering them opportunities to plan for their future. Whilst a tension existed with their uncertain bodies and ageing as discussed already, ART also offered opportunities for the respondents to navigate their lives, and work with their own unfinished resilience. As Rosenfeld et al (2015) found in their study of older people living with HIV in the UK, most respondents who took part in their study had good mental health and felt that their quality of life was largely very good. Participants named different things in which people needed to be happy, which included financial security, physical independence, good physical and mental health, a positive attitude to life, friends, family and partners who supported them, good living environments, active social lives, holding down a job and being a grandparent. It was noted that several long-term diagnosed participants described their joy at living for longer (and into old age) due to treatments becoming available, with newly diagnosed older people stating that they were ‘lucky’ to be diagnosed at a time where they could benefit from effective treatments.

This was particularly pronounced in the ‘controlled but uncontrolled’ nature of ageing with HIV that the respondents faced, as the respondents' own unfinished resilience meant that they held onto ART for ontological security, whilst still facing wider tensions and threats with comorbidities, ageing, and the problems faced, seeking answers from medical institutions. It is important to note that throughout the findings, respondents were not ‘topped’ up with resilience, or found it through ‘ordinary magic.’ Instead, they were evidenced as being largely critical of ‘normal life’ narratives and were actively engaged in questioning medical and healthcare experts who presented them with the ‘unknown’ in terms of how their queries were answered. Due to the lack of firm answers regarding ageing with HIV, many took some sense of control back into their bodies, and their own agency through their reliance on ART. This offered a space in which to develop their own unfinished resilience whilst being buffeted by both the perceived threats of their uncertain bodies, and their changing medical care with the unsatisfactory messages that it provided. As such, resilience and active ageing could be maintained and developed in their lives, leading to agency within uncertain times, mitigating against social withdrawal. Yet this resilience would also be tested by the lack of a wider HIV support community, which will now be discussed.

Unfinished resilience and engagement with community support

A wider HIV community was seen as problematic by most respondents as they highlighted a lack of heterosexual community for people living with HIV. Dean, James, Rachel and June’s accounts, for example, pointed toward a ‘scattered’ community of heterosexuals which they perceived being due to poor historical mobilisation, a lack of representation within HIV support literature and in services, alongside a stigma perceived by heterosexuals in using mixed services they felt were for MSM. This lack of unity amongst heterosexuals living with HIV to organise and campaign has been seen to be symptomatic of the isolation and stigma that has been found to attach itself to them as a group (Rosenfeld, 2015). Rosenfeld (2019 cited in Westwood, 2019) states further that there is a sense that older people living with HIV and their ability to maintain earlier levels of political activism has waned, and instead they are directing themselves to participate in research and/or are recipients of help. Socio-historically, whilst HIV activism was engaged with by members of the heterosexual community, it was (and still is, as respondents note) led largely by MSM which has seen greater cohesion amongst MSM. However, as an effect of this development, it has side-lined the needs of heterosexuals. This marginalisation was also clear in respondents' answers, however, the respondents were not as passive as suggested by the findings of Rosenfeld (2019), which will now be explored.

Whilst many respondents lamented the lack of support amongst traditional HIV services and had withdrawn as a result of this (particularly stark amongst female respondents), this became a test of their own unfinished resilience as they were left to navigate a changing terrain of withdrawing their support from traditional services and their structures, whilst simultaneously providing one for themselves. Respondents used their own unfinished resilience to develop their own communities, albeit not as well resourced, to fulfil their own needs. It would be an over-simplification to state that the respondents had withdrawn and suffered a series of losses leading to disengagement, as all were part of a wider HIV community in their own way. As stressed in chapter three, unfinished resilience has links with the concept of ‘community resilience,’ which refers to, “how communities further the capacities of individuals to develop and sustain well-being” (Hall and Zautra, 2010: 350) and therefore, a community can be thought of as providing the resources that can help individuals cope with stress, emphasising social environmental influences, and placing resilience in a more ecological perspective. Community-level resilience can encompass more intangible resources, such as reframing values and norms and redefining life goals, informal support methods, and personal measures of success (Meyer, 2015; Wright, 2021).

This was also highlighted by Furlotte and Schwartz's (2017) study of older adults living with HIV, whereby participants reported using several coping strategies which they used to form resilience, through making lifestyle changes to engage in social support. For example, some respondents participated in community volunteerism as coping methods to deal with HIV, which appeared in many of the female respondents. Whilst the 'scientific puzzle' (Rosenfeld, 2014) of HIV and ageing on their bodies reinforced a lived uncertainty for many of the respondents interviewed, this did not lead to a loss of active ageing or resilience depletion. Respondents set up support networks (both physical and online) to reflect their more active, forward-facing approaches, despite their own views about their bodies as uncertain and problematic. This manifested itself in creative affirmative groups, WhatsApp lunch groups, engagement with websites and resources, and setting up their own international HIV organisations. Respondents worked with their own agency, whilst still acutely aware of HIV funding cuts and a lack of formalised resources at hand from traditional HIV support groups, to reach out to others and develop their own community despite their structural limitations (Aranda, et al, 2012). In doing so, respondents did not 'find' or 'make' their resilience, but actively negotiated their own unfinished resilience through this. By doing this, they formed their own 'protective resilience' based on social and networked resources (Lakomy and Kafkova, 2017), albeit different to the traditional structures of the wider HIV support community.

Unfinished resilience, changing mindsets, and future goal setting

Regarding resilience strategies, it has been evidenced that resilient individuals use effective strategies such as humour, optimistic thinking, positive reappraisal, problem-focused coping, and infusing ordinary events with positive meaning (Skevington, 2012; Fumaz, et al, 2015). Long-term diagnosed people living with HIV comprise a vulnerable collective since they potentially face age-related comorbidities, however in one of the few studies written about positive and active ageing, respondents showed self-acceptance, will to live, self-management and independence (Emlet, Tozay and Raveis, 2011).

All respondents in the research, to differing degrees, had a clear sense of purpose, active engagement with the social world, and targeted goal setting. Rather than forming a stable category of hardship, isolation and withdrawal, respondents had experienced a transformation from a biographical disruption due to their diagnosis with HIV; they found unique and ongoing transformational ways in which to live. These activities and changing mindsets were not from a resilience which was 'found' or 'made,' but from their own unfinished resilience via negotiation with their own identities and the social world. Whilst recognising their own limitations physically, and aware of the barriers that this caused, they continued to find new identities which they were making and becoming. In the post-ART era, this historical time period offered opportunities for respondents to not become socially withdrawn and isolated, but to find their own ongoing performative construction of their identities. Whilst unfinished resilience was not felt evenly by all respondents, with some respondents fearing the process of ageing with HIV and stigma more than others, they all had strategies they had developed to develop future plans, thereby building resilient coping strategies.

Respondents developed these coping strategies in a number of ways, through:

- positioning themselves as a 'trailblazer' and as part of setting a precedent for younger generations of people growing older with HIV;
- framing themselves with a 'new life' narrative, partly aided by ART, but also a shift in mindset to fostering future goal planning;
- physically planning current and future goals such as travel and living abroad, engaging with training courses, taking part in new ventures, personal development, setting up organisations, planning retirement, changing relationships, and starting to seek intimacy and dating;
- forming their own HIV communities of need and support mechanisms, and;
- through finding spirituality and religion.

Whilst respondents recognised that HIV stigma was an existential threat ‘out there,’ many used coping mechanisms to tackle or mitigate against stigma, which will be discussed later in this chapter. This change of mindset located the respondents in between their own agency and the wider social structures in developing their unfinished resilience (Aranda, et al, 2012). This could be seen in that respondents were not always wealthy or had financial privilege, so some used resources at hand to positively cultivate their current lives and future goals, such as re-framing their lives and futures with HIV, changing their relationships, or seeking religion as a form of mental health support. Others who had more privilege were able to use this to plan travel or had engaged in training programmes.

The respondents anchored and reinterpreted past events in the light of more recent ones within their life stories (such as Lydia, who had a ‘mystery illness’ for decades, and once knowing her status, changed her relationship status from an unhappy marriage) and this was key to developing some respondents’ sense of resilience. By doing this, it allowed them to retain a sense of identity but to also clarify the meaning of adverse experiences as their bodies and minds manoeuvred the social world. In line with Bury (1982), adapting to biographical disruption meant reinterpreting their own biography, and it enabled them to readjust their own mental outlook and expectations to their changing life circumstances, and the wider social world.

The following section will analyse the final theme in light of the respondents’ findings, focusing on two interrelated aspects which framed much of the wider position of the respondents throughout their lives, the socio-historical marginalisation of heterosexuals in HIV narratives, and the role of stigma and the long shadow of death.

Part 3: Ignored historically? Evading stigma and the long shadow of social death

In chapter two, some key questions were asked about active ageing to take forward in this study, they were:

- Do older heterosexuals living with HIV also face stigma and what does this look like?
- Due to the socio-historical background of HIV and AIDS, has this impacted heterosexual populations feeling invisible as they age with the virus? What does this mean for their active ageing and unfinished resilience?
- Are they affected by the long shadow of social death?

It is important to analyse the lives of many of the respondents in terms of the socio-historical background of HIV and AIDS. During much of the known history of HIV in the UK, heterosexuals were largely ignored by institutions, or framed in a certain way during the rise of the HIV epidemic (either as heterosexual men as vectors of disease or heterosexual women as 'victims' of it). This problematic framing, and wider invisibility of heterosexuals in mainstream HIV narratives, led many heterosexual demographics to be 'overlooked' as seen in chapter two. Also, in terms of positioning, in that HIV was not seen as impacting them significantly as a population, or services were strategically 're-gayed' (Weeks, 2000) to offer support services predominantly to MSM.

As chapter two outlined, much of the research on stigma of people living with HIV has tended to skew toward MSM, and this is especially true in research conducted on older people living with HIV. From research so far into older MSM living with HIV, stigma was something which was seen to impact on their lives in powerful and significant ways (Pugh, 2005; Bourne, et al, 2009; Cahill and Valadez, 2013; Dispenza, et al, 2015; Williams and Fekete, 2019). It would seem upon initial glance that stigma would follow a similar trajectory from older MSM to that of older heterosexuals living with HIV. Looking at this trajectory was not aided by the scarcity of the literature, showing that very little has been written specifically about older heterosexual people living with HIV and the effects of HIV-related stigma, with only passing general mentions in several studies (Wallach, et al, 2019; Kall, et al, 2020; Rosenfeld, 2021).

Yet, technological advances have affected the identities of people living with illness and made them more complex and not as easy to claim as deviant or stigmatising, and now with HIV being able to be managed through ART, some authors have argued that social attitudes are beginning to change (Jacoby, et al, 2005; Green, 2009; Pinel and Bosson, 2013). Whilst recognising that stigma has not vanished and is very much present, there is a more hopeful future for people living with HIV (Green, 2009). A range of stigma theories were presented in chapter three as they lack a coherent model (Tyler, 2021) and so it was uncertain as to which types of stigma would be felt by respondents, or whether it might be all of them. Intertwined with stigma is the concept developed in this research of the 'long shadow of social death,' which works in tandem with stigma practices to impact upon the lives of older people living with HIV, which will now be re-examined.

Building upon Sontag's (1989) first application of the term 'social death' to HIV and AIDS, Sontag (1987) argued that a person infected with HIV becomes ill as soon as they are infected, whether or not they have shown any symptoms of HIV. Due to this, they face a social death of isolation by the communities, networks, and institutions in which they live and inhabit. This was a useful framework at the height of the HIV and AIDS epidemic in the West when ART was not available and society saw government silence, inaction, and separation of people living with HIV (for example, HIV wards in hospitals). However, now the landscape of HIV has changed somewhat in the UK. Factors which have aided more progressive social changes in attitudes have been via government action, ART, PrEP, and a somewhat more sympathetic media in the West. The concept of social death was refigured, as it is not as absolutist as it once was with HIV in the UK. Instead, it is more complex, recognising much more agency on the part of the individual to resist stigma practices and social death, and recognising societal limitations placed upon them. Alongside contemporary theorists of social death (Dewing, 2008; Norwood, 2009; Gilleard and Higgs, 2015; Caswell and O'Connor, 2015; Borgstorm, 2017), the long shadow of social death can be reconceptualised in terms of explaining how the lived experience of HIV has advanced positively since the crisis of the 1980s and 1990s, yet it has still held onto some of the stigma of its socio-cultural and historical origins.

When the long shadow of social death is applied to older people living with HIV in the West, it still maintains some of its stigmatising roots and of the associations it had formerly, through new forms of exclusion, such as a series of losses (Norwood, 2009). In the sense that it casts a much more subtle 'shade' or 'shadow' and therefore brings ongoing HIV-related stigma to people and groups living with HIV. This may cumulate in invisibilisation, isolation, and withdrawal from society amongst older people living with HIV, which was evidenced in parallel to some of the literature amongst older MSM living with HIV. Sontag's (1989) version of 'social death' has not been advanced in literature about HIV in contemporary society in the UK, so little is known about what this might mean for people living with HIV. This indicated that the term needed a reconceptualisation to reflect current changes and flows. The key question for this research, seeing as stigma and the long shadow of death are interconnected, asks whether the respondents faced these concepts in their lives. The following section will explore these conceptualisations overall as cutting across the data, as they did not feature in all aspects of the three main themes.

Stigma and the long shadow of social death – felt by respondents?

What was notable in the findings, was that respondents noted that stigma was 'out there,' but they did not see it as something which impacted their future goals. Respondents showed an awareness that HIV-related stigma played a factor in their current and future lives, however, this was minimised or tackled.

Respondents were not necessarily as 'stigma free' as some had stated, and in many ways they were inadvertently part of institutional and public stigmas through not being offered HIV tests by healthcare experts despite presenting with late-stage HIV. Similarly, some respondents showed their own (former) feelings of stigma toward HIV as being the preserve of MSM, or other groups, as some respondents never considered testing, or thought it was not for them, which Dean pointed out in chapter five. In this sense, stigma had ‘muddied the waters’ in the respondents' earlier lives, as they were both unwittingly a victim of wider institutional stigma in the perception that they were not a group to be affected by HIV, whilst also holding their own stigmatic views toward HIV testing and who it was appropriate to test. This stigma process was part of a wider narrative of the invisibilisation of heterosexuals within an HIV narrative, which rendered them not part of the wider HIV discussions as HIV grew and spread. Not until the ‘Don’t Die of Ignorance’ (1987) campaign did the UK government operationalise funding to specifically tackle the population as a whole, yet this advert seemed to have little effect in getting many of the respondents to reflect on HIV as applicable to all heterosexual populations, as all respondents were tested positive for HIV beyond this point. The long shadow of social death was at play in their lives, in that HIV did not hold the same toxicity as previous decades, but instead brought forward older stigmas and cultural baggage which affects MSM populations today. Yet, simultaneously, it also brought forward the socio-historical invisibilisation of heterosexuals as part of this cultural baggage into the present day.

Upon examining the lives of the respondents at first glance, the conditions for heightened stigma and the long shadow of social death seemed initially ripe for both to affect the respondents themselves. The uncertain nature of their ageing bodies, comorbidities, and health-related problems faced when ageing with HIV; the uncertainty of answers from the medical world could have facilitated this. Added to this were the issues around unsuitable services and lack of provision for heterosexuals in traditional support groups, which all had the potential to impact personal well-being, which did indeed see respondents withdraw. However, importantly the respondents did not withdraw entirely, and instead, built up communities of need around them. With their own (albeit not as well-resourced) communities, and emboldened by ART, respondents created transformational opportunities in which to engage, not disengage, therefore weakening the long shadow of social death upon their lives.

Stigma and prejudice toward others living with HIV manifested within respondents rarely in the interviews, with one notable and problematic comment from June toward other service users at a social gathering within an HIV organisation. Generally, though, respondents tended to discuss internalised HIV stigma being something which they faced. However, this was framed in 'anchor points' in their lives, as June, Rebecca, and Lydia felt that it once defined, or threatened to define their lives, but they used strategies to mitigate against this. Key techniques to form stigma coping strategies emerged in different ways by respondents, but all framed the HIV stigma narrative via coping methods, such as regarding themselves as trailblazers, as a 'final frontier' for younger generations living with HIV to follow. Deploying an 'I don't care' narrative to ignore stigma and move on with their lives, respondents found hope in changing public attitudes, and noticed positive messages about HIV on social media which reinforced that. Some respondents who seemed more at risk of sticky stigma, such as Olivia, were keenly aware of HIV-related stigma and the potential of the long shadow of social death, in that she feared others knowing her status. Despite this, it did not affect her own coping interactions with her close family and engagement with HIV research online. It was clear that the older adults could draw upon their own cultural resources to make sense of their diagnosis when coping with HIV, ageing, and the stigma around HIV (Siegel, Raveis and Karus, 1998).

However, there is a point from chapter seven to refer to here, in that respondents also maintained a semi-privileged space, in that they were largely protected from some of the worst of the harms of stigma and the long shadow of social death. Heterosexuals' very invisibilisation from the socio-historical background of the HIV epidemic led the respondents in this research to not face the intense stigma, homophobia, and scrutiny of their lives as faced historically by MSM. This is certainly not to minimise how heterosexuals have also been stigmatised and constructed during this time period, often being framed as two-dimensional caricatures in media representation. However, they were largely protected from the wider panic, stigma, and homophobia of the time. Yet, this is something of a double-edged sword as it is this very marginalisation that has played a key part in the issues faced finding relevant and suitable support systems (for heterosexuals), being perceived as not designed for them. It also meant them being ‘overlooked’ for HIV testing, which led to late diagnosis for a number of respondents later in their lives, culminating in problematic health concerns.

Heterosexual men and women with HIV may themselves be unfamiliar with the process of ‘coming out’ (in this case with HIV), and so stigma is, therefore, likely to be an entirely new experience to them. As stated previously, respondents lacked a community of experienced elders (Rosenfeld, et al, 2014) and had no ‘role models’ about disclosure from which to draw (Crawford, et al, 1997; Power, 2010). Despite some respondents announcing that they would be trailblazers for future generations, many heterosexual respondents had withdrawn from traditional support services, which are often a point of entry for newly diagnosed heterosexual people. This presents an issue in that their own developed HIV communities made by the respondents in this research, could appear to be nebulous and difficult to access without knowing the correct people to access them, potentially leading to newly diagnosed people being isolated, lonely, and at risk of stigma. This has key implications for HIV services to consider reconfiguring support to stop this happening to newly diagnosed older heterosexuals.

Respondents were unknowingly affected by stigma and the long shadow of social death from the roots of HIV and its historical development, however, this was not as strongly highlighted by them as it has been on other populations living with HIV, such as the literature on older MSM. What was clear from the lives of the respondents, was that they were able to mobilise both privilege and resources in which stigma and the long shadow of death were not able to sharply pierce their lives. Stigma and the long shadow of social death were felt by respondents, but they developed their own unfinished resilience and active ageing techniques by cultivating their own agency and a range of anti-stigma coping strategies to deal with stigma ‘out there’ from the wider society.

Conclusion

The accounts of the lives of the respondents presents a complex analysis overall, with the three themes of ‘changing bodies,’ ‘changing communities,’ and ‘changing mindsets and futures’ emerging from their interviews. The theoretical approaches of active ageing, unfinished resilience, stigma and the long shadow of social death have been presented from a backdrop of the socio-historical invisibilisation and marginalisation of heterosexuals in the wider HIV narrative. Whilst all respondents faced the potential for active ageing to disengage, and for resilience to become depleted due to their uncertain bodies and a lack of suitable access to an HIV community, this did not stymie their current and future goals. In fact, respondents show guileful ways in which they build up their resilience and develop their own sense of community using their own sense of agency. Active ageing is a prominent approach in their lives and social development, enabling a strong intertwined sense of resilience-building, despite their social limitations. Stigma played a part in their lives, either propagating it, in the case of a few respondents, but also as a ‘threat in the air.’ Yet, stigma was not as significant as initially expected from conducting the literature review (as so little is written about this topic with older heterosexuals). Interestingly it did not replicate as prominently as the experiences of other groups living with HIV in the UK, such as older MSM. Whilst stigma and the long shadow of social death certainly casts a ‘shade’ on their lives socio-historically and to a certain extent currently, respondents were not defined by it, and actively found ways to manage it.

Findings from this research show a very complex and nuanced picture of ageing with HIV amongst heterosexuals in the UK. Now all three themes have been analysed, it is important to explore what conclusions can be drawn, and what recommendations can be offered for further theoretical engagement, policy, and practice. These important final points will be examined in the next chapter to conclude this thesis.

Chapter Nine: Conclusion and Recommendations

This thesis traversed the lived experiences of a sample of older heterosexual people living with HIV in the UK and it explored how they navigated ageing and sought resilience, despite a background of stigma and the long shadow of death. This thesis examines the following key questions which cut across the study:

- What do the lives of older heterosexual people living with HIV look like, and what barriers, pressures, and opportunities do they face?
- How do older heterosexual people living with HIV experience their own sense of both ageing and resilience?
- If stigma exists for older heterosexual people living with HIV, what does this look like and how does it impact their lives?
- How do older heterosexual people living with HIV shape and mould their own futures in a post-ART era?

To answer these questions, this thesis used the following research aim and objectives to guide its approach:

Research aim

To examine the lived experiences of older heterosexual people living with HIV in the UK and to investigate how this demographic navigates ageing and resilience as they age with HIV.

Research objectives

- to review the existing literature on older people living with HIV in the UK, their experiences, and issues that they face, as they age with HIV.

- to critically examine the impact of social structures and wider socio-historical influences on the lives of older heterosexuals living with HIV in the UK, and what this means for them.
- to critically examine whether the lived experiences of older heterosexuals living with HIV in the UK have a sense of agency as they age with HIV, and what this means for them.
- To examine the impact of ageing, resilience, and stigma on the lives of older heterosexual people living with HIV in the UK, and how they traverse their lived experiences in light of these.
- to interpret the life narratives of heterosexual people growing older with HIV, to further an understanding of this under-researched group in the UK.

Summarising the narrative

This thesis examines how older heterosexual people living with HIV actively age with the virus and in doing this, how they find resilient ways of navigating the ageing process. A comparison is made with the literature on older MSM to see whether heterosexuals followed a similar trajectory in navigating social pressures, such as stigma. This thesis asks whether individual and social factors have led to social withdrawal, reflected and paralleled in much of the literature about older MSM living with HIV. It uses an empirical sociology that utilises active ageing and unfinished resilience as theoretical frameworks, as well as framing these in light of stigma and the long shadow of social death; asking to what extent these formed barriers to the respondents' own unfinished resilience and active ageing. The thesis study grounds itself academically in the sociology of health and illness, ageing and resilience, and the sociology of HIV.

Throughout this study, sociological conceptions of active ageing and unfinished resilience have been used to examine the process of ageing with HIV amongst older heterosexual people. Though differences and nuances of growing older with HIV existed within respondents' lived experiences, this thesis finds three key themes that cut across the lives of all respondents interviewed, of changing bodies, changing communities, and changing mindsets and futures.

This thesis begins with the research justification and the contextualising of ageing with HIV in chapter one, explored by examining some of the general issues faced by older people living with HIV across all demographics, then highlights emerging issues faced by older heterosexuals, identified as an under-researched group. It also highlights, through current statistics, that older heterosexuals living with HIV are a growing 'at risk' group, who have been inadequately examined, despite the significance of the changing world of growing older with HIV. HIV and ageing is still a relatively new emerging field of research, and this thesis recognises the limitations of some of the literature; in that much comes from other nation-states or had a distinct focus on MSM, with few empirical studies conducted within the UK on older heterosexuals. With this in mind, the wider introductory literature highlights a broad number of factors which were important to explore regarding ageing and HIV.

The broader factors facing HIV and ageing across all demographics reveal a lack of sexual health knowledge amongst older people, as well as poorer physical health and mental health outcomes in older people living with HIV. Finally, HIV stigma is also recognised to be a key issue that affects older people's lives. These factors are significant, as chapter one recognises, outlining the foundations of some of the issues that emerged later in the research process which put older people at potential risk of social withdrawal. These include poorer health outcomes, issues around ageing and the body with HIV, and HIV-related stigma. The underlying reason behind some of the poorer mental and physical outcomes is grounded in the effects of stigma, according to an overview of the research at that early point. It became important to examine why this stigma was socio-historically located in the UK, in order to gain a deeper insight into what this meant for older heterosexuals living with HIV.

Chapter two investigates the socio-historical development of HIV and AIDS in the UK, whilst outlining how HIV and AIDS were socially constructed by social agents, institutions, and organisations to frame the HIV epidemic as 'belonging' to certain groups (Weeks, 2000). A key part of this was the attachment of HIV to MSM in the UK, which remains within the public consciousness today. But this has evolved to shift resources, mobilisation, and support for this group. This process has had a significant impact on heterosexuals living with HIV who were either framed in a particular way by the media, invisibilised throughout in terms of support, or marginalised from the discourses that emerged socio-historically. Heterosexual populations have largely been side-lined from the debates, seen as either not at risk, and so not requiring significant government or policy intervention, or perceived as not being a 'deviant' group requiring surveillance until much later in the HIV epidemic when it was seen that HIV and AIDS knew no boundaries of gender, place, or sexual orientation.

This thesis finds that during the socio-historical growth of HIV and AIDS, activist opportunities for people living with HIV emerged as a collective form of mobilisation against media backlash and ignorance, governmental indifference (until later in the epidemic), and negative public opinion. This mobilised better public knowledge, increased government pressure, and pushed for medical trials to find a cure. Whilst heterosexuals were a key part of this journey, most of the larger organisations were set up with MSM as leaders and very often heterosexual voices were not heard as readily as a result. Stigma has worked in two problematic ways via the socio-historical development of HIV in the UK, compounding further the 'public face' of HIV as MSM, who then mobilised well, and dominated HIV services, community networks, activism, and became the public 'face' of HIV. Simultaneously, this stigma process downgraded heterosexuals living with HIV in the UK as not needing priority support, which has had longer-term effects on their later experiences of ageing with HIV, as well as their community networks, and support services. As a side effect of this historical development and of stigma, it is noted that older MSM were more prominent in research compared to older heterosexuals. This has meant research is much more limited about heterosexual experiences. Having only the parallel studies of older MSM, and the scarcer literature that could be found on older heterosexuals, chapter two begins to frame key questions to take forward, being cognisant of this development of HIV, and how this had the potential to impact older heterosexuals today.

Chapter three introduces the theoretical approaches of active ageing and Aranda et al's (2012) unfinished resilience, which were brought forward to examine the life narratives of heterosexual people living with HIV. Active ageing stands in opposition to the disengagement theory of ageing, outlining how older people have a sense of agency in their decisions as they grow older, whilst recognising that social pressures and limitations impact upon their lives. This is important to examine, and evaluate the literature presented, noticing something of a 'grey space' between shifting structure and agency. This led to this thesis asking how older people, who were already marginalised in a grey space in wider HIV narratives, found a sense of active ageing. Shifting the lens away from a more deficit model of ageing, which has dominated much of previous discussions of ageing in research, to examine whether this negativity was present in the lives of the respondents and if so, how they navigated this within their lives.

It was also important at this stage of the thesis to align active ageing with resilience, to see whether the two coincided, as both approaches share a bridge between the macro and micro levels of society. Despite a wealth of research studies into resilience, resilience in diverse populations, and psychological measures of resilience, theoretical approaches tend to fall into distinct camps of knowledge. Either a resilience as 'made' approach, or resilience as 'found.' Both of these approaches are problematic, as they assume that resilience is something either 'topped up' as an empty vessel within an agent from the social world around them, or found within a person as ordinary magic, fitting into neoliberal ideologies of the self. What ultimately emerges from the research, is that respondents actively aged, despite facing issues with their bodies and wider support communities, with ART as a turning point in their lives and activities.

Therefore, resilience in this research is characterised as an unfinished resilience (Aranda, et al, 2012) offering a more meaningful approach and a middle ground to examining the interplay between both structure and agency. This is complimentary to active ageing and enables a fuller understanding of how respondents navigated both in tandem. This thesis finds that as respondents moved throughout their life course, there was a sense of being buffered by their own agency and the impacts of social, cultural and political narratives. In using this approach, the thesis recasts the theoretical lens in which to see how a felt marginalised group within a perceived larger marginalised group, constructs their identities, actively ages or disengages. Through this, how the respondents developed their own sense of unfinished resilience is examined, as they are impacted by both their own lived experiences and the impact of society around them. Chapter three also allows for a theoretical exploration of how HIV-related stigma impacted older people living with HIV, recognising that stigma forms a backdrop to HIV and has the potential to affect the lives of the respondents. However, as much previous research has explored older MSM, scant knowledge was found on the impact of HIV on older heterosexuals; with studies often speaking about them in general terms as part of a wider study of stigma amongst all demographics (Wallach, et al, 2019; Kall, et al, 2020; Rosenfeld, 2021).

The nature of HIV has changed significantly since its genesis in the West, with ART providing a way in which to now live and grow old with it, which means that stigma has also evolved from being absolutist in the lives of people living with HIV, to perhaps something else. This facilitated the need to reconsider earlier theories such as Sontag's (1989) concept of 'social death, in light of the changes to HIV today. Due to this, chapter three also presents a reconceptualising of Sontag's (1989) concept of social death. This enabled the envisaging of a wider framework of how a *long shadow of social death* emerges from the stigmas of the socio-historical development of HIV. With the historical and social stigmas that accompanied the development of HIV having changed, but still holding currency, particularly in that of older MSM in the West. This long shadow of social death still casts a powerful 'shade' and has led many older MSM, from the research examined, to appear to socially withdraw and become isolated. This is evident with practices of serosorting, framed by other members of the LGBTQI+ community as marginalised, and facing stereotypes as the 'lowest rung of the gay hierarchy.' Impacts of this included social withdrawal, isolation, and poorer mental health outcomes amongst many older MSM living with HIV. However, it is noted that structural pressures and forces led some older MSM to find ways to buffer these stressors through support within their own wider HIV community.

In light of this, chapter three postulates whether this would be similar for older heterosexuals also living with HIV, who would also potentially face a series of stigma losses leading to withdrawal, thereby stymying active ageing, and their own unfinished resilience. Whilst the respondents in this research recognised that stigma is 'out there' which has impacted them directly in a few ways, the long shadow of social death has also cast its 'shade' on their lives. This is seen via their own invisibility in wider HIV narratives and a lack of suitable support systems, leading many respondents to withdraw from services. However, powerful stigma management strategies to mitigate the impact of stigma and the long shadow of social death are also evidenced. Despite this, the respondents' lives are not 'stigma free' despite being presented as such by some respondents, as many were denied HIV testing when presenting late-stage HIV symptoms and also found that wider HIV support systems had isolated them further.

The methodology of chapter four allows for three key themes to surface from the life histories and narratives of the older heterosexuals who took part in the research. These three themes of changing bodies, changing communities, and changing futures and mindsets, opened up the worlds of the respondents as individuals sharing their unique insights into experiences of ageing with HIV. Much of the research identified in the early chapters about older people living with HIV pointed to a fragility within this group, in terms of linking them to poorer physical and mental health outcomes, social isolation, and 'at risk' factors both embodied and external to them. Yet this thesis presents some surprising and interesting results. Over chapters five, six, seven, and eight, which set up the three themed findings and subsequent analysis of them, the respondents highlighted threats faced by their ageing bodies and interaction of HIV with them, the renewed control of their bodies with ART, and a sense of their bodies being ‘controlled’ but ‘uncontrolled,’ and what this meant for them. In this research, the respondents noted their own uncertainties surrounding their ageing bodies and showed uncertainty as to how HIV would affect them in the future. This was an area of anxiety for some respondents as they felt part of a scientific impasse, whereby they considered there to be a lack of medical knowledge and clear answers from medical staff, as well as a lack of community elders to support them, as they presented as a ‘medical puzzle.’

This temporary ‘gap in knowledge’ for medical experts appeared problematic for respondents as many considered that HIV was causing a process of deterioration in their bodies. Due to this, some concerns were raised by them about their bodies, ageing with HIV, complications of long-term medication, comorbidities, and effects upon their memory. This led to them challenging the medical narrative that they are living a ‘normal life’ with HIV as they continue to age. Other respondents reported feeling marginalised, in terms of heterosexuals not being brought into clinical trials and because HIV funding cuts have become problematic to their health services, noting that specialist support has been replaced with that of GPs. Yet within this, all respondents were thankful for ART, as it represented a site of taking control of their uncertain bodies in terms of offering a sense of certainty which allowed them to plan their future. This unchartered territory can certainly be said to have tested the respondents’ own active ageing and resilience levels, yet despite this, they navigated both the known and unknown of ageing with their bodies. This is supported through ART and changing medical treatments, which have instilled a sense of control and agency within their lives. Whilst at the same time, this created a feeling of being buffeted by wider social forces which could limit them. This interplay between the micro and macro means a space for active ageing and unfinished resilience emerged, which came out powerfully in accounts throughout the research, as individuals formed their own communities of need and support. At no key points examined within the research, did respondents disengage entirely and when they did (for example, from traditional HIV support groups), they can be seen to be reconfiguring and transforming their lives to counteract this.

To varying extents, this thesis finds that despite their uncertain bodies all respondents did not let this wear them down or increase their sense of isolation, as all were engaged, within their means and resources, with pursuits and activities that kept them active, which helped their mental health and future goal setting. Active ageing and resilience formation was apparent in all the individuals, whether diagnosed with HIV in a post-ART era more recently, or long-term survivors diagnosed from the pre-ART era. However, respondents reported wider structural problems, such as a lack of a defined heterosexual HIV community, and in terms of traditional support groups focussing on the needs of other demographics. Other respondents raised issues of MSM bias at the top of HIV organisations, and of feeling invisible as heterosexuals within HIV literature, yet also noted that traditional support groups felt either unsafe or offered a ‘doom and gloom’ narrative unsuitable to them.

Despite traditional HIV services not providing the support that many respondents said they needed, this thesis notes that respondents sought to make their own forms of active ageing. Therefore, strengthening their own resilience through their own connections, and resources at hand. A number of respondents engaged in networking through global online technologies, for example, including WhatsApp and Facebook. Some having set up their own groups which were more informal and less focused on a medical model of ageing with HIV. Despite the limitations of the wider structures around them, many respondents reported using their agency to access various forms of support, and to alter and reshape support systems so that they were relevant to them. The potential narrative of disengagement states that older heterosexuals who are growing older with HIV, face severe social isolation and disconnection because of their invisible positioning within society. This was overwhelmingly present in the available literature, however, the findings from this research contest this narrative. Instead, many of the older people living with HIV in this research actively engaged with social structures to access support and forms of capital, using their own agency. In doing this, respondents have developed their active ageing and unfinished resilience, which was neither found within themselves, nor made by the structures around them, but a process of both (Aranda, et al, 2012).

As further evidence of this, many respondents used their HIV diagnosis and control of their bodies through ART as an opportunity to engage with new opportunities rather than withdraw and disengage. This approach offered them a renewed sense of purpose, and a changing mindset toward their future goals. Due to their HIV diagnosis, they could make life-altering identity constructions and transformative decisions as they grew older with HIV. ART allowed the notion of 'uncertain bodies' to not affect cognitive well-being, as respondents engaged in activities which changed their previous lives; such as divorce, engaging with spirituality and religion, international travel, taking up new skill training, and making plans to move location in the future to retire. Through this goal setting and future orientation mode of thinking they used their strong networks and personal resources to resist the stigma and narratives of HIV as something which negatively defines their lives, despite them noting the potential frailty of their bodies. Not being able to rely on traditional HIV communities to seek support, meant that they used skills, connections, and resources on hand to navigate the limitations of the wider social world, whilst not being passive in their own agency.

All respondents recognised that stigma is 'out there' in the social world. Some seemed more self-conscious of this than others, with some reporting that stigma affects their opportunities to talk openly about HIV with friends and wider social circles. Nonetheless, most respondents did not feel (knowingly) affected by stigma and the long shadow of death, as living and growing older with HIV was an opportunity to reinvent and recreate their mindsets and so 'transcend the virus' (Barroso, 1997). This process of active ageing and unfinished resilience was not found from within, nor was it made, but instead it was a reflexive process whereby they used external resources, as well as their own cognitive process and strength of will to engage with life as an ageing person with HIV. It is important to note that some respondents did have future concerns about the 'unknown' of growing older with HIV and what this meant for the body, but they simultaneously engaged with new opportunities. With these respondents, they walked a tightrope of both the anxiety of ageing and making fresh plans for their (uncertain) future due to ageing with HIV.

As Rebecca and Brenda stated, the respondents were part of a 'final frontier' and were setting a 'precedent' for the future of heterosexuals growing older with HIV. The findings from this research offer a snapshot of what their lives looked like and so offered some insight as to how they found the process of growing older with HIV as the social landscape of the virus changes. Interestingly, and at the time of writing up this thesis, two articles emerged in UK news outlets about HIV. The first article argued that we need a 'new strategy' in dealing with heterosexuals being tested for HIV, as for the first time in a decade diagnoses among heterosexuals are now higher than that of MSM (The Guardian, 2022). The second article highlighted the first heterosexual woman in the world who was believed to be 'cured of HIV,' being the third person globally through stem cell transplants (BBC, 2022). Whilst expensive, experimental, and not suitable for all people, this offers a change in dynamic and a beacon of hope to many people now living with HIV. Both articles represented the very dramatic change in how HIV narratives have started to shift in the public realm, and how there is a recognition of the urgent necessity to examine why heterosexual populations are presenting with HIV as they grow in number, as well as considering the progression of HIV treatment and what this means to people living with HIV in the future. What the future holds regarding HIV and those who live and grow older with it is uncertain. What is certain is that the landscape of HIV is evolving and shifting, and so research should continue to reflect and chart this journey.

Research limitations, reflections, and future directions

It must be recognised that this research only offers a snapshot of heterosexuals ageing with HIV, and that the respondents' views and experiences have emerged within a particular historical, social, and cultural context, and so this should be considered in exploring the impact of this research. Within all research studies there are limitations, and these will be explored in this section, starting with my own considerations and reflections as a researcher.

When starting this research, I had to reflect on my own positionality as an HIV researcher and an HIV activist. As someone who has been involved within the HIV community for a number of years, I initially thought that the research would yield negative results of disengagement and frailty as I had seen in much of the literature produced from the Third Sector. I suspected that this may be similar to that of the research around MSM, if not worse, due to older heterosexuals being a marginalised group within the wider HIV community. Leading this research made me question my own professional background, and my own reproduction of the wider narratives of heterosexual (and especially older heterosexual) people 'simply not engaging' with HIV services. It is clear from the research that the respondents I interviewed are engaging, but differently and unexpectedly. This led to a personal challenge to my own initial beliefs as I moved through the research process.

I also entered the research process intending to use a slightly different lens to examine the lives of older people living with HIV, as I initially wanted to interview respondents with a view to discussing their intimate lives, and how they engaged with dating and meeting others. This did emerge to a smaller degree in some of the interviews, however, I noticed that the theme of resilience and active ageing were much stronger throughout their lives, and so this led to the lens being recast in order to capture this. Developing a more reflexive approach as a result of these findings (Novak, 2016), I was able to react and respond to this, and make research decisions which led to a richer study altogether.

Early in the research, I proposed to use photographs, significant objects, and visual cues to accompany these life history narratives and to further the narrative discussion (Sarantakos, 2013; Marion and Crowder, 2013). It was hoped that these would offer spaces in which respondents could reflect upon their own life course and consider how they viewed their own lives being affected by social forces around them. Unlike narratives, which can unfold progressively, images can present ‘everything’ at once (Marian and Crowder, 2013) and can present complex content and relationships to “move us both more quickly and more powerfully, in ways that words alone may not” (Marian and Crowder, 2013: 3). Looking, seeing, and knowing are inextricably linked and can provide context and insight to the researcher and participant through the use of visual methods. It was an original aim to incorporate this approach into the data gathering process and this could have presented the research with interesting additional data. However, this did not work out as expected as no single respondent presented visual materials either before, during, or after their narrative discussions due to forgetting to do so, even after receiving reminders. As noted in Bagnoli’s (2009) work, planned visual activities may impose a particular way of thinking about the world that respondents do not always share (Bagnoli, 2009), and so this was an interesting finding in itself, as respondents preferred a more narrative interview approach instead. Nonetheless, the data gathered from the narrative method was extremely rich (Plummer, 2006; Sarantakos, 2013; Squire, et al, 2014) and thus led to respondents being able to open up about their lives, which I hope I have done justice to within this study. Some reflective considerations to learn for future studies would be to consider whether visual methods are effective alongside life narrative approaches within my future professional development as a researcher, and to implement research design with respondents on a much closer level in the future.

Further limitations were found around the lack of background information as I started to collect data for the literature review. Much of the analysis of older people living with HIV has been conducted primarily in the USA and Australia, and whilst these studies were still useful to feed into the literature analysis, they were also culturally specific to those nation-states. A key study at the beginning of my research journey did examine UK-specific issues, which was Rosenfeld, et al’s (2015) landmark HALL (HIV and Later Life) study, which examines all demographics of older people living with HIV through life narrative approaches. This study was very useful but lacked significant information on key areas of the lives of older heterosexuals living with HIV in the UK, despite them being part of the sample, as comments tended to be generalised amongst the findings from other demographics.

Whilst revisiting literature throughout the years of the study, it was notable that older heterosexuals living with HIV were still under-researched, and the literature had not moved significantly past medical knowledge, HIV statistics, and drug adherence. All of these limitations regarding the literature feed into a wider recommendation that more sociological analysis of older people living with HIV needs to be instigated, as there is still much to be learnt about this demographic group.

In terms of the sample, some limitations presented themselves. One was a natural part of the interview process, in that one respondent withdrew from the study for personal reasons, which meant that additional data was unable to be used. However, this was an understandable feature of the research process and so I worked with the data from the sample that I could use. A second limitation of the study surrounds the selection bias of the sample, as the research initially aimed at using a ‘self-selection’ sampling method (see chapter four). However, when this did not work out as planned, snowball sampling was utilised. This was helpful in increasing the numbers of the sample, but it also ensured that voluntary bias played a part and that respondents were connected to each other. Whilst this research is *still* a sample population of older people living with HIV, it also meant that respondents knew of each other through support networks, which may have had implications on the people who came forward for the study. For example, all respondents except for two people were White (one Black and one Mixed-Ethnicity), and so results tended to predominantly reflect the concerns of the White population. Further study of BAME heterosexual populations growing older with HIV is recommended, as well as a deeper outreach for respondents who were not necessarily connected.

Furthermore, all of the sample self-identified as cisgender (there were no limitations to gender identity or expression within the research blog used to advertise it). More gender diversity could have aided a deeper understanding of issues faced by respondents, especially as Public Health England has started to gather statistics on transgender populations in recent years, finding that most HIV transmission comes from heterosexual sex in this population (Public Health England, 2020).

Finally, some limitations presented themselves in terms of theoretical considerations. Whilst Rosenfeld et al (2015) have begun this process in some of the most prominent research, much of the landscape of theory around older heterosexuals living with HIV was barren and underdeveloped. Whilst this thesis reframes active ageing, unfinished resilience, stigma and the long shadow of social death, much of this needs deeper exploration and new conceptual models to examine the lives of this group of people.

Whilst these limitations were clear within the research process, the results of the research alongside these limitations, allow for future recommendations to take this field of study further, which will be addressed in the final section of this chapter below.

Recommendations from this research

The research and themes analysed in this investigation bring up several recommendations, and these have been separated into theory, policy, practice and research, which will contribute to the knowledge, debates and conceptual discussions around growing older with HIV.

Theory

One of the most fundamental recommendations of this research is that the lived experiences of older heterosexuals living with HIV need far more academic and sociological research, tending so far to be more represented in quantifiable surveys and demographic studies. Qualitative studies do exist but are less common, with much of the literature emerging from the USA and elsewhere, with only some data being UK-specific (Rosenfeld, 2015, 2016 and 2018). Whilst research into HIV and ageing is still a relatively new field of study in academic terms, and with the Third Sector having tackled the needs of older people in more depth on a practice basis, much of the deeper theorisation of the 'why' behind older people ageing with HIV is missing. There is an important need for academics to take this theorisation forward, which is explored further in the research recommendations in this chapter.

One recommendation to take forward is to ensure that academic literature and theorising within sociological thinking should consider the role of unfinished resilience and active ageing. Engagement with active ageing theories for older demographics living with HIV, in this case, older heterosexuals, still needs to be examined in the academic literature, as much of their lives are under-researched and under-theorised. A great deal of the academic literature on resilience has only focused on the theorisation of the 'found' and 'made' models, consequently a development of the conceptual notion of resilience as ongoing and unfinished needs to be explored. Overall, more depth of theoretical understanding of active ageing and unfinished resilience in light of ageing with HIV is needed beyond the limits of this study.

Where theory blends into practice (praxis), many HIV organisations are offering resilience training to service users, and staff members. Further academic theorisation of resilience would be useful here to show that resilience is not a process of being, from 'within' or 'topped up.' In maintaining the 'made' and 'found' models theorised and presented in the literature, organisational approaches to dealing with older people living with HIV need to be addressed.

This would help avoid neoliberal trappings of individuals being able to produce resilience on demand, especially as HIV services are affected by austerity cuts.

A final theoretical recommendation would be to conceptually examine the ‘long shadow of social death’ in more detail, and with further academic rigour. It would be useful to see whether this theorising also applies to empirical studies of other older demographics living with HIV. This thesis contributes to new knowledge in reconceptualising Sontag’s (1989) work, and has made a refinement of this theoretical approach, opening the door to further theoretical exploration in future academic work.

Policy

One policy recommendation is to ensure that HIV organisations (and non-HIV organisations that deal with people living with HIV, such as mental health services) aim to update their policies to address how they interact, and to provide services with older heterosexual people. Appropriate information should reflect heterosexual people living with HIV to avoid assumptions of applying to some groups over others, which creates marginalisation within HIV communities. This representation should be written into organisational policies to reflect this and feature in staff training of key staff within medical and healthcare environments. In terms of the ageing body with HIV, medical professionals should take into consideration the anxieties of older people living with HIV, who are not just part of a puzzle or ‘gap’ in medical knowledge but have genuine anxieties about their bodies ageing, and so these need to be addressed in patient care beyond that of the ‘normal life’ narrative.

Respondents were actively ageing with HIV and led active lives in this research. Policymakers within the statutory sector should consider this when implementing policies that affect HIV funding. With the Health and Social Care Act (2012) shifting funding to tendering processes within local authorities rather than directly to HIV Third Sector organisations, a key recommendation is that active ageing funding should be a priority for older people living with HIV. Offering tendering themes for HIV organisations around active ageing projects would have a significant impact on services being offered to all older groups, not just older heterosexuals. This would then continue to enrich the lives of older heterosexuals (and by consequence older MSM), support active ageing, resilience development, and enable all older people living with HIV to have less medicalised HIV services offered to them.

Practice

Recommendations for community and Third Sector organisations are inevitably less structured, however many respondents in the research wanted less of a focus on the 'medical narrative' within traditional Third Sector HIV support services, and instead, wanted more informal person-centred approaches. The legacy of the medical approach to HIV services is deeply embedded due to the socio-historical emergence of HIV, and the post-ART era whereby medical discourses have become dominant (Dalton, 2017). As respondents actively aged with HIV and had changing mindsets for the future with goal-planning in mind, opportunities to engage in enrichment and identity construction beyond 'coping with HIV' as an older person should be offered. These measures are well within the measures of Third Sector organisations to implement and could make a key difference in older heterosexuals engaging with their services in the future, rather than finding their own ways to find a sense of community.

Future research

There is a trajectory of future research which could develop from the findings of this study. This section will outline future ideas for research and further sociological thinking.

Firstly, more needs to be understood about HIV organisations and their services for older heterosexuals living with HIV. With the socio-historical background of HIV bringing the voices of older MSM to the forefront of research, and advocacy, there is space for participatory-style research projects to work with HIV organisations, and older heterosexuals living with HIV. This could examine their specific needs, creative and affirmative approaches, and less medicalised models for offering support. Respondents in this study set out in broad terms what they would like to see from traditional HIV support services, but this needs to be advanced further. Sociological theorising about the historical backdrop to services and why disengagement is happening would offer not only practical support for organisations, that may struggle to recruit older heterosexuals, but would also develop a more in-depth theoretical analysis as to what these services could look like, and why.

Secondly, sociological research is needed to understand the needs of BAME and non-cisgender heterosexual populations growing older with HIV. These groups were not as well represented (or at all in terms of non-binary and transgender populations) in this study. Late diagnosis rates were higher among Black African heterosexuals (59%) compared with White heterosexuals (51%) in 2019 (Public Health England, 2020). There are, as yet, no studies that I could locate around BAME heterosexual populations which focus on growing older with HIV. This area needs not only further research, but deeper sociological thinking as to structural barriers which are affecting BAME heterosexuals from testing. Additionally, how BAME heterosexuals have found the process of growing older with HIV, and whether they face unique societal pressures and stigmas.

Finally, my own concept of the long shadow of social death and its inter-relationship with stigma needs deeper exploration and unpacking as a concept. It would be useful for further sociological studies to recognise how HIV-related stigma has changed in light of the accelerated shifts in HIV in the UK and whether there is space to theorise around stigma management strategies. Importantly, would be to examine whether these concepts can be applied to all older people living with HIV, to see if they are felt evenly by all demographics.

In summary, this thesis contributes to furthering knowledge about heterosexual populations, HIV and ageing. Taking an under-explored group brings a different approach to the often quantitative and demographic studies of older heterosexual people living with HIV. Through the qualitative life narrative approach, I could go deeper into their lives as respondents’ own lived accounts of their social worlds are highlighted, thereby extending an understanding of an under-researched group who are living with HIV. It is hoped that the benefits of a sociological analysis can be engaged in future to examine ageing, resilience, and the lives of older heterosexual people living with HIV.

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Appendix 1: Interview topic guide

Question:
Could you please tell me your life history, from your childhood onwards, leading up to today?

Areas to focus on:

A) Respondents
- Life so far from childhood onwards
- Family
- Education
- Work and volunteering
- Religious beliefs
- Migration and movement
- Interests

B) HIV status
- Knowledge of HIV before diagnosis
- Diagnosis
- Stigma
- Medicine and treatment
- Changing attitudes to HIV change over the years

C) Ageing
- Ageing
- Ageism
- Concerns about growing older
- Concerns with growing older whilst living with HIV?

D) Relationship history
- What is your relationship history?
- Where are you at now?

E) Thoughts for the future?
- What do you think is the future for HIV within the UK?
- What does the future hold for you?
- Goals and ambitions

Appendix 2: Participant information sheet

Title of the research project:
What are the problems and barriers, faced by older (50+) heterosexual men and women living with HIV, when seeking intimate relationships with others?

You are being invited to take part in a research project. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this project?
This research project's purpose is to examine whether there are any barriers or problems faced by older people, aged fifty and above, when meeting others for relationships and sexual contact. The research will ask about your own experiences of living with HIV and of meeting others for intimacy. It will also ask you about ageism and HIV-related stigma and whether you have come across any forms of it when meeting others. This is part of a part-time PhD study at the University of Leeds and interviews will be taking place from July 2017 until October 2017 and it will form a research project where older people's lives can be documented to raise awareness of what it is like to be living with HIV, in today's society.

Why have I been chosen?
I hope to interview ten heterosexual men and ten women, aged over fifty and living with HIV, to explore their own experiences of dating and intimacy. All people will be approached by a staff member who works at the HIV voluntary organisation that you use and attend, to see whether you are interested in taking part in the study or not.

What do I have to do and what will happen to me if I take part?
If you take part in the research, you will be asked to take part in a two-hour interview which will ask you about your life experiences. There may be a need to come back at an arranged point between yourself and the researcher if any extra points need clarified. This interview will be held at the HIV organisation where you were approached by a staff member, in a comfortable private room.

The interview will take a 'life history' approach and so will not just ask about your experiences of living with HIV and intimacy, but about your life more generally. Questions will be open and will allow you to give as much or as little detail as you wish. This can enable the Lead Researcher to see how people have been affected by different social views toward HIV at different time periods of their lives. Reimbursements for travel or time cannot be offered for this research, however, tea, coffee and biscuits will be supplied.

What are the possible benefits of taking part?
Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will add to the knowledge of people's lives living with HIV and will be used to help

to provide information for Third Sector organisations in offering services to older people living with HIV.

Do I have to take part?

Taking part in the research is entirely voluntary and it is up to you if you wish to do so. If you do not wish to take part, there will be no penalties involved. If you do decide to take part in the research, you will be given a copy of this information sheet (and be asked to sign a consent form) and you can still withdraw at any time up until the final writing up of and then publication of the research in 2018 without it affecting you in any way. You do not have to give a reason for withdrawing from the research. However, it will not be possible to withdraw your responses once the analysis of the data has begun and/or before the final writing up.

Will my taking part in this project be kept confidential? What will happen to the results of this research project?

All of your details will be confidential, anonymous and any identifying features or locations will be altered. Strict security procedures for maintaining the data will ensure that your transcripts and details will be kept behind a secure, password-protected computer. The storage and use of the research data (including your personal data) will comply with the Data Protection Act (1998), the Human Rights Act (1998) and the University of Leeds Code of Practice on Data Protection.

The only time confidentiality would have to be breached would be if you disclosed an intention to harm yourself or others. The final results of the research will be written into a PhD thesis and will be then published in both journal publications and a summary report which will be disseminated to voluntary sector organisations who work alongside people living with HIV, including any other interested voluntary organisations who may wish to also view the research. This summary research report will be produced in September 2021, and you can gain a copy of the published research and results for you to read. You will not be identified in any future report or publication.

Will I be recorded, and how will the recorded media be used?

The audio recordings of your interviews made during the research will be used only for analysis and for illustration in conference presentations and lectures. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings. Direct quotations may be used in publications and/or the final thesis.

Contact for further information:
Lead Researcher: Drew Dalton
Phone: (0191) 515 3204
Email: ssakd@leeds.ac.uk

Supervisor of the PhD and research: Prof. Nick Emmel
Phone: (0113) 343 6958
Email: N.D. Emmel@leeds.ac.uk

This study has been reviewed and given a favourable opinion by the University of Leeds Research Ethics Committee. You will be given a copy of this information sheet and a signed consent form to keep for your records. **Thank you for taking the time to read this.**

Appendix 3: Consent form

Consent to take part in a research project exploring the experiences of older (50+) heterosexual men and women, living with HIV, when meeting others for relationships and sexual activity	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. The contact number of the lead researcher Drew Dalton is (0191) 515 3204 and my email is ssakd@leeds.ac.uk should you wish to decline. If you withdraw, your data will be destroyed.	
I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I understand that my responses will be kept strictly confidential.	
I agree for the data collected from me to be stored and used in relevant future research in an anonymised form.	
I understand that other genuine researchers may use my words in publications, reports, web pages, and other research outputs, only if they agree to preserve the anonymity/confidentiality of the information as requested in this form.	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change.	

Name of participant	
Participant's signature	
Date	
Name of lead researcher	
Signature	
Date*	

*To be signed and dated in the presence of the participant.

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/ pre-written script/ information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be kept with the project's main documents which must be kept in a secure location.

Appendix 4: Ethics approval form

UNIVERSITY OF LEEDS

Andrew Dalton
Sociology and Social Policy
University of Leeds
Leeds, LS2 9JT

ESSL, Environment and LUBS (AREA) Faculty Research Ethics Committee
University of Leeds

7 January 2025

Dear Andrew

Title of study: **What are the problems and barriers, faced by older heterosexual men and women living with HIV, when seeking intimate relationships with others?**
Ethics reference: **AREA 15-106**

I am pleased to inform you that the above research application has been reviewed by the ESSL, Environment and LUBS (AREA) Faculty Research Ethics Committee and following receipt of your response to the Committee's initial comments, I can confirm a favourable ethical opinion as of the date of this letter. The following documentation was considered:

Document	Version	Date
RE AREA 15-106 provisional opinion.txt	1	13/05/16
AREA 15-106 5 - Appendix A Ethical Approval Form.doc	1	07/04/16
AREA 15-106 5 - Appendix B Risk Assessment.doc	1	07/04/16
AREA 15-106 5 - Appendix E Consent Form.doc	2	16/05/16
AREA 15-106 5 - Appendix F Participant Information Sheet.doc	2	16/05/16
AREA 15-106 5 - Appendix I Interview Topic Guide.doc	1	18/04/16

Please notify the committee if you intend to make any amendments to the original research as submitted at date of this approval, including changes to recruitment methodology. All changes must receive ethical approval prior to implementation. The amendment form is available at http://ris.leeds.ac.uk/EthicsAmendment.

Please note: You are expected to keep a record of all your approved documentation. You will be given a two-week notice period if your project is to be audited. There is a checklist listing examples of documents to be kept which is available at http://ris.leeds.ac.uk/EthicsAudits.

We welcome feedback on your experience of the ethical review process and suggestions for improvement. Please email any comments to ResearchEthics@leeds.ac.uk.

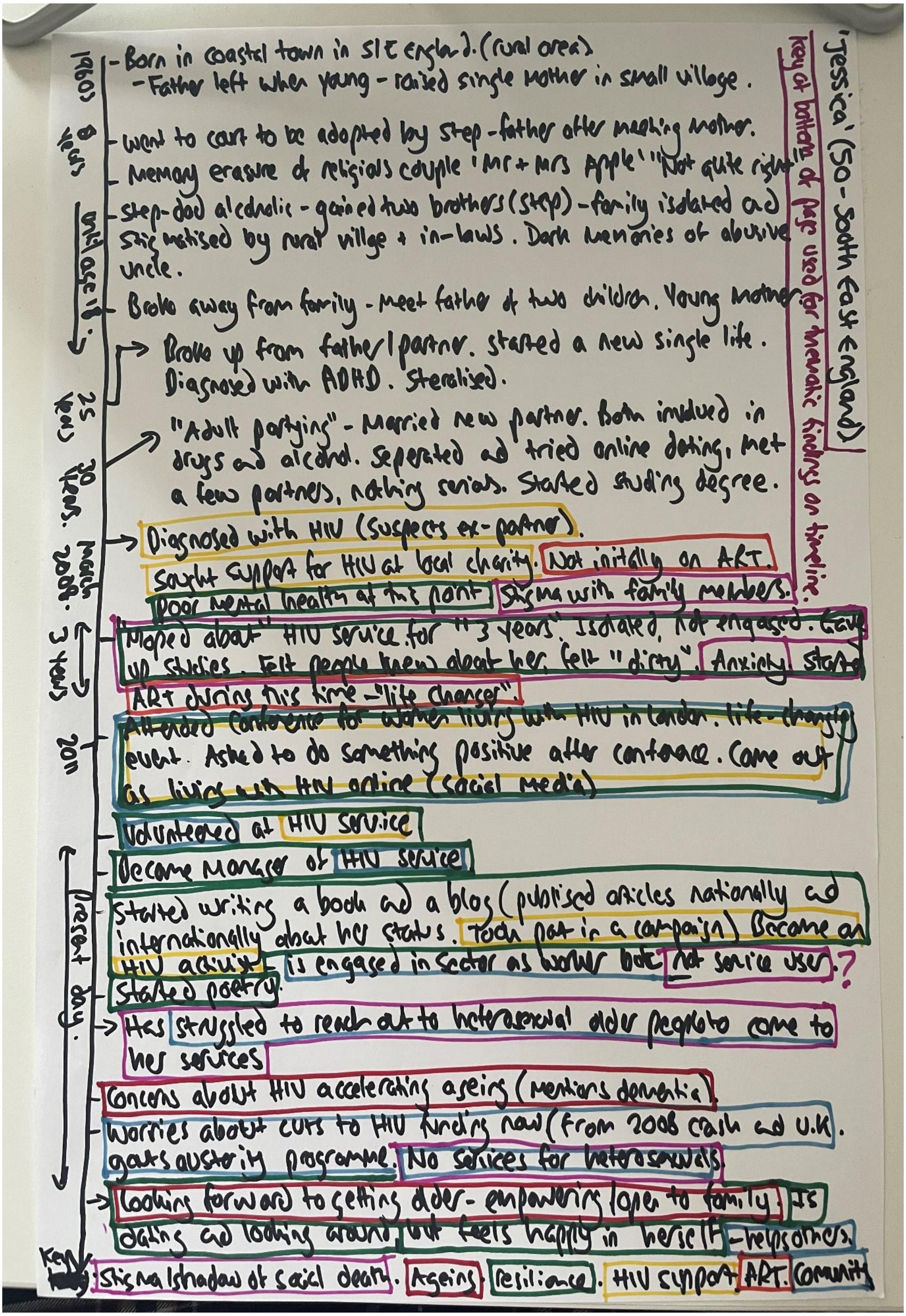
Yours sincerely

Jennifer Blaikie
Senior Research Ethics Administrator, Research & Innovation Service
On behalf of Dr Andrew Evans, Chair, AREA Faculty Research Ethics Committee
CC: Student's supervisor(s)

Appendix 5: Link to blog

https://hivandageing.wordpress.com/drew-dalton/

Appendix 6: Example of a Respondent's Timeline: 'Jessica'



'Jessica' (50 - South East England)

Key at bottom of page used for thematic findings on timeline.

1960s - Born in coastal town in S/E England. (rural area)
- Father left when young - raised single mother in small village.

8 years - Went to court to be adopted by step-father after marrying mother.
- Memory erasure of religious couple 'Mr + Mrs Apple' "Not quite right"
- Step-dad alcoholic - gained two brothers (step) - family isolated and stigmatised by rural village + in-laws. Dark memories of abusive uncle.

until age 18. - Broke away from family - Meet father of two children. Young mother.

25 years → Broke up from father/partner. Started a new single life. Diagnosed with ADHD. Sterilised.

30 years. → "Adult partying" - Married new partner. Both involved in drugs and alcohol. Seperated and tried online dating. Met a few partners, nothing serious. Started studing degree.

March 2008. → Diagnosed with HIV (suspects ex-partner). Sought support for HIV at local charity. Not initally on ART. Poor mental health at this point. Stigma with family members.

3 years - "Moped about" HIV service for "3 years". Isolated, not engaged. Gave up studies. Felt people knew about her, felt "dirty". Anxiety. Started ART during this time - "life changer".

2011 - Attended conference for women living with HIV in London. Life-changing event. Asked to do something positive after conference. Came out as living with HIV online (social media)

- Volunteered at HIV service

Present day. - Became Manager of HIV service
- Started writing a book and a blog (published articles nationally and internationally about her status. Took part in a campaign) Became an HIV activist - is engaged in sector as worker but not service user. ?
- Started poetry.

→ Has struggled to reach out to heterosexual older people to come to her services
- Concerns about HIV accelerating ageing (mentions dementia).
- Worries about cuts to HIV funding now (from 2008 crash and U.K. govts austerity programme. No services for heterosexuals.
→ Looking forward to getting older - empowering / open to family. Is dating and looking around, but feels happy in herself - helps others.

Key: Stigma/shadow of social death. Ageing. Resilience. HIV support. ART. Community