

**People Living with HIV Considering a  
Transition to Aged Care – an emerging phenomenon.**

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## **Acronyms**

AIDS - Acquired immune deficiency syndrome

ASHM - Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine

cART - combination antiretroviral therapy

CINAHL - Cumulative Index to Nursing and Allied Health Literature

Cth - Commonwealth

GRAI - Gay, Lesbian, Bisexual, Transgender and Intersex Retirement Association

Incorporated

HIV - Human immunodeficiency virus

LGBTI - lesbian, gay, bisexual, transgender or intersex

NICMs – noninfectious comorbidities

PLHIV - People living with HIV

Pp – Polypathology

UNAIDS – United Nations Programme on HIV/AIDS

WHO – World Health Organisation



## **Abstract**

People living with HIV (PLHIV) are an ageing population. In 2017 those aged 50 and over represented 46% of those living with HIV in Australia, and that number is expected to increase. This is a result of a combination of factors, primarily the continuing advances in antiretroviral therapy, which have reduced the incidence of HIV-associated mortality. PLHIV are now living into their 80s and 90s with varying degrees of physical and/or cognitive decline. It is during this decline that PLHIV may need to consider a transition to aged care. The aim of this research is to explore and understand the experiences of older PLHIV facing the prospect of a life lived in aged care.

To explore this topic an interpretative hermeneutic phenomenological methodology was considered most appropriate. This could best uncover the meaning behind the lived experience of older PLHIV considering transitioning to aged care. In this thesis, issues pertaining to the use of a hermeneutic phenomenological approach in this research are discussed, as well as issues around research representation or, as Koch states, “whose voice is being heard – the researcher’s, the participant’s or both”. Issues of integrity and trustworthiness are also discussed.

Fifteen PLHIV aged 60 years and over volunteered to participate in this research, and their stories were collected in one-on-one, face-to-face interviews that were digitally recorded and transcribed. They shared their experiences of their life lived with HIV from their diagnosis to the present. This was useful to understand how that past history informed how they feel about their life as they age and as they consider their future. Paramount for this research was to learn their feelings and concerns around a transition to aged care and how these might be addressed and ameliorated.

This study found that this group had different experiences of a life lived with HIV. This often depended on the era of their diagnosis. As well, there were differences in their considerations around a life lived in aged care in the future. Some participants completely rejected the notion of a transition to aged care, with a few mentioning euthanasia as their preference. Other participants believed that, with increased

education around HIV and the existence of anti-discrimination legislation and aged care quality standards, they would be treated or cared for with respect and dignity, like others in the aged care sector. They felt that, with all the above in place, a life well lived within aged care would be achievable.

Through this research the silence of the older PLHIV who participated, and hopefully of the larger older PLHIV community, has been broken. The new knowledge gained through this research has illuminated the meaning behind their experiences and future prospects. The findings from this research have given hope for many in this group that, with appropriate structures and practices, they would feel welcomed and embraced in aged care, resulting in a life well lived. It is now over to those who provide aged care to meet those hopes and expectations.

## **Declaration**

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint award of this degree.

I give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library Search and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

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## **Chapter One: Introduction**

The majority of people living with HIV (PLHIV) are living longer and into older ages than once thought possible. In 2015, when the literature review was first undertaken for this research, within Australia it was revealed that PLHIV aged 55 and over currently represented 25.3% of those infected with HIV and it was estimated that by 2020 that number would increase to 44.2% (Jansson & Wilson 2012). In 2017, the percentage of PLHIV aged 50 plus years has risen to 46%, with that number estimated to further increase over time (Kirby Institute 2017). The ageing population of PLHIV is testament to the success of combination antiretroviral therapy (cART), for those who have access to, are adhering to and responding well on this therapy. This is not, it must be acknowledged, the lived experience of all PLHIV around the world. As a result, some within this group, especially those without family or significant other support, will be living to an age or stage in life where frailty and inability to cope and function independently will gain real prominence. For some, this will involve consideration of formal community support, for others transition to living in long-term residential aged care facilities.

### **Statement of problem/issue**

PLHIV may have concerns and anxieties about the transition to aged care. As with many in the ageing non-HIV population, PLHIV may feel reluctant to move into the aged care sector. They may have concerns about isolation, changes in lifestyle and perhaps end-of-life issues. Added to these, research has found that PLHIV considering the transition into aged care perceive they will enter a predominantly “heteronormative” (Comfort et al. 2010, p. 28) environment, and fear stigma and discrimination based on their sexuality or lifestyle choices. As well, there are issues related to the attitudes and specific HIV knowledge of the aged care sector workforce (Cummins & Trotter 2008).

### **Significance of this research to this researcher**

I have been working as a Registered Nurse in the area of the management of HIV and care for PLHIV for the past twenty years in both primary care and tertiary care settings

in metropolitan South Australia. Over this period of time I have been witness to the transformation in quality of life and life expectancy for PLHIV who are doing well with and who are adherent to therapy. Conversely, I have also witnessed the health ramifications for those who are not doing so well, those not fully adherent to therapy, or those who decline active therapy. These groups have experienced more rapid impairment of health and poorer health outcomes. They are more likely to experience physical and/or mental decline, and life-threatening conditions that required multiple admissions to hospital. These groups are more likely to succumb to the effects of advanced HIV. More pertinent to this research endeavour, I have witnessed an ageing population of PLHIV, some of whom are experiencing age-related conditions at much earlier stages in their lives than those in the non-HIV population.

In my role as HIV Nurse Consultant within the Infectious Diseases Unit in the tertiary care setting of a major inner-city hospital I am a member of the team that manages the care of the majority of PLHIV in a jurisdiction within Australia. This role involves assisting PLHIV to better understand and to follow their therapeutic regimens and assisting at times when problems manifest. My aim in this role, along with the team, is to maintain better health outcomes for this client group for longer periods of time. In this role I am also actively involved in supporting those who may not be managing as well living with HIV, especially those who are living alone and in varying degrees of isolation. In such circumstances the role of the HIV Nurse Consultant is to identify and assist in accessing higher levels of community support for those requiring such support in their home or, when required, assistance with transition to residential aged care. The number who fall within this category of needing these extra supports and transition, as the above statistics demonstrate, has increased.

HIV and aged care has been a passion for me for many years. Indeed it was the impetus to study and research this phenomenon at a Master of Nursing level and now further at the PhD level. This interest in and passion for the topic of PLHIV and aged care stems from my professional experience of assisting PLHIV transitioning into aged care, often at a younger age than others from the non-HIV community. It is acknowledged that there exists government sponsored Home Care Packages for those who qualify to receive care at home. To remain at home while receiving care would be the preferred option for many people. Receiving care in one's home environment gives those



receiving care a sense of control, ownership and a sense of power over their life world. Such control, ownership and power set up the relationship between those receiving care and the care giver. For PLHIV receiving care at home, this sense of control and ownership in this relationship would mitigate against any concerns of potential feelings of stigma and discrimination that the person living with HIV may experience. For PLHIV requiring a life lived away from the home environment, one that was now lived in the environment of residential aged care, that sense of control and ownership is reduced or non-existent. This sense of loss of control for PLHIV within this foreign environment may render them concerned about and vulnerable to feelings of potential stigma and discrimination. Thus, for the purposes of this research, the rationale for the focus of PLHIV transitioning to residential aged care is central. I therefore believe that this is a topic of acute importance and, as the current literature demonstrates, needs to be further investigated.

With my history of caring for PLHIV, my interest in their health and well-being for a number of decades, and my passion for this research project, I make the following declaration. I bring to this project my own historicity of working with PLHIV for many years, in a variety of settings, observing the various challenges PLHIV have faced and their levels of health and ill health as they age. I therefore bring to this research my own situatedness and pre-understanding of these issues. This historicity, pre-understanding and fore-structure brings to this research project a level of prejudice that I believe neither hinders, nor gets in the way of, the telling, the analysis and discussion of the stories of these participants.

### **Significance to the population group, PLHIV**

The concerns raised by PLHIV about the transition into aged care relate to attitudes and levels of comfort, or not, in residential aged care facilities. Recent studies (Howard et al. 2013; Cummins & Trotter 2008) have shown that these concerns may include anxiety regarding the attitudes of nursing staff within these facilities towards caring for PLHIV. Staff feelings about sexuality, or lifestyle choices, lack of education about HIV, concerns about occupationally acquiring HIV from the resident and, most importantly, ensuring antiretroviral therapy is given as prescribed may loom large. It is imperative, from the perspective of PLHIV, that there is as seamless a transition as possible from

home to care facility and that there are no barriers to PLHIV receiving the same quality of care as would be provided to others within these facilities. Research into this topic is significant for these reasons and has been my passion since commencing work in this area of nursing.

While society's perspectives around homosexuality and HIV may have changed over the past several decades, PLHIV have often been subjected to and made vulnerable to stigma, marginalisation and discrimination because of their sexuality, or life choices. This vulnerability has often been the lived experience of this group during their youth, middle age and now into their old age. As those who have suffered from these feelings approach decisions about moving into a residential aged care setting, to what extent will their HIV status magnify this vulnerability? How can this vulnerability be mitigated? PLHIV should receive the same quality of care as is provided to the non-HIV population. If there are issues in relation to this then these need to be addressed and settled prior to admission into the aged care environment.

### **Background: History of HIV**

To provide a more scientific context about HIV and its relevance to this thesis, it may be beneficial now to include a brief history of HIV, its epidemiology, the natural science of HIV, current statistics of groups most affected and current global and local initiatives to reduce new HIV infections. This information will be presented in order to highlight the impact of HIV on those affected.

HIV was first identified in 1983 in France by Dr Luc Montanier and Dr Françoise Barre-Sinoussi, followed in 1984 by more comprehensive characterisations of HIV by Dr Robert Gallo and Dr Jay Levy in different centres in the US. This followed on from presentations to a number of clinics in San Francisco and Los Angeles in 1981 by a number of gay-identified men with illnesses that were later described as Kaposi's sarcoma and *Pneumocystis carinii* (now known as *Pneumocystis jiroveci*) pneumonia, who were subsequently found to be immune deficient. The culmination of these presentations over that year and the following were documented in 1982 in the *Morbidity and Mortality Weekly Report* (Kearney et al. 2010; Crock 2017; Carr 1992). These dates of first presentations and identifications of HIV notwithstanding,

retrospective studies testing stored blood samples dating as far back as 1959 (ANCARD 1998) add to the belief that HIV has existed for the past 100 years (Shehu-Xhilang & Oerlich 2009; Cameron & Kelly 2009). Initially isolated and endemic to a particular region in Zaire in Africa, HIV appears to have crossed species from wild African monkeys and was spread to other regions by increasing numbers of African and European travellers throughout the latter part of the 20<sup>th</sup> century, entering the US and Europe probably in the mid-1970s (Shehu-Xhilang & Oerlich 2009; Cameron & Kelly 2009).

Acquired immune deficiency syndrome (AIDS) is a less frequently used term these days. AIDS, essentially an umbrella term, “was the name given in 1982 to a group of symptoms (a syndrome) which appeared to have a common cause, an acquired immunodeficiency” (Carr 1992, p. 3). The term was used to describe what was otherwise known as ‘late-stage’ or ‘end-stage’ disease and described the level of immune depletion (a CD4 cell count – a marker within the white blood cells – of fewer than 200 cells per millilitre), when certain opportunistic infections and malignancies were more likely to present. The term AIDS, these days, is generally deemed unnecessary. HIV is the virus that is acquired; AIDS is purely a stage of HIV infection when depletion of the immune system has become manifest in the form of opportunistic disease. It is a term that tends to conjure unnecessary fear and stigma. Therefore, for the purposes of this thesis, I will not use the term AIDS unless I am directly quoting from the literature or from the words of the participants in this study. The basic virology of HIV is more fully described in many scientific texts (texts from the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine [ASHM], within which is published the on-line resource titled HIV Management in Australasia – a guide to clinical care (are strongly recommended). Thus, I will refer readers to those texts for a more detailed description of the disease. For the purposes of this thesis, a brief description will follow.

HIV is a virus that attacks the human cellular immune system, particularly the CD4-positive T cell, depleting this defence system over time to a state where the body is unable to fight some infections and malignancies, rendering the person, if untreated, more prone to opportunistic disease leading to poor health outcomes (Kelly 2009; Craft et al. 2010). Transmission of HIV occurs via a number of pathways: 1) blood borne –

HIV-infected blood enters another person through sharing injecting equipment, tattooing, etc.; 2) unprotected sex – sexual activity where HIV-infected blood or bodily fluids enter through the vulnerable tissues of another person; 3) mother to child – in utero, during birth or breastfeeding. Those who are most prone to acquisition include men who have unprotected anal intercourse with other men; injecting drug users; sex workers; healthcare workers; those who are disadvantaged and marginalised; those discriminated against on the basis of their sexuality; and youth – those under 20 years of age. In Australia, in 2017, HIV transmission predominantly occurred via unprotected homosexual contact (63%), the combination of male-to-male sexual activity and injecting drug use (6%), and injecting drug use alone (3%) (Kirby Institute 2017, p. 23).

At the time of gathering statistics for this research there were an estimated 35 million PLHIV globally, daily new infections numbering 6000 and 1.5 million deaths per year (UNAIDS 2013; Crock 2017). In Australia in 2013 it was estimated that 25,000 people were living with HIV, with deaths numbering 6800 since the beginning of the epidemic (Kirby Institute 2013). In South Australia in 2013 there were believed to be approximately 1200 PLHIV (Kirby Institute 2013). Reviewing the literature more recently, in 2018 the worldwide population of PLHIV was estimated to number 37.9 million (WHO 2018). In Australia it is estimated that there are 27,000 PLHIV (Kirby Institute 2017). In Australia, of the 27,000 PLHIV, those aged 55 years and above by 2020 will represent approximately 46% (Jansson & Wilson 2012).

Since the introduction of antiretroviral therapy in the mid-1980s, and especially since the advancement in what was termed combination antiretroviral therapy (cART) from 1996, PLHIV have better outcomes and life expectancy than previously thought possible. This has changed the demography of HIV significantly. No longer a disease predominantly of the young, with the prospects of a shortened life span, HIV is now considered a chronic, manageable disease that affects all age groups, with prospects for longevity that approximate those of people without the infection.

### *Public health initiatives*

Since the beginning of the HIV epidemic there have been various government and community public health initiatives aimed at informing the public about this infection,

especially targeting those who may be at higher risk of infection. The impetus of these initiatives was slower in some regions of the world than others. In Australia, in the early period of the epidemic, community groups most affected by HIV and the federal and state governments joined in partnership in a campaign to stem the rise of HIV (Altman 2013). One such campaign, developed in partnership in 1987, was the ‘Grim Reaper’ campaign.

The ‘Grim Reaper’ campaign (circa 1987) was a federal Government of Australia initiative as a result of the global incidence of heterosexual transmissions. At the time, in some circles, HIV/AIDS was referred to as the ‘gay plague’ (Sendziuk 2003, p. 136), but it was also seen to be infecting some members of the heterosexual community. Therefore, it was thought that if no action was taken HIV would continue unchecked. The purpose of the campaign was “to inform Australians that HIV did not discriminate between age, sex, or gender and that prevention was the only method Australians had for combating AIDS” (Sendziuk 2003, p. 138).

Debate still rages about the ‘Grim Reaper’ campaign, with commentators representing viewpoints from both the heterosexual and homosexual communities (Sendziuk 2003; Lupton 1994). Critics argue that the campaign was oppressive and unnecessarily scared the population, the vast majority of whom were “at little, or no risk” (Sendziuk 2003, p. 144) of HIV transmission. Today, public health HIV campaigns strive to be more nuanced and target specific regions and groups with high levels of HIV.

The UNAIDS organisation, over many years, has emboldened the world to adopt various strategies to eliminate HIV. UNAIDS (2015) has set targets to be achieved by 2030 to achieve this aim. This strategy is referred to as ‘95-95-95’. That is, by 2030, 95% of people who have been infected with HIV will know their HIV status; 95% who have been diagnosed with HIV will receive antiretroviral treatment, and 95% of those receiving treatment will have HIV viral levels that are undetectable. And finally, that by 2030, there will be zero discrimination for those living with HIV. The strategy behind these aims is to reduce the numbers of new infections and reduce the spread of the virus, leading to the eradication of the virus. The strategy involves encouraging more HIV testing, knowing one’s own HIV status, adopting safe sex behaviours, knowing where to receive care and treatment, commencing and adhering to therapy and thus

living with a virus under control (UNAIDS 2015). These are essential elements to achieve these aims.

The following sections will outline the steps used to explore this topic more fully. They will set out the research aim, the research questions, and objectives. A more detailed description of the rationale behind the choice of methodology and methods in pursuit of achieving these aims and objectives will be discussed in Chapters Three and Four.

### **Aim of this research**

The aim of this research is to empower PLHIV needing to transition to the aged care environment to lead a life well lived.

### **Research questions**

To achieve this aim, two research questions were chosen:

What are the concerns of PLHIV considering a future life well lived in aged care?

What issues do PLHIV perceive need to be addressed to facilitate a life well lived in this transition?

### **Objectives**

The objectives of this research are:

- 1) To explore the expectations of PLHIV of the aged care environment including impacts on their lifestyle.
- 2) To explore the levels of anxieties and fears that PLHIV may have in relation to a transition to living in the residential aged care environment.

- 3) To explore participants' anxieties and fears related to discrimination while transitioning to living in a residential aged care facility.
- 4) To identify what strategies participants will put in place to assist them in their transition.

### **Research design**

I believed that the best way to achieve the above was to adopt a critical qualitative methodology, in the form of hermeneutic phenomenology. Originally, I believed this research would follow a grounded theory format as I considered that this research was an area little explored. However, in the research that has been conducted, there is enough evidence, both formal and informal, to suggest the use of a different research methodology, or to explore this topic through a different lens, that of hermeneutic phenomenology. Research at this level, or through this lens, better enables a deeper exploration of the lived experience of PLHIV as it relates to their feelings about ageing and their transition to a life lived in aged care. There is a more detailed discussion of the research methodology and method in Chapters Three and Four.

### **Assumptions**

The assumptions I held at the commencement of this research and which formed the impetus to research this topic are declared as follows:

- That participants will hold and express real concerns and fears with regards to a transition to the residential aged care environment.
- That some of these concerns will be around the participants' sexuality and how they perceive they will be stigmatised and discriminated against by both the staff and other residents in what they would believe to be a predominantly heteronormative environment. In relation to the concerns that the LGBTI community may have regarding residential aged care, Comfort et al, (2010), describe heteronormativity as the "presumption and preferences of

heterosexuality” (p27), of the residents within that environment.

Heteronormativity is the assumption that all those within a group or within a location identify solely as heterosexual.

- That participants will have real fears around their HIV status. This includes fear about discrimination based on their status and real fears that the staff working in this environment will be ill-equipped educationally and attitudinally to care for their unique condition.
- That PLHIV are not a homogenous group. Within this population are those whose sexual identity is diverse, those who identify as lesbian, gay, bisexual, transgender or intersex (LGBTI) and those whose sexual identity is heterosexual. They have myriad life experiences, the impact of which may have been profound or not. As well, there are those for whom disclosure of their HIV status or sexual identity is of no concern, and those for whom such disclosure will have a major impact, especially in relation to their well-being when transitioning to aged care.

## **Summary**

This chapter has introduced the topic of HIV, describing the history of this infection, global and local statistics concerning its incidence and prevalence, its natural history and treatment success. The chapter also discussed several issues associated with a life lived with HIV as they relate to discrimination, legislation, ageing, and prospects of a life lived in aged care. It has also described the significance of this issue from my own perspective, as well as that of the population group at the centre of this research and for the aged care nursing workforce. Finally, this chapter outlined the aims, research questions and objectives to reach the answers to the questions asked. It also has provided a declaration of my assumptions as I entered this research. In essence, this research begins to develop a theory that will best help PLHIV achieve a life well lived as they transition to the residential aged care sector.



## *Chapter outlines*

The following outlines the chapters of this thesis.

**Chapter Two: Literature review.** This chapter will discuss the literature around the topic of HIV – its history, its impact globally and locally, HIV and ageing, and HIV and aged care.

**Chapter Three: Methodology.** This chapter will discuss the methodology to be used to answer the research questions.

**Chapter Four: Methods.** This chapter will discuss and outline the methods used, including the steps taken to recruit PLHIV and capture their views to explore the phenomenon under investigation.

**Chapter Five: Findings.** This chapter will bring forth the various elements that resonated from the interviews. These elements have been constructed into units of meaning or themes. Within these themes the voices of the participants will be presented as they tell their stories of a life lived with HIV and their thoughts about a future lived in aged care.

**Chapter Six: Discussion.** This chapter will bring out and discuss the deeper meaning of the stories told by the participants as articulated by them and interpreted by me. The participants' stories will be compared with those of others in the broader PLHIV community. Stories of other lives lived with HIV as they pertain to discrimination, living in secrecy, ageing and thoughts of aged care have been captured in published research, or from stories that I found, gathered and explored. My intention is to determine whether there are any similarities or differences between the stories told by the participants in this research and those of other PLHIV in the broader community. This was done to better illuminate, to give deeper meaning, to this research and was deemed worthy of inclusion.

**Chapter Seven: Conclusion.** This chapter will summarise the findings of this research as they pertain to the aim, objectives and research questions. This chapter will speak to

the rationale for the research methodology and methods used in acquiring the stories from the research participants and provide the rationale for the inclusion of myself as a participant in the gathering of, the analysis of and the discussion of these stories. Included in this chapter will be a discussion of the limitations of this research, recommendations and implications for future research. This chapter will also speak of the participants who volunteered to take part in this research and speak of those who, for reasons unknown to me, felt unable to participate. Those voices, those stories and those concerns may be diametrically different from those who did participate. Their voices, stories and concerns are lost to this research.

## **Chapter Two: Literature review**

This chapter will discuss the literature around HIV as it relates to ageing and aged care. It will discuss the accelerated ageing process experienced by some PLHIV, a phenomenon distinct to this group. The chapter will also discuss issues around homosexuality, including the history of its criminalisation and decriminalisation in Australia. This history will focus on the stigma and discrimination experienced by PLHIV who were subject to these experiences throughout those times. Issues relating to PLHIV and the effects of discrimination experienced by this group will be explored from a number of studies as this may impact their considerations concerning a transition to a life lived in aged care, if this becomes necessary.

The literature review for this qualitative research was conducted in two stages: the preliminary stage and the secondary post-analysis stage motivated by the data collected from the research participants. To help guide the research at the beginning, the preliminary stage focused on exploring what had been written around HIV and ageing and HIV and aged care. This preliminary stage of the literature review accorded with Streubert and Carpenter's (1999) description of the conduct of a literature review for a qualitative project. They note: "[Q]ualitative researchers do not generally begin with an extensive literature review ... [however] a cursory review of the literature may help focus the study" (p. 20). The secondary post-analysis stage of the review of the literature focused on what was important to further explore the meanings that emanated from what the participants had expressed. The emphasis in the secondary review was on exploring the elements of previous work that most resonated with those data. Streubert and Carpenter (1999) believe that in qualitative research "[I]t is important to conduct the literature review after analysing the data. The purpose ... [being] to place the findings in the context of what is already known" (p. 20). The following will describe how this literature review was conducted.

### **Literature search**

Research for this study has been collected from the following sources: PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL) via EbscoHost

platform, Embase via Elsevier platform, HIV-dedicated journals, monographs, books and papers from non-government organisations and HIV-dedicated conferences. The first stage of literature retrieval was conducted in 2014–2015 and included literature extending back to 2009. The second stage of literature retrieval occurred in 2019 to explore research published in the past five years. For both stages literature relevant and deemed significant to this study were included.

The logic grid used for data searches has the following main categories: HIV/AIDS; aged care; attitudes; nursing, as illustrated in Table 2.1.

**Table 2.1: Logic grid for PhD literature search**

<b>HIV/AIDS</b>	<b>Aged care</b>	<b>Attitudes</b>	<b>Nursing</b>
Aids [sb]	Homes for the aged[mh] OR homes for the aged[tiab] OR old age home*[tiab] OR aged care[tiab] OR nursing homes[mh:noexp] OR nursing home*[tiab] OR residential facilities[mh:noexp] OR residential facilit*[tiab] OR skilled nursing facilities[mh] OR long term care[mh] OR long term care[tiab]	Therapeutic commitment[tiab] OR health knowledge, attitudes, practice[mh] OR attitude[mh:noexp] OR attitude*[tiab]	Nurs*[tw] OR jsubsetn[text]

### **HIV and ageing**

This section on HIV and ageing will outline some reasons why PLHIV are more prone to ageing and consider why they may be ageing at a quicker rate than members of the non-HIV population. Terms such as ‘senescence’ and ‘immunosenescence’ will be explained to help explain the science behind this phenomenon.

The increase in the number of people ageing with HIV, those aged 50 years and over, “is as a consequence of younger adults ageing with HIV, in addition to new diagnoses in later life” (Kearney et al. 2010, p. 537). Thus, it must always be remembered that

HIV diagnosis does not only occur in the young; people in older aged groups are also susceptible to infection. As Kearney et al. (2010) state:

As HIV is transmitted through sexual intercourse, exposure to contaminated blood and by perinatal transmission, it is often presumed that older individuals are at lower risk of contracting the virus. However, emerging social practices such as divorce and impotence treatments provide opportunities for additional relationships. This now means older adults may have increasing numbers of sexual partners and consequently, greater risk of exposure. (p. 537)

The older age group now being diagnosed with HIV is a concern. A missed diagnosis at or soon after seroconversion to HIV and consequent delay in the initiation of treatment until years later, when opportunistic diseases and opportunistic cancers present, can have deleterious outcomes for this older age group (Wheeler & Seager 2015, pp. 26–27). Seroconversion to HIV occurs when HIV-infected semen or blood enters the bloodstream of a non-HIV-infected person. The effects of seroconversion can occur within a number of weeks post infection; during which time symptoms “suggestive of acute viral infection [may occur] ... Most illnesses are mild, but all tend to be prolonged, lasting from two to six weeks” (Bannister, Begg & Gillespie 2000, p. 311).

As discussed, HIV is no longer considered purely a young person’s disease where one is diagnosed and death is a likely outcome within a few years. With the advent of antiretroviral therapy, people who are diagnosed with HIV can be better monitored, receive successful treatment earlier and lead longer, healthier lives. Improved treatment and control of the virus has improved longevity so that PLHIV can live into old age in a way not dissimilar from those in the non-HIV population (Crock et al. 2017; Slavin & Ogier 2011).

HIV and ageing has not previously been deemed relevant to consider, resulting in a paucity of literature on this topic. In more recent years, because of the realisation that an ageing HIV population exists and the prediction that 50% of PLHIV will be aged 50 and over by 2020, the topic of HIV and ageing has gained much more attention. Indeed, it is now said that “HIV and ageing is an active field of research and publication”

(Woods 2019, p. 10). Headlines such as “The first HIV/AIDS generation reaches retirement age”, from an article published in *Newsweek* in October 2014, is public recognition of the fact there exists an older group of PLHIV. Reading this headline was, for me, encouraging and heart-warming. HIV and ageing, as an actuality, has come to the forefront of people’s minds, not only those affected, their families and significant others, but also their healthcare providers. This phenomenon has been explored from a number of viewpoints. From a medical perspective, authors have explored the signs and symptoms to observe in those ageing with HIV. The authors who have investigated this area include Guaraldi et al. (2011); Schouten et al. (2014); Kearney et al. (2010); Slavin and Ogier (2011); Deeks (2011); and Deeks and Phillips (2009). In more recent times long-term care for the older person living with HIV has started to be explored (Murray, Cummins & Bloom 2014; Schouten et al. 2014; Menadue 2014; Positive Life SA 2014; Cummins & Trotter 2008; Wheeler & Seager 2015).

In a monograph published by the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM), in relation to the changing demography associated with an ageing population of PLHIV, Herrmann and Skinner (2016) state:

In Australia, between the years 1996 and 2006 the number of people with HIV infection over the age of 65 years grew tenfold. By 2012 about 10% of new diagnoses were in people aged 50–59, reflecting a global trend of prolonged survival and late acquisition among older adults. However, despite the positive outcomes of effective and tolerable treatments, it is becoming increasingly evident that independent factors related to HIV infection are complicating the ageing process for people living with HIV.  
(p. 1)

These authors also clarify what is meant by the term ‘older’ population. They say that the definition given by the Australian Government “considers age chronologically and, accordingly, people aged 65 years and older are classified as ‘older’” (p. 1). This then is what is meant in this research by the term ‘older PLHIV’. One criterion for this research was that the participants needed to be 60 years of age or older. The majority of those who participated in this current research were in their late 60s, thus qualifying them to be classified as part of an older population of PLHIV.

In their monograph on HIV and ageing, Herrmann and Skinner (2016) describe ageing as:

biological ageing ... [which can be] modifiable or preventable. However, HIV infection in the absence of cure, is not inherently modifiable and evidence suggests that HIV infection augments biological ageing directly by way of prolonged immunodeficiency, chronic immune activation and side effects of treatment; indirectly via anxiety and depression. In addition to conditions commonly associated with ageing in the general population, HIV-associated immunopathology and the diverse pathways that have led to the HIV seropositive status ... such as injecting drug use, sex work and men who have sex with men, represent additional risk factors influencing health in later life. High rates of anxiety and depression, substance use and comorbidities together with cumulative unresolved side effects of earlier therapies, e.g. peripheral neuropathy and lipoatrophy, are additional stressors on physiological and psychological systems, which affect health-related quality of life .... It is becoming evident that people with HIV infection, especially those with a history of prolonged immunodeficiency, have complex care needs at the end of life. (pp. 1–2)

It is now recognised that not only are PLHIV ageing, but that the ageing process and age-related multimorbidities, such as those related to cardiac disease, cancer and osteoporosis, may be occurring at a quicker rate and at an earlier age than in the non-HIV population (Bretaña et al. 2018; Kearney et al. 2010; Reiss 2014; Green 2012; Barlow 2011). The terms senescence and immunosenescence are often used in the literature on HIV and ageing. These will now be explored.

**Senescence** is the outcome of the body's decreasing ability, as we age, to maintain or to reproduce effective cell function, particularly that related to muscle and bone cells. This decrease in effective muscle and bone cell function leads to these becoming weakened, leading to a "greater risk of falling and ... [the breaking] of major bones" (AIDS MEDS, 2011, p. 2). Senescence, or ineffective cell production, also applies to brain cells, which

can lead to coordination and memory problems. Further, it can result in defective immune cells that are unable to keep infections and cancers at bay. This last form of senescence, called immunosenescence, has a particular relevance for people with HIV (Nasi et al., 2014; Ndumbi, Gilbert & Tsoukas 2015; Deeks 2011; Slavin & Ogier 2011).

**Immunosenescence**, otherwise termed ‘immune exhaustion’, is “seen in the very old ... that are likely related in part to persistent inflammation” (Deeks 2011, p. 141). In PLHIV it is a result of the long-term effects of the continual inflammatory response to HIV. Despite receiving and responding well to combination highly active antiretroviral therapy (cART), with a replicating virus under control, PLHIV still have the HIV virus in their systems, albeit in small quantities, which they are fighting on a daily basis. This fight constantly triggers an inflammatory response. Using microscopic examination on the immune cells of PLHIV, scientists “find that these cells often have the same degree of immune exhaustion as HIV-negative people who are many decades older” (AIDS MEDS 2011, p. 3). Thus, older PLHIV are experiencing aged-related conditions several years earlier than the non-HIV population. The consequence of these ageing cells is the phenomenon termed “premature ageing” (Barlow 2011, p. 1) for those with HIV.

In a study conducted by Schouten, et al, (2014) they found:

HIV-infected participants, compared with uninfected controls of similar age, had a significantly higher prevalence of age-associated non-communicable comorbidities (AANCCs), both in terms of composite comorbidity burden, and more specifically of hypertension, cardiovascular and peripheral vascular disease and impaired renal function” (p1792). Schouten et al. conclude that PLHIV in this study had significantly higher prevalence of several age-related conditions than the non-HIV cohort. Indeed, Schouten et al. found that “age related illnesses typically developed five years earlier than their HIV negative peers” (Schouten et al. 2014, p1792). Examples include: hypertension (45% versus 31%); heart attack (4% versus 2%); peripheral artery disease (3% versus 1%); and impaired renal function (4% versus 2%). Schouten et al. conclude that



HIV infection is associated with inflammation, innate immune activation and altered coagulation, which are generally considered important drivers for co-morbidity in both HIV un-infected and HIV infected individuals ... [and] this might support the hypothesis of premature or accelerated ageing in PLWH. (Schouten 2014, p. 1792-1794).

In another study conducted by Guaraldi, et al (2011), their findings were similar to those of Schouten et al. In the Guaraldi et al study, they found their HIV-infected participants were experiencing age related comorbidities, such as cardiovascular diseases, hypertension, renal failure, bone fracture, and diabetes several years younger than their non-HIV participants. In their study they focused on noninfectious comorbidities (NICMs) and polypathology (Pp) – more than two NICM.

We found a significantly greater likelihood of NCIM risk among HIV-infected persons, compared with controls, particularly at younger ages ... for example, a 40-year-old HIV-infected person displayed a Pp risk similar to that seen in a 55-year-old control subject” (p1122).

These findings corroborated those of an earlier study by Deeks (2011) where he observed “that HIV-associated immunosenescence contributes to immunodeficiency and the early onset of age-associated diseases” (p145), these he lists as cardiovascular disease, cancer, frailty, liver, kidney, bone disease and neurocognitive complications” (pp. 141–144).

Accelerated, premature ageing for PLHIV, described in these references, has great significance for the purposes of the present study. For PLHIV, suffering the effects of physical and cognitive impairment is consequential. These effects will impact on their quality of life and requirements for extra support at home. They may also result in an inability to remain at home. The need to transition to aged care is being considered by some PLHIV, especially if they are currently living alone with few or no external support systems in place. It is at this point that interventions will need to be considered and acted upon by the person living with HIV, as well as the health system caring for this person. Such actions need to be conducted in a coordinated way so as to streamline this transition, assisting all in this process. The discussion will now focus on aged care.

## **Aged care**

In Australia in 1997 the Commonwealth *Aged Care Act* was enacted. Its stated objects are to

provide for funding of aged care that takes account of: the quality of the care, ... the need to ensure access to care that is ... appropriate to the needs of people who require it; and appropriate outcomes for recipients of the care; and accountability of the providers ..., [and] to promote a high quality of care and accommodation for the recipients ..., to protect the health and well-being of the recipients ..., to facilitate access to aged care services by those who need them, regardless of race, culture, language, gender, ... to encourage diverse, flexible and responsive aged care services that: are appropriate to meet the needs of the recipients ... [and] to help those recipients to enjoy the same rights as all other people in Australia. (section 2-1)

Alongside the *Aged Care Act 1997* (Cth) sits a document created by the Australian Government, Department of Health, titled *Charter of Care Recipients' Rights and Responsibilities – Residential Care* (subsequently replaced by the Charter of Aged Care Rights in 2019). The earlier charter outlines the following rights that people residing in residential care are entitled to. These are the right

to quality care ...; to be treated with dignity and respect, and to live without exploitation, abuse or neglect; to live without discrimination or victimisation ...; to be treated and accepted as an individual ...; to select and maintain social and personal relationships with anyone else without fear, criticism or restriction; to be involved in the activities, associations and friendships of his or her choice. (Australian Government, Department of Health 2014, p. 2)

The key principles of both these documents are that all people residing within the residential care environment, regardless of their gender, sexual identity, or cultural and

friendship affiliations, should expect to receive quality of care, respect for the individual and care without discrimination.

The *Aged Care Act 1997* (Cth) includes a section naming lesbian, gay, bisexual, transgender and intersex (LGBTI) people as a population group requiring special consideration. Section 11.3 lists the following groups as “people with special needs”:

people from Aboriginal and Torres Strait Islander communities; people from culturally and linguistically diverse backgrounds; people who live in rural and remote areas; people who are financially or socially disadvantaged; veterans; people who are homeless or at risk of becoming homeless; care leavers; parents separated from their children by forced adoption or removal; lesbian, gay, bisexual, transgender and intersex people.

This was the first time LGBTI people were included for consideration in legislation governing aged care in Australia.

In 2012, the federal Government of Australia released its aged care reform package titled ‘Living Longer, Living Better’. Amongst the reforms within this package was a new strategy that placed greater emphasis on the needs of the LGBTI population entering aged care. Pivotal to these reforms was the involvement and contribution by the National LGBTI Health Alliance who lobbied the government over a number of years to include a focus on LGBTI people residing within the aged care sector. With this collaboration the release of the National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy was announced by the federal government.

In his foreword to this strategy, Mark Butler MP, the then Minister for Health, stated that the “Australian Government is committed to ensuring equitable access to high-quality, culturally appropriate aged care for all LGBTI people” (Australian Government, Department of Health and Ageing 2012, p. 2). The strategy recognised and articulated for the first time

that there have been decades of inequitable treatment for LGBTI; many LGBTI people have suffered stigma, family rejection and social isolation; and many LGBTI people have had a life experience of fear of rejection and persecution, coupled with the impact of potential or actual discrimination. (Australian Government, Department of Health and Ageing 2012, p. 2)

The strategy also acknowledges that, while

LGBTI people rarely want to be solely defined by their sexual orientation, sex or gender identity, for many it is an important part of who they are. Aged care services need to ensure that they provide a consumer directed approach to meeting the care needs of older LGBTI people, resulting in appropriate and targeted services. (p. 2)

Previously to the *Aged Care Act 1997* and the 2012 'Living Longer, Living Better' package, little or no attention had been given to the LGBTI population within the aged care setting. Aged care services had

assume[d] that all people are heterosexual and gender conforming. Such approaches have reinforced the invisibility of older LGBTI people and as a result have ignored a sizeable group of Australians of diverse sexual orientation, sex or gender identity, which is estimated to be up to 11% of the Australian population. (Australian Government, Department of Health and Ageing 2012, p. 4)

In this document, it is highlighted that this 11% is not a homogenous group. Within this group there exists “‘diversity within diversity’... [which would include] people living with HIV” (p. 5). This was the first official recognition that members of the PLHIV population need consideration with regards to aged care. As will now be discussed in the review of the literature, aged care facilities in the past had not factored into their policy frameworks that some of their residents may be LGBTI identifying, and may or may not be living with HIV, or indeed some might not be members of the LGBTI

community, but might be living with HIV and require consideration in aged care. Some aged care facilities have still failed to do so.

Up to the time of writing, there appear to have been only four Australian publications exploring HIV and aged care. These publications are Crock et al. (2017), Murray, Cummins and Bloom (2014); ASHM (2014); and Cummins and Trotter (2008). The authors of these publications have found some interesting results and ways to proceed to assist in streamlining the transition of PLHIV into aged care.

In summary, the findings of these studies were similar and highlighted a number of concerns raised by participants about their transition to aged care. These concerned ageing with HIV and the co-morbidities associated with the infection that they may experience, as well as the skill set of those within the aged care environment caring for them. Other concerns included the attitudes of staff in relation to caring for PLHIV, their sexual identity, HIV status, stigma and discrimination. With all the above concerns expressed, Cummins and Trotter (2008, p. 63) found that 61% of their respondents were concerned about placement into an aged care facility in the future.

In an effort to ameliorate these concerns, Murray, Cummins and Bloom (2014) developed a protocol to better streamline transition to aged care for PLHIV. These authors believed that current practices regarding this transition were “inconsistent, with consequent variable outcomes for PLHIV and residential aged care facilities” (p. 34). Along with issues relating to the care and treatment of the various co-morbidities that may be experienced by PLHIV within the aged care environment, these authors added that “stigma and discrimination based on ... [the client’s] HIV status and/or sexuality” may also need to be addressed in the residential aged care setting (Grierson et al. 2013, as cited in Murray, Cummins & Bloom 2014, p. 35). These authors proposed a model to redress and improve the current “ad-hoc” (Murray, Cummins & Bloom 2014, p. 34) process of transitioning into residential aged care facilities (see Appendix 6 for their protocol). Issues of stigma and discrimination as they relate to PLHIV will now be discussed.

## **Stigma and discrimination**

In Australia the ‘Grim Reaper’ campaign to educate the community on HIV/AIDS began in 1986. This campaign was a result of the growing, but still small, numbers of the heterosexual community becoming HIV infected. The campaign was widely displayed in print and on television around the country. There was a sense that, while powerful, this campaign was one of ‘shock and awe’. It startled people, the vast majority of whom were highly unlikely to be at risk. It could be argued that the ‘Grim Reaper’ campaign added to the feelings of stigma and discrimination felt by PLHIV, a group in society who already felt marginalised and who may have experienced lifelong fear of stigma and discrimination because of their sexuality or lifestyle choices. For those within this group who were diagnosed with HIV, these fears may have multiplied. Some may have decided to become hidden, to go *underground*.

Stigma is well described by Erving Goffman (1963). Goffman described stigma as “... a powerful negative social label that radically changes a person’s social identity and self-concept. Stigma ... [overpowers] ... other dimensions of social identity so that a person is reduced in our minds from a whole and usual person to a tainted, discounted one” (Goffman, 1963, p 3).

The effect of stigma “impacts on people’s psychological well-being and health” (Rojas Castro et al. 2010, p. 961). For those suffering from an illness the deleterious effects of stigma associated with that illness would likely be compounded. This is especially so for PLHIV. Herek (2002) describes stigma in relation to PLHIV:

AIDS related stigma and its attendant prejudice and discrimination are significantly shaped by misunderstanding and fear of HIV disease, coupled with social attitudes toward the people who contract it and the conditions under which it is transmitted ... AIDS-related stigma is manifested in prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV and at the individual groups, and communities with which they are associated”. (pp. 594–595)

Another group in society who have historically been subject to the effects of stigma and discrimination are those identifying as LGBTI and, as has been discussed, those living with HIV. The following will speak of research conducted within the aged care environment around caring for the needs of the older LGBTI community living within that environment.

Researchers from the Gay, Lesbian, Bisexual, Transgender and Intersex Retirement Association Incorporated (GRAI) and Curtin University in Western Australia were interested in exploring what they believed were the unmet needs of the older LGBTI community as they applied to aged care. A formative study conducted by these organisations in 2006–2007 “confirmed that older and ageing gay, lesbian, bisexual, transgender, intersex individuals accessing retirement and residential aged care facilities in ... [Western Australia] experienced unmet needs and fears of discrimination” (Comfort et al. 2010, pp. 26–27). They commented that their findings were similar to “other national and international research indicating that GLBTI people were likely to be disadvantaged in the aged-care sector due to their minority sexuality” (Comfort et al. 2010, p. 27). They found that “in addition to the usual issues facing older adults, such as loneliness, isolation, loss of autonomy, and increasing dependence, older GLBTI individuals may experience further stressors” (p. 27). Such stressors were those “associated with sexual orientation, disclosure of sexual orientation and/or gender identity to health care providers, discrimination, lack of legal recognition, little, if any, protection of life-time partnerships” (p. 27). Another concern raised in their study was that the

heteronormativity ... of retirement and residential aged-care facilities ... [was] a concern for many older GLBTI people ... [where they felt] that their same sex relationships are not valued or understood and that partners will be excluded in care planning and decision-making. (p. 27)

From my reading of this research, this would render older LGBTI, their partners and “families of choice” (p. 28) feeling unrecognised, undervalued or ignored within the aged care environment.

In these authors' report titled *We don't have any of those people here* (Comfort et al., 2010), they explored the attitudes of aged care providers including chief executive officers and facility managers around the topic of older LGBTI accessing care within their facilities. In summary, the findings from this research revealed that the participants, in the majority, "were unaware of any LGBTI residents or supporting families currently or previously accommodated within their facility; [and] a non-recognition by the minority of participants that LGBTI individuals had 'specific needs'" (p. 27). A small majority said that, while they did not currently provide specific LGBTI inclusivity training within their facilities, "they provided a LGBTI-friendly ... environment which treated everyone the same" (p. 27). These authors concluded by saying that

It is clear that older LGBTI people currently accessing retirement and residential aged care are a hidden population. Older LGBTI people in general do not feel safe to disclose their sexual or gender identity to aged-care providers as a result of their past experiences of discrimination. (p. 27)

Additionally, these authors say that "heteronormativity and homophobia exist within the broader community and they are also likely to exist in retirement and residential facilities ... [thus] it is essential that agencies provide inclusivity training for their staff at an organisational and facility level" (p. 28).

One statement from the above research into the sentiments expressed by those at the management level of these aged care facilities that stood out for me was the comment that their aged care facilities "treated everyone the same". Treating everyone the same is a contentious position. Joosten (2016) argues that "treating everyone the same is not the same as treating everyone well" (p. 193). Treating everyone well would mean acknowledging and respecting the differences among people for whom the aged care facilities provide care. If those working within an aged care facility do not consider and respect the differences in their residents, with the assumption that all residents are heteronormative, this would lead to "an attitude of denial and diminishment of people's identities" (Joosten 2016, p. 193).



The loss of identity within the aged care environment for LGBTI people and PLHIV was felt strongly by those who participated in a project conducted in Australia during 2008 titled “My People” (Barrett 2008). In this research participants expressed their concerns about living within the aged care environment where they felt they needed to suppress their sexual identity and diversity for fear of being treated differently or poorly. The experience of one such participant, Tom (not his real name), was embedded within the sentiments of his favourite song: “Why not take all of me?” With the permission of one of the authors of this study, Barrett (personal communication, 13 June 2019), Tom’s story will now be summarised.

Tom was a gay, HIV-positive man aged in his mid-fifties who was admitted into aged care as a result of a cerebrovascular accident, the effects of which rendered him unable to live independently at home. In this project Tom told a story of a life lived within an environment in which he felt estranged. In this environment he felt unable to fully express to the aged care staff caring for him about his life, his interests, his sense of who he was. This inability stemmed from his fear that the staff would not understand and that he would feel discriminated against, leading to him saying “I am worried my care would be worse” (Barrett, Harrison & Kent 2009, p. 1). These fears led to him withdrawing into himself, experiencing loneliness and then depression, for which he was prescribed antidepressants. Life for Tom, however, was enhanced by the district nurses and support workers from the Victorian AIDS Council who regularly visited him in this facility and who took him to social events. With these external supports Tom felt fully comfortable to articulate and express himself. As well, these workers provided HIV education to staff. The cumulative results of this engagement benefited Tom’s well-being, improved the staff’s attitudes towards him and ultimately improved the quality of his care. Tom no longer felt lonely, nor the need to hide who he was; his selfhood had re-emerged, aligning with the sentiments expressed in his favourite song, “Why not take all of me?”

Tom’s story mirrors in a number of ways those previously described by Comfort et al. (2010). Comfort and her collaborators found that “GLBTI people currently accessing retirement and residential aged care are a hidden population. Older GLBTI people in general do not feel safe to disclose their sexual identity to aged-care providers as a result of their past experiences of discrimination” (p. 28).

Fear of stigma and discrimination are real for those born, raised and reaching sexual maturity in an era when homosexuality was not generally accepted. It must be remembered that until relatively recently between males “homosexuality was illegal and those found to be engaging in homosexual activities were prosecuted” (Comfort et al. 2010, p. 26). Indeed, in Australia male “homosexuality had not been decriminalised in most states until the 1980s and 1990s and the World Health Organisation had kept homosexuality on its list of diseases until 1992” (Green 2012, p. 1). Further, “the negative attitudes of society in general towards homosexuality led to persecution, condemnation, hatred and discrimination, with homosexuality commonly viewed as a ‘sickness, sin and disgrace’”, (Kimmel et al. 2006, p. vii). This had a great impact on the homosexual community at that time. There would have been great fear amongst this community and the need to stay hidden. This was the experience of the older HIV client group today who lived through this period, what we now call the ‘baby-boomer’ generation (Green 2012, p. 1).

To provide a historical background of the law in Australia around homosexual activity – its criminalisation and decriminalisation – the following time lines may be informative.

#### *Homosexual law reform and HIV*

Homosexual law reform pre-dates the emergence of HIV in Australia (1983), with South Australia, the Australian Capital Territory and Victoria beginning this process several years before. Once HIV infections did emerge it was strongly believed by “AIDS organisations and public health advocates ... [that] decriminalisation of homosexuality in ... [jurisdictions] where anti-homosexual laws remained” (Carbery 2014, p. 4) was essential. This was so those who identified as homosexuals and other men who engaged in sexual activity with men, who were the predominant group becoming infected with HIV (Herrmann & Skinner 2016), could have access to safe sex messages, come forward for testing for HIV and receive treatment for the disease “without the fear of legal repercussions” (Carbery 2014, p. 4).

To clarify the distinction, “to identify as homosexual has never been an offence in any Australian jurisdiction; it is homosexual acts which have been outlawed” (Bull, Pinto, & Wilson 1991, pp. 1–2). “Homosexual behaviour between males has been illegal in most countries for several centuries” (p. 1). One only needs to recall the famous tragic case of the Irish author Oscar Wilde, who in 1895 was charged with engaging in homosexual acts and imprisoned for two years’ hard labour, resulting in the ruin of his career, bankruptcy and his death in disgrace at the age of 46 (Ellmann 1987). Indeed, even today, in some parts of the world, for example “Nigeria, Russia, Uganda and closer to home, in the Pacific” (New South Wales, Legislative Council 2014, p. 26955) and in other regions, criminalisation, imprisonment and even death still occur for those accused of engaging in homosexual behaviour.

Little wonder, it can be imagined, why those identifying as homosexual in these regions of the world would hesitate to present for or be provided with safe sex education and then ask for HIV testing, let alone to be diagnosed with HIV and treated. This group would become a hidden group in the community with seriously poor health outcomes. Happily, laws in most regions of the globe have been amended to decriminalise homosexual behaviour. However, it must also be acknowledged that this has taken many years. As Bull, Pinto and Wilson (1991) highlight:

it was only in recent decades that a number of nations began to implement legislative reforms which allow for certain consensual homosexual acts. In Australia, all jurisdictions have responded to this trend and have decriminalised homosexual acts between consenting adults. (p. 1)

These amendments to the criminal law may have relevance to PLHIV who gained sexual maturity in these jurisdictions. The following will break down the different jurisdictions in Australia to show when amendments were made to their criminal law to proclaim that it was not an offence to engage in homosexual activity in private:

- South Australia, *Criminal Law (Sexual Offences) Act 1976*
- Victoria, *Crimes (Sexual Offences Act) 1981*

- NSW, *Crimes Amendment (Sexual Offences) Act 1984*
- Northern Territory, *Criminal Code 1984*
- Australian Capital Territory, *Crimes (Amendment) Ordinance (No 5) 1985*
- Queensland, *Criminal Code and Another Act Amendment Act 1990*
- Western Australia, *Law Reform (Decriminalisation of Sodomy) Act 1990*
- Tasmania, *Criminal Code Amendment Act 1997* (Carbery 2014, pp. 1–58).

Defining the age of consent for the homosexual population to be similar to that of the heterosexual population was another battle which took much longer in certain jurisdictions. For example, although NSW and the Northern Territory both decriminalised homosexual behaviour in private in 1984, it was not until 2003 in NSW and 2004 in the Northern Territory that the age of consent was equal for both homosexual and heterosexual sex (Carbery 2014).

While noting this progress in legislative change to remove the burden of a criminal charge for one's sexual behaviour and at a time when "same sex couples ... [are now] being treated equally under the law ... [around Australia] there are many men today who have lived their lives with a conviction that has had practical and personal ramifications" (New South Wales, Legislative Council 2014, p. 26955). Different states had different penalties. For example, in Victoria "the crime of buggery (anal intercourse) ... was punishable by death penalty until 1949 (thereafter 20 years imprisonment, later reduced to 15 years" (Carbery 2014, p. 2). In more recent years, in Australia, states and territories have enabled acts of parliament to expunge, or, in some states, enacted 'Spent' historical convictions under these former laws (Victoria, 2014; New South Wales, 2014; Western Australia, 2018; South Australia, 2018; Queensland, 2017; Northern Territory, 2018).

The intention of this chapter, or indeed this thesis, is not to presume that all those who identify as homosexual or all those who are HIV positive are a homogenous group who feel the same level of concern around disclosure of their sexuality or HIV status, or the quality of care they will receive in the residential aged care environment based on these disclosures. From my personal history of working with PLHIV, having friends who are HIV positive and reading the literature around PLHIV, significant numbers of this

group are forthright and strong about who they are, know their rights and are ‘out and proud’. However, there may be some within this group who may have major concerns and anxieties about disclosure. Their level of concern may depend on where they lived during their formative years, and the environment within which their sexual maturity evolved; crucially, in which jurisdiction these evolutions took place. For example, in Australia, if one was living in South Australia in 1976, where homosexual acts were decriminalised, such concerns may not have been felt as acutely as those felt by those living in other jurisdictions, such as Tasmania, for example, where the decriminalisation laws were enacted some twenty years later. So, there will be varying levels of concerns or fears felt by members of the homosexual or PLHIV populations, especially when they are considering a transition into residential aged care. Some may have no concerns while others may have great concerns.

From the above discussion, it is perhaps little wonder, I assert, that those who lived through the period of criminalisation based on one’s sexual behaviour might have been worried, indeed one might say terrified, of disclosure. They may have been worried about disclosing their sexuality for fear of being ‘outed’, ostracised, discriminated against or losing their freedoms. It perhaps is no wonder many members of this group led a ‘hidden’ life and that some who lived through this period may continue to do so. It is perhaps no wonder some, today, may carry with them this ingrained concern and fear of being identified as homosexual. These concerns and fears, it could be imagined, may play a considerable role in their attitudes or resistance towards transitioning into an environment they may perceive as heteronormative – the residential aged care setting. Added to this, for some in this group and others who do not identify as members of the LGBTI community, would be fear of the consequences of disclosure of their HIV status.

In summary, there are certain elements that make PLHIV transitioning into residential aged care unique in comparison to the heterosexual, non-HIV client group making this transition, which I will now highlight. Some of the ‘uniquenesses’ I contemplate are: fear of disclosure of their homosexuality for those identifying as homosexual, fear of stigma and discrimination upon these grounds, fear of disclosing their HIV-positive status, and concerns around the added levels of care required from staff caring for this group such as the importance of regular administration of medications, signs of

deterioration of physical or cognitive health, and infection control issues for all involved – the client and staff. As well, the residential care facility should recognise the need to welcome visits from partners/kinship/support networks with whom the LGBTI person or PLHIV may be associated. These are a few reasons that, I assert, may make the client group at the heart of this thesis unique in comparison to their non-HIV heterosexual cohort inhabiting the residential aged care environment.

It also needs to be remembered that many people fear getting old and facing the possibility of needing aged care whether they have HIV or not. In this, such concerns for all people facing aged care are not unique. However, people living with HIV have expressed added fears directly related to HIV infection. One PLHIV gay man is quoted as saying “I am scared of being gay and isolated in aged care and being HIV positive in aged care”. (Wheeler & Seagar 2015, p. 26, quoting Lillicrap 2014)

In this literature review, key words expressed by PLHIV and others around this topic appear to repeat themselves: fear, concern, anxiety and apprehension. These words were used in the context of fear or concerns of being identified as homosexual, fear of HIV and its ramifications for short- and long-term health, fear of ageing with HIV and fear of transitioning to aged care as a member of a minority sexuality group and/or with the diagnosis of HIV. Also articulated were concerns about the ‘skill sets’ of those caring for PLHIV in the aged care environment. Anxiety about the disclosure of their sexuality and fear of not being treated equally and with respect were also expressed. Other sentiments expressed were fear of negative attitudes, condemnation and persecution, and becoming hidden or going underground. As one person who in recent years had ‘come out’ as homosexual and was now living with HIV, and who was considering the notion of aged care, remarked, “It frightens me that in aged care I will be unwelcome and the freedoms I’m just beginning to experience will unravel ... Will I be leveraged back into the closet?” (Lillicrap 2014, p. 6).

With the above concerns expressed, PLHIV who either identify or not with the LGBTI community should take a degree of comfort that the residential aged care environment is regulated by Acts of Parliament and protocols that are aimed at addressing their needs. These are the *Sex Discrimination Act 1984* (Cth), the *Aged Care Act 1997* (Cth), the Charter of Aged Care Rights, the Australian Aged Care Accreditation Standards,

and especially the National LGBTI Ageing and Aged Care Strategy. The existence of these may assuage their fears as they transition to, or consider transitioning to, the aged care setting. Time will be the judge.

## **Summary**

This chapter has reviewed the literature on HIV and ageing, aged care, and HIV within the aged care setting. It was necessary to discover what is known about these areas of interest, what is not known and what needs to be known about the transition of PLHIV into the residential aged care setting.

What is known is that HIV transmissions continue to occur and in some regions of the world HIV prevalence is up to 30% of those regions' population. Today PLHIV who have access to, who are adhering to and responding well to their antiretroviral therapy are ageing and living to older ages not previously considered a possibility. Prospective studies have revealed that by 2020 approximately 50% of PLHIV in Australia will be aged over 55. This number will understandably increase. As a result of access and adherence to effective antiretroviral therapy, HIV today has become a chronic manageable disease for the majority of PLHIV. Although antiretroviral therapy has proven to be effective in improving immune function and reducing the viral burden for the majority of PLHIV, resulting in better health outcomes, HIV has not yet been eradicated. As has been discussed, PLHIV, as they age, are more likely to experience an accelerated ageing process in comparison to the non-HIV population, especially in relation to certain conditions such as osteoporosis, cancer, cardiac disease and cognitive deficits. As a consequence of this accelerated ageing process some PLHIV, as they age, will become physically and/or cognitively frail and unable to care for themselves independently. Transitioning into aged care may be an option that is looming. It is also known from the scant literature on the lived experience of PLHIV already residing within aged care that they have concerns. These include fear of discrimination and stigma based on their HIV diagnosis, as well as concerns that the aged care workforce will be ill-equipped to care for their special needs. PLHIV are a group that until relatively recent times have not required, nor given much thought to, a transition to aged care. Moreover, as research in Australia has demonstrated, nor has the aged care

sector previously given much thought to this phenomenon occurring. Both groups now need to give serious consideration to this eventuality.

The following chapter will discuss the methodology used for this research.



## Chapter Three: Methodology

This chapter will discuss the rationale behind the choice of methodology used to explore and find the answers to the aims, objectives and questions of this research. I will briefly outline the steps taken in deciding which methodology to use.

Firstly, as Polit and Beck (2012) state, nursing research

is systematic inquiry that uses disciplined methods to answer questions or solve problems. The ultimate goal ... is to develop, refine, and expand knowledge .... [that] benefits nursing and its clients, and that contribute[s] to improvements in the entire healthcare system. (p. 3)

In order to develop, refine and expand knowledge, nurse researchers need to situate their research on a theoretical and methodological foundation.

With much reflection on different philosophical perspectives or theories that may be suitable to underpin this research, I asked myself a series of questions. These questions were: Which theories would most resonate with me personally, and professionally in my nursing experience? And how would these suit the people at the centre of this research? Which would be most suited to exploring and answering the questions of this research? I felt this important to explore. As a nurse, the theories that resonate with me, and I believe may also resonate with those at the focus of this research, concern adaptation and transition. On a daily basis, clients who fall under my care or under my professional purview are adapting constantly to varying levels of health or ill health. This is managed by their own physical and cognitive abilities as well as with the support of their medical, nursing, allied health and non-clinical support. The combination of these physical, cognitive, medical and support networks will hopefully lead to a more positive adaptation and transition into the next phase of their lives. This personal philosophical stance, as it applies to my client group (PLHIV), led me to identify phenomenology, in particular hermeneutic phenomenology, as the most appropriate methodology for this research. A hermeneutic phenomenological positioning provided a framework within which to truly understand the meaning of the

lived experience of the group at the centre of this research, as it relates to their life lived with HIV and during the phase when they are considering a transition to aged care. The ultimate aim is for them to anticipate a life well lived in the aged care environment.

Before reaching my final decision on the methodological pathway to undertake for this research, I explored the literature on relevant methodologies. The following will describe some of the methodologies I considered to explore this topic, provide the rationale for dismissing some, and justify my choice of methodology.

I instantly dismissed a quantitative approach for my research. This is because the focus in quantitative research is to find results “using observational and analytic means to control and manipulate variables ... to demonstrate statistical significance in cause-and-effect relationships” (Roberts & Taylor 1998, p. 100). This approach was foreign to me. I did not wish to research this topic by controlling nor manipulating data in order to find cause-and-effect relationships. This methodology would not be appropriate when the plan for this research was to explore the lives of PLHIV, their histories and what it would mean for them to contemplate a transition to a life lived in aged care. I believed that the best way to approach this topic, to address the aims and questions of this research, was to hear the voices of the participants, and see and feel their emotions, as integral components of the research process. Using a quantitative approach for this study was considered inappropriate and therefore dismissed immediately. The next consideration for me was to search the qualitative literature to find the most appropriate qualitative approach to take.

To better understand and decide which qualitative approach to use, Roberts and Taylor (1999) separate these methodologies into “interpretive and critical approaches” (p. 102). These authors believe the differences between these methodological approaches are that “interpretive forms are concerned mainly with creating meaning, while critical forms focus on causing socio-political change” (p. 15).

The aim of this research was for me to explore and understand the lived experience of older PLHIV contemplating transition, when needed, to aged care. The participants in this research are not as yet at the stage of needing transition to aged care; they are not yet living the experience of a life lived within aged care, thus they cannot be observed

receiving care in that environment. They are, however, at the contemplative phase. Therefore, research using a methodology that applied an action research approach and one that aimed for socio-political change in the lives of these participants, at this contemplative stage of their lives, was deemed not appropriate for this research and was therefore dismissed.

Instead, within the qualitative interpretive branch, in Roberts and Taylor's (1999) description, is an approach described as phenomenology. Phenomenology is focused on exploring and understanding the meaning behind the lived experience of something. As the focus of this research was endeavouring to explore and understand the lived experience of PLHIV contemplating a potential transition to aged care, I selected a phenomenological approach, in particular one that was oriented towards the hermeneutic phenomenological approach.

Before discussing this approach, as it relates to this research, I acknowledge the vast published academic literature available that explains the history of and development of phenomenology and hermeneutics and how these two streams can and have interacted. While there are many, I list the following authors who were instrumental in the development of phenomenology and hermeneutic phenomenology, as well as those whose work using these methodological approaches, or critiques thereof, were inspirational to me and gave me a better understanding of how to use these approaches in my research: Husserl, Heidegger, van Manen, Gadamer, Polit and Beck, Streubert and Carpenter, Guba and Lincoln, Koch, Paley, Horrigan-Kelly, and Millar and Dowling. The literature includes many more. I encourage readers and future researchers to explore this vast field to gain a more expansive understanding of the development of these approaches. Suffice to say, for this chapter, I will provide a brief overview and speak to the key tenets of interpretive hermeneutic phenomenology as it has been applied in this research.

## **Phenomenology**

To begin, "Phenomenology, rooted in a philosophical tradition developed by Husserl [Edmund Husserl, 1859–1938] and Heidegger [Martin Heidegger, 1889–1976], is an

approach to understanding people's everyday life experiences" (Polit & Beck 2012, p. 494). Polit and Beck (2012) explain:

Phenomenological researchers ask: What is the essence of this phenomenon as experienced by these people and what does it *mean*? Phenomenologists assume there is an essence – an essential invariant structure – that can be understood, in much the same way that ethnographers assume that cultures exist. Essence is what makes a phenomenon what it is, and without which it would not be what it is. (p. 494)

The purpose of this research is to discover the essence of the thoughts and feelings articulated by an older population of PLHIV contemplating transition to aged care.

As described by Polit and Beck (2012), "There are several variants and methodologic interpretations of phenomenology. The two main schools of thought are descriptive phenomenology and interpretive phenomenology" (p. 495). Developed by Husserl, descriptive phenomenology asks the question "[W]hat do we know as persons?" (Polit & Beck 2012, p. 495); it focuses on the "descriptions of human experience" (p. 495). Researchers using descriptive phenomenology focus on the "careful description of ordinary conscious experience of everyday life – a description of 'things' as people experience them. These 'things' include hearing, seeing, believing, feeling, remembering, deciding, evaluating, and acting" (Polit & Beck 2012, p. 495).

Some of the key tenets of Husserl's theory of phenomenology are the concepts of intentionality, essences and bracketing. Husserl's view is positivist, believing in the mind-body split of Cartesian theory (Koch 1995). He views research in an objective way, with the researcher observing, or removed in some way from the data collected and analysed. It seems to me, from a reading of Husserl's theory, that he believes the researcher is not included as an active participant in the data generated nor its analysis.

The other form of phenomenology is interpretative, or hermeneutic, phenomenology. This approach, developed by Heidegger (1962), "uses lived experiences as a tool for better understanding the social, cultural, political, or historical context in which those

experiences occur” (Polit & Beck 2012, p. 490). Heidegger, in further developing phenomenology, moves away from the purely descriptive Husserlian stance to a more interpretive form of exploration. He believes that phenomenology “as a method, lies in interpretation ... The phenomenology ... is a hermeneutic in the primordial signification of this word, where it designates this business of interpretation” (Heidegger 1962, as cited in van Manen 1990, p. 25).

In his description of phenomenological research, van Manen (1990) says:

Phenomenological research is the study of the lived experience ... the study of the life-world ... Phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences ... Phenomenology asks, “What is this or that kind of experience like?” (p. 9)

Van Manen (1990) proffers that there is “a distinction in human science research between phenomenology (as pure description of lived experience) and hermeneutics (as interpretation of experience via some ‘text’ or via some symbolic form)” (p. 25).

The use of hermeneutic phenomenology as a research methodology aims both to interpret a phenomenon and to describe that phenomenon. These aims co-exist in the exploration and understanding of what is at the core of the research; the essence of the research. Van Manen defines this succinctly by saying “Hermeneutic phenomenology ... as a human science ... studies persons” (1990, p. 6). By using the word ‘person’, Heidegger, in his research methodology, does not reduce the person in a research enterprise to an object or a thing. The sample participants in my research are considered as people. On reflection, this, for me, is a further step removed from Husserl.

The purpose of this research, as has been stated, is to better understand and interpret the human experience of PLHIV contemplating a transition to aged care. At the same time it is essential to keep in focus the context surrounding the historical, social and political contexts which may underpin this group’s lived experiences and their thoughts about their future. So that I can more fully describe, interpret and understand the lived

experience of this participant group, as it applies to my research interest, I will now focus my discussion on hermeneutic phenomenology.

### **Hermeneutic phenomenology**

Two authors renowned for exploring interpretive phenomenology from a hermeneutic approach are the aforementioned Martin Heidegger and Hans-Georg Gadamer (1900–2002). It is to be noted, despite efforts, this researcher was unable to access original source material from these key authors, which were also written in German. Although translated by others, I chose to use other prominent authors whose interpretations of this source material better resonated with me and that I understood. The following will describe hermeneutic phenomenology from those interpretations.

Hermeneutic phenomenology is a “special kind of phenomenological interpretation, designed to unveil otherwise concealed meanings in the phenomenon” (Spiegelberg 1975, p. 57, as quoted in Streubert & Carpenter 1999, p. 54). Gadamer explains that “Its field of application is comprised of all those situations in which we encounter meanings that are not immediately understandable but require interpretative effort” (Gadamer 1976, p. x11, as quoted in Streubert & Carpenter 1999, p. 54). “The theory of interpretation is closely tied to the concept of text” (Ricoeur 1981, as quoted in Streubert & Carpenter 1999, p. 54).

Polit and Beck (2012) argue that for Heidegger the critical question is: what is being? He stressed interpreting and understanding – not just describing – human experience. His premise is that the lived experience is inherently an interpretive process ... [I]ndeed, the term hermeneutics refers to the art of philosophy of interpreting the meaning of an object (such as a text, work of art, and so on). The goals of interpretive phenomenological research are to enter another’s world and to discover the practical wisdom, possibilities, and understandings found there. (p. 496)

For Heidegger, the key tenets of his phenomenology centre on “two notions ... the historicity of understanding and the hermeneutic circle ... these two notions are inextricably linked” (Koch 1995, pp. 828–829). The historicity of understanding for Heidegger means that there needs to be an acknowledgement that the participant came

to the research with their own truths. These are described as “background, pre-understanding, co-constitution, and interpretation” (Koch 1995, p. 832).

Briefly described, historicity of understanding encompasses

background – a person’s history is handed down and presents a way of understanding the world; pre-understanding describes the meaning and organization of a culture ... which are already in the world before we understand; co-constitution refers to the philosophical assumption of indissoluble unity (‘person-world’). This means being constructed by the ‘world’ in which we live and at the same time constructing this world from our own experience and background; interpretation [is] ... based on the person’s background, in its ‘historicity’ [as Taylor (1987) explains] ... “We are self-interpreting, self-defining, living always in a cultural environment ... we are dealing with interpretations and interpretations of interpretations”. (Koch 1995, p. 831)

Finally, Koch (1995) describes the hermeneutic circle: “The researcher ... brings her/his pre-understanding to the text ... All claims to understanding are, for Heidegger, made from a given set of fore-structures which cannot be eliminated, but only corrected and modified. Hence the famous ‘hermeneutic circle’” (p. 832).

To summarise, the participant comes to the research with their own history; a history that includes their upbringing, their culture, and their understanding of their own being within the world. This is what Heidegger refers to as “Dasein – one’s being in the world, one’s sense of self” (van Manen 1997, p. 175). The hermeneutic circle infers that, equally, the researcher comes to the research with this history and Dasein. Thus, within the research enterprise and its analysis and interpretation, a hermeneutic circle is completed (Horrigan-Kelly, Millar & Dowling 2016). The merging of the histories of the participants in this research illustrates the hermeneutic circle or, as Gadamer refers to it, the ‘fusion of horizons’. Hekman describes this as that time when the particular vantage points of the researcher and the researched come “together ... the horizons of the interpreter and interpreted are fused” (Hekman 1983, as cited in Koch 1996, p. 177).

In hermeneutic phenomenology, Heidegger rejects another of the key tenets of Husserl's theory, namely the concept of 'bracketing'. Husserl believes that the researcher needs to always suspend their own "beliefs ... in order to study the essential structures of the world" (van Manen 1997, p. 175). In contrast, "For Heidegger, it was not possible to bracket one's being-in-the-world. Hermeneutics presupposes prior understanding on the part of the researcher" (Polit & Beck 2012, p. 496). For Heidegger, to fully immerse oneself in and engage with the data from the participant, and be part of the hermeneutic circle, bracketing could not occur. In undertaking research using hermeneutic phenomenology the concept of bracketing must be refuted. As Polit and Beck (2012) describe, "Bracketing is the process of identifying and holding in abeyance preconceived beliefs and opinions about the phenomenon under study" (p. 495). Bracketing would mean the researcher is content in "suspending one's various beliefs in the reality of the natural world in order to study the essential structures of the world" (van Manen 1990, p. 175). In other words, from my perspective, I would need to be content to remove myself, my history and pre-understandings, from the data and its collection. I am not content to do so. As I declared in Chapter One, I approach this research with a history, level of knowledge, preconceived beliefs and assumptions that I cannot bracket. This history and the concerns raised from this history were the underpinnings of my original interest in and undertaking of this research. I believe that this historicity will add to the data obtained from the participants in this study and potentially provide a deeper understanding of that data. I therefore rejected descriptive phenomenology, as described by Husserl, for many reasons, for use in this research.

With this said, the researcher needs to acknowledge and be respectful of the data obtained, its analysis and its interpretation. One way to achieve this is described by Gearing (2004). Gearing developed a number of typologies of bracketing. One of these, which I used in this research, is reflexive bracketing. Used most frequently in hermeneutic phenomenology, reflexive bracketing is used to enable the researcher to identify internal suppositions of their own to facilitate greater transparency, but without bracketing them out totally. Gearing states that "in reflexive bracketing, external suppositions are not bracketed out, as it is impossible to remove the context, culture, and environment from the phenomenon. Furthermore, a researcher wants to include larger world suppositions (eg, culture) essential to the phenomenon being investigated"



(p. 1445). Moreover, as Horrigan-Kelly et al. (2016) advocate, “Reflexivity ... plays a central role in the researcher’s attempts to keep a check on their preconceptions ... reflexivity during data analysis aims to avoid reaching an interpretation prematurely” (pp. 4–5). As Polit and Beck (2012) explain, “Interpretative phenomenologists ideally approach each interview text with openness – they must be open to hearing what it is the text is saying” (p. 496).

Acknowledging the need for reflexive bracketing and the researcher’s need for openness to the text, it also needs to be acknowledged that both parties in the research, the participant and the researcher, bring to the research degrees of prejudice or, as Gadamer (1976) refers to this, our histories, our traditions. Thus, in this research, each party brings to the research the richness of our backgrounds, co-constitutions and forestructures – our traditions. The researcher strives to collect the data, produce the text, and interpret and represent these stories while respecting these traditions. As Koch (1996) states: “neither the [participant] ... nor the researcher can assume a privileged position in interpretation” (p. 177).

In further describing the researcher’s relationship with the data, Polit and Beck (2012) refer to the writings of Hans Gadamer:

Gadamer (1976) ... described the interpretive process as a circular relationship known as the hermeneutic circle where one understands the whole of a text (eg, a transcribed interview) in terms of its parts and the parts in terms of the whole. In his view, researchers enter into a dialogue with the text, in which the researcher continually questions its meaning. (Polit & Beck 2012, p. 496)

Van Manen (1990, 1997), in his description and explication of hermeneutic phenomenology, breaks these terms down by saying that this methodological approach

tries to be attentive to both terms ... it is a descriptive (phenomenological) methodology because it wants to be attentive to how things appear, it wants to let things speak for themselves; it is an

interpretive (hermeneutic) methodology because it claims that there are no such things as uninterpreted phenomena. (1997, p. 180)

Van Manen (1997) further explains this by adding that any perceived

contradiction may be resolved if one acknowledges that the (phenomenological) ‘facts’ of lived experience are always already meaningfully (hermeneutically) experienced. Moreover, even the ‘facts’ of lived experience need to be captured in language (the human science text) and this is inevitably an interpretive process. (pp. 180–181)

The rationale for choosing a hermeneutic phenomenological methodology as the theoretical framework of this research on PLHIV considering a transition to aged care will now be discussed.

The participants at the centre of this research come to this research with a background, a pre-understanding, fore-structure, co-constitution, indeed a historicity, as it applies to their lives lived with HIV and their experience of ageing with HIV. Moreover, I believe that the understanding and explication of this historicity, or “the lifeworld, the world of lived experience” (van Manen 1997, p. 53) of the participants, is suited to the hermeneutic phenomenological approach. Equally, as the researcher, I come to this research with some of the aforementioned elements. These include my history working with PLHIV over many years, my pre-understanding of the health outcomes of a life lived with HIV over that period of time, in general, my interest and my historicity, and therefore my own lifeworld, as it applies to the subject matter and purpose of this research. These elements, I believe, fit with the use of a hermeneutic phenomenological framework to underpin and surround this research; one that acknowledges and respects the contribution of both parties in this research – the participants and the researcher.

To learn, understand and interpret the lived experiences of the participants at a deeper, more personal level, I undertook one-on-one, digitally recorded interviews. This better enabled me to capture the stories and the lived experiences of the participants at a number of levels. I captured their stories at the auditory, sensory and emotional levels. By this one-on-one method of data collection, or story collection, I was able to hear, see

and feel the lived experiential stories from the participants. Those sensory memories remained and remain with me still, like lightning bolts of clear memory, throughout the reading of and listening to the transcribed texts, and throughout my reflections during and after the analysis and discussion in this thesis. To this day, as I reflect and write this, I can still remember the time, location and the ways in which the participants expressed what they did at interview. These memories help bring their lived experiences and stories to life to this researcher in an illuminating and always respectful way.

## **Summary**

The above description of the process undertaken in researching and choosing the right methodology for this research has provided an explanation and rationale for the dismissing of methodologies that I believed inappropriate and the justification for that which was chosen. Following the precepts of hermeneutic phenomenology, respecting the histories, stories and feelings of both parties in this research enabled a full exploration, analysis and true reflection of what it means for those in this research to consider a transition to a life well lived in aged care when this is needed.

This chapter has described the process of reaching a decision on which methodological framework to use that supports the aims, objectives and questions of this research. Along the way, it described the reasons behind the dismissal of others and the selection of the framework chosen – interpretative hermeneutic phenomenology. In so doing, I have described and discussed the key tenets that underpin this methodology that support its selection. I believe that using this methodology provided the opportunity for the participants in this research, for me the researcher, for the nursing fraternity and for the broader public to gain an understanding, at a deeper level, of what it means for older PLHIV to consider a transition to aged care, and to find what they would describe as a life well lived within that environment. The following chapter will discuss the methods used to gain the interest of and the participation of the older PLHIV community in discussing this topic, to gain their input, their stories, and the steps followed for the analysis of their stories.

## **Chapter Four: Methods**

### **Introduction**

Following on from the discussion in Chapter Three on the philosophical framework and the methodological approach decided upon, this chapter will outline the process by which this research was conducted. To achieve the aim and objectives and answer the questions of this research I will now outline the methods taken.

To be discussed will be the following processes: obtaining ethics approval, obtaining consent, issues around confidentiality and the process taken to ensure anonymity, the population group for the sample, selection criteria, recruitment activities, data collection settings and data collection, the way data was analysed and issues related to the trustworthiness of the findings.

### **Ethics approval**

Human research ethics for low/negligible risk was applied for through the University of Adelaide Human Research Ethics Committee (HREC) and the Royal Adelaide Hospital HREC within the Central Adelaide Local Health Network on 19 February 2016. See Appendix 1 for the hospital's ethics approval letter. The level of risk to the participants undertaking this research was deemed low level because the collection of data from participants was through one-on-one interview between the participant and the researcher, where the purpose was to hear the stories of the lived experience of this group of a life lived with HIV and their thoughts for their future. While it was envisaged that retelling experiences from some periods might engender some level of anxiety, there were safety measures in place which were known to the participants prior to interview. If anxiety was experienced by the participants, information was provided for access to counselling services. This was part of the Ethics requirements.

## **Inclusion/exclusion criteria**

Among the inclusion criteria for this study, participants had to be HIV positive and aged 60 or over. The reason for specifying this age group is that people younger than this will perhaps be less likely to have given thought to ageing with HIV, let alone contemplating seriously a transition into aged care. It is also because PLHIV aged 60 and above may be experiencing, perhaps for the first time, the process of ageing and this, as research has shown, occurs several years earlier than for the general non-HIV population. Fluency in the English language was also an essential criterion. The reason for this is that the phenomenon of this study was the lived experience of older people living with HIV and that this understanding was best gained through interviews. As this researcher speaks only English, participants, therefore, needed to be fluent in English. The use of interpreters for those whose English is not their first language was not considered. This was because, from my professional experience of working in this field, for clients from non-English speaking backgrounds, the use of interpreters at medical appointments is often a problematic and contentious issue. This stems from the concern clients have about confidentiality regarding their medical conditions, especially their HIV status, becoming known within their small communities. Because the kinship/language groups of these clients are so small, these clients fear that interpreters may disclose, by accident or purposely, their HIV status. I am aware of instances of such disclosure. This client group therefore is often apprehensive and less forthcoming in giving information when interpreters are present at their appointments. Such apprehension from those of non-English speaking backgrounds would negate, or render less likely, the possibility for this researcher to engage in a free-flowing, open and honest conversation about the topic of this research. Another consideration would be the cost of employing interpreters. Future research on this topic, where there is capacity for funding to employ an interpreting service, may be considered.

To gather the views of the broadest population of PLHIV in South Australia, research flyers were displayed at venues frequented not only by those who identify as LGBTI, but also those who identify as heterosexual living with HIV. Research recruitment flyers were displayed at a variety of sites across metropolitan Adelaide and this potentially broadened the scope and captured the views of a disparate group in the data.

## **Recruitment**

I recruited participants by displaying a recruitment flyer (see Appendix 2) at various venues in the metropolitan area with permission from the various heads of units and site managers. Recruitment flyers were displayed within the Infectious Diseases Units at two metropolitan tertiary care settings, at two primary care settings with large caseloads of PLHIV, a community drop-in centre at Positive Life South Australia and a community pharmacy that was, at the time of this recruitment drive, the only pharmacy that dispensed antiretroviral medication. PLHIV who saw the flyer then contacted me to express an interest in the research.

Recruitment was also supplemented by the use of the 'snowballing' technique (Polit & Beck, 2012, pp516-17). This included participants recommending this research to others who fitted the selection criteria but who had not seen the recruitment flyer. Those recruited by the snowballing technique included those recommended through doctors at the various recruiting sites, or other health professionals, or community agencies aware of this research recommending their clients to participate. The researcher's contact details were displayed on the flyer for those interested in participating in this research.

## **Consent**

People who volunteered to participate in this study were given a full disclosure of the intent, purpose and method of the study. Issues of confidentiality and anonymity were discussed and considered paramount, and the means by which these issues were to be addressed were fully explained, accepted and agreed upon by the participants. The data was gathered for this research by face-to-face, one-on-one interviews where topics of some sensitivity were outlined and discussed. The potential for some participants to experience moments of distress in the re-telling of their stories was acknowledged and strategies were put in place to address this if this were to occur.

The participants were provided with contact details of the principal supervisor for this research, the counselling services available if they felt they needed to debrief, and contact details of an independent party through the HREC if the participant wished to

make a complaint away from the researcher. These contact details were supplied on the Participant Information Sheet that was given to each participant.

The participants signed a consent form before undertaking this research (see Appendix 3). A consent form is a declaration that participants understand the purpose, intent and method of obtaining, analysing and interpreting the data from their stories as they pertain to the stated research purpose. I have no skills in dictation and did not want to miss any words spoken, inflections and pauses in speech. Therefore, participants signing the consent form understood that the interviews would be one-on-one, face-to-face, and that they would also be digitally recorded. To safeguard their anonymity and confidentiality, participants understood and agreed that they would be de-identified by being allocated a number, rather than the use of their name or even a pseudonym. I deemed that the use of a pseudonym created a risk of identifying a participant. The participants were informed of the potential risk to their emotional well-being in the re-telling of their stories, with safeguards such as an external counselling service provided if required.

The participants, when signing the consent form, acknowledged that the findings from this research were to be published and presented at a variety of fora, but that for the purposes of maintaining participants' confidentiality their details would be de-identified as described above. The participants were informed that they would be attending a single one-on-one interview with the researcher and were told the types of questions they would be asked to comment on. There was no second interview. However, the participants were informed that they could contact me if, after reflection on their interview, they wished to add further information. The right to revoke their consent to participate in the research was understood by the participants, including that no adverse events would occur as a result of revocation of participation in this research.

## **Participants**

The participants were all male. There was, however, one female who came forward to participate at the end of the data collection period. But in discussion with my supervising panel it was considered that the risk of this participant being identified as the only female voice was too great and was therefore excluded. The participants were

aged sixty (60) and over, with the eldest aged eighty-eight (88) at interview. The participants' year of HIV diagnosis ranged from a relatively recent diagnosis, ten years prior to interview, to those diagnosed throughout the 1990s and those diagnosed at the beginning of the HIV epidemic in 1983 and 1984. The length of living with HIV is relevant to the participants' perspectives on living with a disease that once was considered a short life sentence, to one that now, as a result of better treatment, has become a chronic condition where people are living into older ages.

The number of participants was originally planned to be twelve (12). This number was decided upon as I believed (Guest, Bunce & Johnson 2006) that the participant group at the centre of this research would be a relatively homogenous group, recruited based on the distinct criteria for the objective purpose of this study. This group share the same virus, to a greater or lesser degree share similar life histories, and one might assume similar concerns that focus on the objectives of this research. The group was to be HIV positive, aged 60 years of age or over, ageing with HIV and, one might presume, considering the future. Within the above parameters, in order to achieve data saturation, which is the end point for research, it is believed that "twelve interviews should suffice" (Guest et al. 2006, p. 79). However, once these twelve participants had been interviewed, a further three who fitted the selection criteria wished to participate. My supervising team and I considered that the inclusion of these three was appropriate as I believed that they would add further value and perspectives to the research. The total number of participants therefore was fifteen (15).

### **Data collection settings**

Interviews occurred in a number of different settings. Primarily, they occurred in the offices of the Nursing School of the university of this research. For the convenience of some participants, three interviews were conducted in their homes. This was due to difficulties for some participants in travelling to the university, or participant preference. At all times the health and safety of both the participants and the investigator were considered, and when location choice was within the participant's dwelling, the Safety Management Plans Guidelines as documented in the university's Health, Safety and Wellbeing Handbook were adhered to. When interviews were



conducted outside the premises of the university, this was done with the consent of the principal supervisor and details of the venue and contact details were provided.

### **Data collection**

Once participants expressed an interest in this research they were invited to a preliminary meeting with the researcher, either face to face or by telephone, to discuss the research in more detail. At this meeting, amongst other issues, we discussed the most suitable venue for the interview, and a date and time for the interview. At this preliminary meeting the Participant Information Sheet and the Consent Form were given to the participant for them to read before the interview (see Appendix 3). When the initial interaction was via phone, these documents, with the permission of the potential participant, were posted or emailed. At interview, prior to its commencement, I asked the participant whether they understood all aspects of the research, and the Participant Information Sheet, and if they were happy to sign the Consent Form. Once they had signed, the interview proceeded.

Prior to each interview, I discussed with the participant that in order to best de-identify them, they would be given a number, such as Participant One, rather than for them to be given a pseudonym. A number I believed was less identifying than a pseudonym. All the participants agreed with this decision. As already discussed with participants and consented to, the interviews were digitally recorded. These interviews were one-on-one, face-to-face, and semi-structured, but with the ability for free-flowing narrative as the story unfolded. This interview technique was chosen to give some structure to the interview, but also to give a less formal, less rigid atmosphere to the interview as the participants' stories unfolded (Koch 1994, 1996).

Data collection was undertaken within a three-month period commencing in early May 2016 and concluding in late July 2016. Flexibility of the time for data collection was built in depending on a number of factors. These related to a participant being away or unwell at the time of the planned interview and the need to re-schedule, or a late presenter through the snowballing process, or when the stated participant number had not been reached at the commencement of the data collection stage while the researcher waited for further recruitment. The uptake of interviews was slow at the beginning, but

the pace of enrolment quickened and within three months the data collection was concluded.

At the beginning of each interview I gave the participant a demographic profile sheet to complete (see Appendix 4, p144). This demographic history included questions about the participant's age, sex, sexual identity, the year of HIV diagnosis, country of birth, whether they were partnered or not, home ownership, living arrangements (sharing, living alone), support networks and employment history. Other questions included whether the participant was receiving antiretroviral therapy, their adherence to therapy and its effectiveness, as determined by the participants' giving details of their recent pathology results (although they were not asked to furnish actual laboratory results).

Capturing the above demographic profile of the participants was important. This profile helped to fill out the details of the participants' past and present lifeworlds and their illness trajectory, adding richness to the data gathered. At this early stage, this preliminary interaction, I was able to gain a brief understanding of the participant. This gave an opportunity for both parties (the participant and the researcher) to establish the flow of the research interaction, which helped make the interview a more relaxed experience. Essentially, this demographic data more fully provided colour to and filled out the lifeworld of the participant and laid the framework around which a more free-flowing interview could occur.

Following on from the gathering of this preliminary demographic picture of the participant, the interview proceeded in the aforementioned semi-structured format. The semi-structured interview included 'trigger' questions that pertained to the focus of this research. (See Appendix 4 for these trigger questions.) For example, questions explored how the participant currently felt regarding their health, and whether they had given any thought to ageing and living in old age with HIV. Had the participants thought about how they will feel about this? Had they thought about support as they age? What support structures do they currently have in place? Had they thought about living within an aged care setting? What are their feelings around these questions? Further questions emerged as conversation flowed during each interview. Essentially, I asked the participants to tell me how they felt about their "lived experience" (Koch 1999, p. 24) around the above questions.

The interview provided the opportunity for participants to narrate their life experience and their understanding of it. As Cohen, Kahn and Steeves (2002) state:

A basic premise of the hermeneutic phenomenological method is that a driving force of human consciousness is to make sense of experience. In general, people try to reach this understanding by interpreting their lives as they occur by treating them as narratives that are unfolding. In other words, the understanding people have of their world and their life situation and the meaning they have made of this is usually contained in the narratives or stories they tell. (p. 59)

There was no second interview with participants. However, I informed the participants that if they wished to add any further comments, upon reflection subsequent to their interview, they could contact me. No participants made contact with me after their interview. The rationale for this was that the interviews were digitally recorded and captured the participants' responses to the research questions. In addition, the researcher was present at interview, listening to, observing and writing notes throughout. The combination of all these data collection strategies, I believe gave the data a high degree of accuracy that the data collected and transcribed was true and accurate. This I found, during the reading of the transcripts, against my own notes and memory of each interview to be true.

As soon as practicable after each interview I listened to the recording and made notes. I wrote notes in my research journal as a personal reflection. I also wrote notes in my research journal during the reading of the transcribed interview for personal reflection. I repeated this process for each participant and the process was continuous throughout this research project.

### **Data storage**

I stored all data on a password-protected USB device and on a secure, password-protected university computer student drive. Individual documents were password protected using Word 2010 security options. During data analysis I used hard copies

and stored them in a locked cabinet in my home office during the project. Data will be stored for a period of five years and destroyed in accordance with the protocol of the University of Adelaide.

### **Data analysis**

The data analysis was a continuous process in which I immersed myself, to describe and explicate what participants had said and the way they said it. I analysed the data by reading and re-reading the interview transcripts numerous times in search of key themes. This data analysis began by separating each question and the key sentiments expressed within by each participant. These were then compared with the sentiments expressed by other participants around each question in search of similarities or differences, depending on the relevance or irrelevance of the question to the life of the participant. This process was helpful in identifying the essence of what participants said and felt around the questions as they related to their lives with HIV and thoughts of transition to aged care.

For this research, the research method, including data collection and analysis, was guided by van Manen's (2017) six research activities and four lifeworld existentials. Briefly, the six activities that I followed were: "turning to the phenomenon; investigating experience as we live it; reflecting on the essential themes; describing the phenomenon; maintaining a strong and oriented relation to the phenomenon; balancing the research context by considering parts and whole" (pp. 30–31). These research activities, van Manen (2017) proffers, may be "practical approaches that may be helpful in doing hermeneutic phenomenological human science research" (p. 30). I found these research activities of enormous help in guiding this research project. The four lifeworld existentials are "lived space (spatiality); lived body (corporeality); lived time (temporality); and lived human relation (relationality or communality)" (van Manen, 2017, p. 101). Van Manen offers them as "helpful ... guides for reflection in the research process ... and productive categories for the process of phenomenological question posing, reflecting and writing" (pp. 101–102). I found considering these lifeworld existentials illuminating as a way to a better understanding of the lifeworlds of the participants in this research.

This analysis was also undertaken by employing the tenets of what Gadamer (1976) describes as the ‘hermeneutic circle’. This is a process by which the researcher “understands the whole of a ... transcribed interview ... in terms of its parts and the parts in terms of the whole” (Gadamer 1975, as cited in Polit & Beck 2012, p. 496). It is a circular process by which Gadamer believes the researcher is better able to “enter into a dialogue with the text, in which the researcher continually questions its meaning” (Polit & Beck 2012, p. 496). Guided by both van Manen and Gadamer, these techniques of data analysis identified the core themes that arose as paramount to this research. These were central to understanding the ways PLHIV would adapt and transition into a new living setting, potentially one within an aged care setting.

Through the process of data analysis, using the hermeneutic phenomenological framework, I engaged in much reflection on the data obtained from the interviews. This was to gain a better insight into the lived experience of the phenomenon under question: how the participants felt about a life lived with HIV as they considered a transition to aged care. Van Manen (1997) writes:

[T]he purpose of phenomenological reflection is to try to grasp the essential meaning of something ... the essence of a phenomenon ... [through] a process of reflectively appropriating, of clarifying, and of making explicit the structure of the lived experience. (p. 77)

Van Manen (1990) describes the reflective phase as a way to discover themes within a text, “reflecting on the essential themes which characterise the phenomenon” (p. 30).

In search of the essential themes that emerged from the data in this research, I conducted a thematic analysis. Van Manen (1997) describes thematic analysis as “the process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work ... [T]heme gives control and order to our research and writing” (pp. 78–79). The writing phase commenced at the beginning of the data analysis, which van Manen (1997) proffers as “describing the phenomenon through the art of writing and re-writing” (p. 30). Benner (1994) also supports this position when she states that “writing is part of the intellectual work of doing interpretation” (p. 101).

My analysis was based on an understanding and an appreciation of the writings of Heidegger in his *Being and time* (1962). As described by Koch (1995), Heidegger suggests that the essential notions to be considered in hermeneutic phenomenological analysis are “historicality of understanding and the hermeneutic circle” (p. 831). As discussed in Chapter Three, this means that the researcher must understand the data at a deeper level, and be mindful of the background, pre-understanding, co-constitution and interpretations of both the participants and the researcher. The researcher uses these to describe this process. In analysing the data the researcher appreciates that the researcher is part of the data and not to be left out, or as Heidegger says ‘bracketed’, thus enabling the researcher to be part of the hermeneutic circle. While this research is about the stories of PLHIV as they reflect on their past and present and as they consider their future, my own past, present and considerations of the future cannot be ignored in this analysis. During my close professional working association with those living with HIV over decades, I have witnessed the changes in treatment and prognosis with the resultant improvements in physical and emotional outcomes over that period for many PLHIV. Acknowledging the historicality of the participants and that of the researcher, co-joining in making the data for this research, is to also acknowledge the union or level of understanding that exists between the participant and the researcher or, as Gadamer (1976) describes it, the ‘fusion of horizons’. Koch (1995) describes succinctly what Gadamer meant with this term, arguing “that primary data be regarded as contextualised life events, with the ... [participants’] and the researchers’ perspectives specified” (Gadamer 1976, as cited in Koch 1995, p. 832). Koch further elaborates on Gadamer’s sentiments, adding

that a value-oriented approach is unavoidable because all research contains a pre-understanding which originates in the researcher’s historical context. These values, rather than getting in the way, make the research meaningful to its consumers. He rehabilitates the notion of prejudice. (Koch 1994, as quoted in Koch 1995, p. 833)

Therefore, the analysis of the data for this research needs to be seen in this light.

Themes derived from the data obtained from this research emerged by implementing one of the three approaches suggested by van Manen (1997): “the selective reading and highlighting approach” (pp. 92–93). This approach will now be described. I repeatedly listened to the digitally recorded interviews and repeatedly read the interview transcripts. Each time I underlined or highlighted key words and phrases, and wrote my own notes on the side of the page. On each occasion throughout this process I wrote a brief summary of the stand-out points of the interviews and stapled this to each interview transcript. I did this to give myself a brief snapshot of each participant, including details of their demographic data, employment and date of HIV diagnosis. This snapshot enabled me to remember the participants and what they said, placing the participant and their data into quick context. This assisted me to learn if there were similarities or differences in the sentiments expressed by each participant. In the process it brought forward the uniqueness of each participant and the essence of their sentiments. This re-writing at each point in the re-listening and re-reading process helped me better understand participants’ histories and their thoughts about the questions asked. This approach, van Manen (1997) explains, occurs by

listening or reading the text several times and asking “what statements or phrases seem particularly essential or revealing about the phenomenon or experience being described?” These statements we circle, underline, or highlight ... The task is to hold on to these themes by lifting appropriate phrases or by capturing singular statements the main thrust of the meaning of the themes. (p. 93)

Themes from the data of this research emerged by following the above steps and were accumulated when a number of participants expressed similar points of view, as well as when only a small number, or just one participant, expressed something so powerful and resonant to the heart of the research that it warranted inclusion.

As described, the data was analysed by reading and re-reading the interview transcripts and listening and re-listening to the audiotaped interviews many times, simultaneously taking notes at each point of this cycle as well as at times of subsequent reflection. I engaged intensely with the data collected, engaging in an internal conversation and questioning of the data and of myself in what has been described by Gadamer (1976) as

the 'hermeneutic circle'. This was a period of deep reflection and internalisation of the data collected. The process of writing and re-writing resulted in the emergence of themes that came directly from the data and the spoken words of the participant and resonated with me.

### **Issues of integrity and trustworthiness**

As discussed, this research followed the precepts of hermeneutic phenomenology in order to capture and understand the lived experience and the lifeworlds of participants contemplating a life lived within the aged care setting. This was garnered through the data gathered at the interviews, as well as the immersion, analysis and subsequent reflections I undertook. This included participants' words, observations of unspoken communication and the participants' body language during the interviews. As well, to be abundantly clear, another component of the gathering, making, analysing and reflecting on this data was myself. In the previous chapters I have declared my own background, 'fore-structures', prejudices and assumptions gained from many years working with and observing PLHIV at various ages and life points. As Koch (1994) declares in her research, "I bring my pre-understandings and prejudices to this construction. No attempt is made to disguise these" (p. 985). In reference to prejudice, Koch (1994) adds that "prejudices are not necessarily erroneous or necessarily distortions of truth. Our situatedness as interpreters, our own historicity, do not constitute an obstacle ... [T]hese values, rather than getting in the way of research, make research meaningful" (p. 977). Understanding research using the philosophical hermeneutic approach "affirms the position of the researcher in the hermeneutic circle ... [and as such the researcher] participate[s] in making these data and construction" (Koch 1994, p. 985). This said, issues around the integrity and trustworthiness of the analysis and findings of this research, and the steps taken to achieve these, now need to be discussed.

To achieve integrity in the findings of this research, while staying within the methodology of the constructivist, iterative, interpretative, hermeneutic phenomenological paradigm of this research, I have chosen to follow Lincoln and Guba's (1985) framework for achieving integrity and trustworthiness. The steps followed from this framework are: credibility, dependability, confirmability,



transferability and authenticity. I decided to follow Lincoln and Guba's steps because they aligned with my methodological stance. This stance is counter to the positivist paradigm found, in particular, within the quantitative methodological approach, which focuses on rigour and validity as central to claims of achieving quality in research.

In this research, I wanted to distance myself from the use of the term rigour. In the literature, rigour, as a way to achieve validity in findings from qualitative research, has been a contentious concept for a number of years (see Sandelowski 1988; Koch 1996; Koch & Harrington 1998; Polit & Beck 2012, to name but a few).

Sandelowski (1993), in her paper "Rigor or rigor mortis", states:

the problem with rigor in qualitative research continues to arouse, beguile and misdirect ... There is an inflexible and uncompromising harshness and rigidity implied in the term "rigor" that threatens to take us too far from the artfulness, versatility, and sensitivity to meaning and context that mark qualitative works of distinction. (p. 1)

From my own stance and as it applies to my approach to achieve integrity in the findings from this research project, I will provide the steps I followed using Lincoln and Guba's model. Following this, I will include the recommendations from Koch (1994) in supporting the criterion for trustworthiness by providing an audit trail of reflections and decisions I made in my journey throughout this research.

The following will describe Lincoln and Guba's (1985) criteria required to achieve trustworthiness, as summarised in Polit and Beck (2012).

**"Credibility** refers to the confidence in the truth of the data and interpretations of them" (Polit & Beck 2012, p. 585). This is best achieved through "prolonged engagement – the investment of sufficient time collecting data to have an in-depth understanding of the people under study" (p. 585). In this research, this was achieved through my long professional engagement with the topic PLHIV and my prolonged engagement with the participants during the interviews and the analysis of the data.

**Dependability** ... refers to the stability (reliability) of data over time and conditions. The dependability question is: Would the findings of an inquiry be repeated if it were replicated with the same (or similar) participants in the same (or similar) context? (p. 585)

Regarding this criterion, I cannot make an absolute guarantee that the same findings found in this research would be replicated elsewhere in another study with different participants. That would depend on the location of that research, which may have higher numbers of PLHIV and higher numbers of participants whose life experiences living with HIV and ageing are significantly different from those in this research. With that qualifier, the views expressed in this research were considerably varied and I have confidence that, if the study was replicated, they would be shared by others. I also believe that those who participated in this research would articulate similar sentiments in other studies as they expressed in this research.

**Confirmability** refers to objectivity ... the potential for congruence between two or more independent people about the data's accuracy, relevance, or meaning ... [and] that the data represent the information participants provided are not invented by the researcher ... for this criterion to be achieved, findings must reflect the participants' voice. (p. 585)

In this research, this criterion is achieved as I have made every attempt to accurately present the voices of the participants and to be clear to the reader whose voice is being heard – the participant's, my own or the related research literature.

**Transferability** refers to the potential for extrapolation ... the extent to which findings can be transferred to or have applicability in other settings or groups ... the investigator's responsibility to provide sufficient descriptive data so that consumers can evaluate the applicability of the data to other contexts ... [the researcher] cannot specify the external validity of an enquiry; he or she can provide only the thick description necessary to enable someone interested in making a

transfer to reach a conclusion about whether transfer can be contemplated as a possibility. (p. 585)

In addressing this criterion, I can only state that I have provided as thick a description of the participants of this research as appropriate, with anonymity of participants crucially upheld. There can be no guarantee that this research is transferable or generalisable to other settings or groups. This research is unique to older PLHIV considering their potential future in aged care. The transferability criterion may or not be achievable, nor does this research, I argue, need to be transferable. As described in the above criterion on dependability, the findings of this research are pertinent to these participants and to the particular location of this research. Its transferability, or lack thereof, is for researchers in other locations or with different groups to determine.

**Authenticity** refers to the extent to which researchers fairly and faithfully show a range of realities ... authenticity emerges in a report when it conveys the feeling tone of participants' lives as they are lived ... When a text achieves authenticity, readers are better able to understand the lives being portrayed "in the round", with some sense of the mood, feeling, experience, language, and context of those lives. (Polit & Beck, 2012, p. 585).

In this research I have presented and described the different heartfelt and vivid experiences expressed by the participants who are living with HIV and considering their future. I make the claim that the authenticity criterion for this research has been achieved.

I did not conduct any member checking, or proof checking, meaning returning the interview transcripts to the participants to check their accuracy, as another measure to achieve trustworthiness. I made this decision for a number of reasons. The interviews were digitally recorded and sent off for professional transcription. Once returned I checked the transcribed interviews and confirmed their accuracy, in accordance with the notes I had taken during and after the interviews. Another reason for not conducting a member check was that in the time between the interviews and my confirmation of the accuracy of the transcripts, a number of participants, sadly, had passed away, while the

health of some others had deteriorated, rendering their checking unobtainable. I felt that conducting member checking with those remaining would be incomplete, and unfair to those who were unable to participate in this process.

Issues surrounding the member checking process have been commented on by a number of authors, in particular Sandelowski (1993), and Koch and Harrington (1998). These authors cite similar reasons for not conducting member checking in their research endeavours as I have listed above. Sandelowski (1993), in her description of why member checking can be problematic, states:

members will inevitably look for themselves and their own reality in researchers' accounts of their lives, but researchers strive to represent multiple realities in a way that still remains faithful to each member's reality ... members are sometimes more interested in concrete descriptions of their own experiences than in abstract synthesis that incorporates them with other members' experiences. (p. 5)

Additionally, Sandelowski (1993) writes:

the stories that members tell in interview are themselves constantly changing. They represent members' efforts to order, find meaning in, and even live with the events in their lives at a particular moment in their lives ... stories are not simply vehicles for the communication of information that can easily be categorised and conducted for consistency; rather they are time-bound interpretive, political and moral acts. (p. 5)

Thus, with the issues raised above, member checking, as a measure to demonstrate the trustworthiness of the data gathered and analysed in this research, was not undertaken.

I will now speak to the other criterion for achieving the integrity and trustworthiness of this research, namely the audit trail described by Koch (1994, 1996), and later described by Koch and Harrington (1998) as the reflexive journal. The audit trail describes the "theoretical notes, methodological decisions, plans for analysis and interpretive frameworks" (Koch 1996, p. 178) that are made along the way in the research. This is

done because the “legitimacy of knowledge claims ... are dependent upon demonstrating that the research study is trustworthy and believable” (Koch 1996, p. 178). In my research journal I documented the steps I took and my reflections over the decisions made in this research journey through the analysis, discussion and the findings made from the research data – the participants’ stories. This is my claim about achieving integrity and trustworthiness in this research. The audit trail enables the reader to understand at least, if not agree with, the decisions made and my interpretations of the data. The journal within which this decision trail is documented is available on request.

### **Interpretation**

To make sense of the analysed data I underwent a stage of interpreting what I found. This stage consisted of immersing myself in the data by reading, re-reading and reflecting on the data collected. This enabled me to re-think and to make changes to my original decisions about the themes of the research. It helped me to make statements about what the data meant or, as Roberts and Taylor (1999) say, what the data “mean[s] in light of the intentions, methods and processes of the research” (p. 337). This process, as these authors describe it, gave me the opportunity to elaborate and articulate the meaning of this data as expressed by the participants and, as well, to interpret what the data meant to me. In so doing, I could better explain to the reader how I came to my interpretations and to the conclusions I made.

### **Summary**

This chapter outlined the methods undertaken to obtain the data necessary for exploring the thoughts and concerns PLHIV have in relation to a potential life lived within the residential aged care sector.

This chapter described the following processes: the ethics application, selection criteria, gaining of consent, the steps taken for recruitment and sample size, design of the research, data collection, steps taken to ensure confidentiality of participants, and the procedure for data storage. Data analysis was described and its interpretation as it

applied to the research methodology, that being within the precepts of interpretive hermeneutic phenomenology.

Also described were issues of trustworthiness and validity that applied to the analysis of the data. This was by the use of an audit trail in the form of a journal into which I would write reflections throughout the various stages of the research project. As described in the methodology chapter, reference was made to the co-existence of the hermeneutic circle within which the participants and the researcher are equal respectful partners in the collection of, and analysis of, the data gained. The next chapter will present the findings.

## **Chapter Five: Findings**

This chapter reports on the themes that emerged from the data generated from the interviews with people who are living with HIV. It begins with an introduction to the participants at the centre of the research. It then presents the major themes and associated sub-themes that emerged from the findings.

### **Summary of the participants**

Summarising the demographic characteristics of the fifteen participants at the centre of this research has been an interesting task. They are individuals with unique life experiences which make them not a truly homogenous group. However, they have more in common than their HIV status, male gender and being over 60. Some participants were diagnosed with HIV at the beginning of the HIV epidemic in 1983 and 1984 and some later in the 1980s, and another group were diagnosed in the 1990s and 2000s. The majority of participants identified as homosexual, with three identifying as heterosexual. The ages of participants ranged from those in their early or late 60s to early 70s to two who were aged 80 and 88 at interview.

Predominantly, these participants are in long-term relationships with their partner or spouse. The majority own their own home, with a small number living in rental accommodation or within community housing. The majority of the participants are well educated, with a number educated to tertiary level. Some are still in the workforce and all are fully engaged in life. The working lives of the participants are varied, including five who either worked in or are still working within the healthcare sector in a variety of capacities.

This articulate, engaging, yet disparate group of participants brought to this research an enlightening overview of HIV as a lived experience. Their lived experiences span different periods in time and different perspectives. These experiences have shaped participants' views about their long-term future as they pertain to thoughts around ageing with HIV, their thoughts around aged care and their potential transition to this new living environment.

Using the process of data analysis described in Chapter Four, the following themes emerged from the interview trigger questions and subsequent discussion throughout the interview. I broke down the themes into major themes and sub-themes, the latter intended to more fully describe these themes as they relate to the main focus of this research: a life lived with HIV and what a contemplation of a transition to aged care meant to this particular group of PLHIV. The analysis in this chapter will highlight what the participants said and the language they used that stood out as unique to that group.

For clarity, to outline what will be described and discussed, the content is displayed in the following table.

**.. 5.1: Themes and sub-themes from the analysis of the interviews**

<b>Themes</b>	<b>Sub-themes</b>
1) Life lived from diagnosis of HIV	<ul style="list-style-type: none"> <li>• At diagnosis</li> <li>• Getting on with life</li> <li>• Standing outside from a distance: secrecy and separateness</li> </ul>
2) HIV today	<ul style="list-style-type: none"> <li>• A changed landscape</li> <li>• A life experienced in a new world</li> </ul>
3) Considering a transition to a life well lived in aged care	<ul style="list-style-type: none"> <li>• The right place</li> <li>• A sense of connection</li> <li>• Attitudes of staff</li> <li>• Aged care: A welcoming environment for PLHIV?</li> </ul>

**Theme One: Life lived from diagnosis of HIV**

The participants were diagnosed with HIV at different times. The participants had different experiences of life lived with HIV, largely reflecting the era of their diagnosis. Understandably, those diagnosed with HIV at the beginning of the epidemic



experienced challenges that were not faced by those diagnosed in more recent years. The challenges experienced by those diagnosed at the beginning of the epidemic would have included the fear of an illness not well understood, with no or few treatment options and a life expectancy perceived at that time as markedly reduced. To gain an understanding from these participants about their individual experiences of a life lived with HIV, I asked the participants to describe their experiences. In response to this question participants commonly began with the words “at diagnosis”. That moment and the subsequent life lived with HIV for these participants is discussed under the sub-theme “At diagnosis”.

### *At diagnosis*

Initially I asked each participant to describe their lived experience of living with HIV. This was to give me an understanding of their history including what an HIV diagnosis meant to them and how this experience was for them. Asking the participants to describe that experience was a way to better understand their life journey. The ensuing discussion invariably began with the participant describing the moment of their HIV diagnosis.

If there was one experience all participants of this research shared it was the moment of their HIV diagnosis. Their reactions at diagnosis, however, did vary in subtle ways. Their reactions often depended on the year of their diagnosis – whether the participant was diagnosed early in the HIV epidemic, or in more recent years. As well, not to be overlooked, is the resource base of the participant at time of diagnosis. This includes the participant’s support networks, and their coping and adapting strategies, to name but a few, that may have helped or hindered them during this time. Some examples of words used by the participants which capture their memories of their feelings at their HIV diagnosis are “devastated”, “very scary”, “ostracised”, “panicked”, “shame”, “anger” and “oh dear”.

The sub-theme “At diagnosis” captured what I considered to be a pivotal moment in the lives of the participants. The participants in this research may not have shared many aspects of a life lived with HIV, but the moment of their diagnosis was a moment they each did share. I felt that it was appropriate to begin by asking about how their reactions

at the time of diagnosis may have informed their subsequent journey of living with HIV. The participants described a range of experiences in response to this question. This was often as a result of the year of their HIV diagnosis, or how developed the treatment for HIV was at time of their diagnosis, but other factors as well will be described. The reactions of participants to a life for them lived with HIV from diagnosis, and how this may or may not have impacted on their feelings in respect to the theme of this research, add colour, depth and context to the participants' responses. The following are sentiments described by the participants about their lived experience of being diagnosed with HIV.

At diagnosis. In those days it was very scary. It was very threatening. I spent a long time in ... [hospital] I was virtually told ... that unless they could turn things around I'd be gone within a couple of weeks ... and that gave me the boost to do something about it ... I saw them being wheeled out in the middle of the night, deceased, and I tried to ignore it as much as I could ... I was ... [in hospital] for a very long time.

(Participant Fourteen)

When asked to speak about his experience of diagnosis one participant expressed his feelings in the following way: "Frightful. Embarrassed. Shame and anger at myself ... for being so stupid ... wished I had never been born homosexual" (Participant Fifteen). This participant felt very deeply the sentiment that he "wished I had never been born homosexual". The oldest of the participants, Participant Fifteen had lived through a time when being homosexual was an identity that most men felt they needed to keep secret, or, as it was commonly euphemistically referred to, 'closeted'. In his statement, this participant was clearly laying blame on his sexuality for placing him at risk of and then subsequently acquiring HIV.

Other participants described their feelings at diagnosis a little differently from the above, often determined by their different year of HIV diagnosis. The participants who were diagnosed at the beginning of the epidemic when HIV was an unknown illness and when one's prospects were poor may have felt more fear than those diagnosed in more recent years. The following are some examples of those feelings.

A participant who was diagnosed in 1993, in response to the question about his feelings at his HIV diagnosis, replied:

That day I remember well. I got the result and the doctor said “positive”, so I immediately went to ... [a Sydney tavern] and had three schooners and sat there and thought, “No, this can’t be right. This is ridiculous.” So, I rang the doctor back and said, “Are you sure?” And he said, “Yes, I’m sorry, but I am sure.” And I thought, “Oh God, oh dear, oh dear, oh well”, had another drink and thought, “Oh well, I’ll probably be dead in five years.” And that was the initial ... reaction. (Participant Six)

One participant who was diagnosed in 1989 stated that he felt his life as he knew it was at an end:

Totally panicked and quite bereft. Thought the world had come to an end. Of course it was really in the early days and the prognosis was very poor and that’s what everyone imagined and it was not well understood, so it was a disastrous diagnosis ... Devastated. Absolutely devastated. (Participant Thirteen)

A similar sentiment about life coming to an end was repeated by another participant:

Well, when I was diagnosed ... when I was told I was HIV positive I thought, well, end of the world is here. I went to see a specialist and I’d ask him how many days, months, years I have to live, have I got and he said, “Well I don’t know when you will be run over by a car because that could happen before you die of HIV.” He did remind me not do anything stupid because in twenty years’ time I might regret it and I thought, “Twenty years, gosh my doctor is optimistic”, but I have been diagnosed twenty years ago and I never think about it. I never worry about it. (Participant Eleven)

Following on from his feelings of looming mortality and a life shortened, this participant went on to describe his experience of distress and despair when collecting his antiretroviral medications from the pharmacy for the first time:

When I went to the chemist I came home with a bag ... [gesturing the large size of the bag] of medications and I thought, "Nah, I'm not going to take that. I'll take my own life before I do this." But I changed my mind because I would have to write so many notes to my friends and to the place where I was working, why I let them down ... so I changed my mind. It was easier. (Participant Eleven)

Illustrating a sense of his determination and tenacity at the time of his diagnosis, another participant said he felt his life living with HIV at the beginning was:

A bit of a rollercoaster, a bit of a rollercoaster ... I then rapidly, though, steadied up on the whole thing and ... I told myself, "I'm not going to be a virus, I am going to be a person living with HIV and like a person living with diabetes or cancer, I've got to take medication, but it's not going to rule my life" and it never did. (Participant Two)

Some participants who were diagnosed in more recent times, in the mid to late 2000s, said that their fears and concerns in relation to their future life with HIV were assuaged by their doctors. These doctors said that treatment had improved significantly and that their prognosis and life expectancy would be largely similar to that of the non-HIV population. The following are some examples of these sentiments.

At the time of his HIV diagnosis one participant had momentary concerns; however, he replied: "I was immediately relieved of my, any worries I had when they said it's no longer a death penalty and you probably would not succumb. After that I had no worries at all" (Participant Nine).

Another participant, who was diagnosed in 2011, described his response to his diagnosis:

I was more concerned about whether my, I had passed it on to my wife, which thankfully didn't happen. I wasn't so concerned about myself at that particular stage until I actually spoke to a doctor and got her opinion as far as what was needed in the future; medication, etcetera, etcetera ...

I was more concerned for my wife than anything else. (Participant Ten)

The participants articulated many other responses to their diagnosis of HIV, but the above experiences succinctly encapsulate how it felt for the participants in this research from the time of their diagnosis. As expressed by a number of participants, however, once they had adjusted to what some said was the shock of an HIV diagnosis, they also believed they needed to proceed with life. The following sub-themes describe the different ways some participants managed their life lived with HIV. These sub-themes are "Getting on with life" and "Standing outside from a distance: Secrecy and separateness".

#### *Getting on with life*

After the initial reaction to a diagnosis of HIV, for many of the participants there was a focus on getting on with life, however long or short that life may be. As a testament to this instinct for perseverance, and resolve, and to the ongoing advancement in HIV treatment, the majority of these participants have now lived with HIV for many decades. Some writers now describe this group as "HIV positive veterans" (Escota et al. 2018, p. 57).

One participant's response to his 2004 diagnosis was:

I think, to put it bluntly, when the doctor told me, I was pissed off, but I thought, well, there's nothing I can do about it and work carried on ... life has to carry on ... [O]ther than taking my tablets ... [my life has been] not much different to the way it was before ... No point worrying about something you can't do anything about. (Participant Four)

One participant said that initial concerns or alarm were raised by his doctor, whom he remembers saying to him: "Your prognosis is pretty grim and consider your future

with regards to maybe retiring and spending whatever superannuation', but I delayed that" (Participant Six). Despite his doctor's warnings, this participant added later in his interview that his feelings about his life with HIV "was just getting on with life, getting on with really enjoying what you had to do ... because people started to die ... to be where I am now I feel absolutely wonderful" (Participant Six).

After his and his sero-discordant partner's initial reactions of panic and devastation at the time of his HIV diagnosis, one participant said he got through this difficult period, saying: "it's always with you and you accommodate it and you move on. You can't actually be stuck in that space forever and a day, otherwise what's the point?" He added that his partner is "incredibly supportive ... we're both of a mind that we just get on with things, that's the way to do it" (Participant Thirteen).

Getting on with the rest of their lives was paramount for the participants in this research. The sentiment that there is no point in dwelling on something that cannot be changed was common amongst these participants. The following describes ways some participants managed their lives living with HIV by standing outside from a distance with secrecy and separateness.

#### *Standing outside from a distance: Secrecy and separateness*

As I reflected on the interviews, certain sentiments expressed by some participants began to resonate more deeply. They resonated and gathered meaning for me to the extent that it was clear that a number of participants were indeed standing outside from a distance to their HIV diagnosis. Some participants did this by keeping their diagnosis a secret, while others separated their lives completely from their diagnosis. I felt that these elements were worthy of description and deeper exploration, as will now follow.

**Secrecy.** A small number of participants described employing secrecy as how they believed they 'got on' with their experience of living with HIV. The following are examples of secrecy about their HIV status playing a major role in how these participants managed to live their lives with HIV.

I did have a great worry about people finding out ... I was always worried that somebody would find my boxes of tablets. I never, ever learnt what tablets I took and if anybody asked me what tablets I was on, I could honestly tell them I didn't know and even today I still don't know. I know what I have to take. I know the colours and I know what they are and what they are [for] but if you ask me the name of them, I couldn't tell you. It's a deliberate thing that I did over the years, so that I would never unconsciously tell somebody what I was on, or consciously tell somebody what I was on. (Participant One)

This participant said he used his not knowing what medications he was taking as a mechanism to keep his HIV diagnosis a secret from others: "It's prominent. Has always been and always will be. I still think there's a lot of stigma out there and I don't believe people are given a fair go if they know that you've got an illness like that" (Participant One).

Secrecy was a key theme in the interview conducted with another participant. He lived in fear and dread that if his HIV status was known by his family his homosexuality would also be disclosed. It was his family discovering his homosexuality and how they would react that concerned him most, rather than his HIV status becoming known: "How they would take [my homosexuality], they might not respect me anymore, which, as I said, they've got me on a pedestal. They think their granddad is the greatest thing since cream cheese" (Participant Eight).

While the majority of the participants in the research did not articulate the same level of concern regarding living a life in secrecy with HIV, or with their sexuality, the examples above illustrate that there were some who expressed real concerns about these issues. Others chose to live in separation from their illness, as will now be discussed.

**Seperateness.** Participant One stated that he was 100% adherent to taking his antiretroviral medications and that he had an undetectable HIV viral load – the gold standard result of adherence to therapy, a viral load at levels illustrating complete viral suppression. This information demonstrated to me that Participant One was engaged, to a certain degree, with his HIV status and therapy. Based on this, plus referring to the

participant's decision and determination not to know the name of his antiretroviral medications, I posed the question whether these were mechanisms, as well, for the participant to separate himself from his HIV status. Participant One responded: "I've separated it completely."

Further discussing this separation or separateness from his life living with HIV, Participant One said:

I completely separate the HIV from everything in my life. It's [his HIV status] over there [pointing to the other side of the room] and I'm here [pointing to himself] and I live here and my friends and everyone are in this group and the HIV is over there.

Separating himself even further from his HIV status, Participant One said that his treating HIV specialist was in charge of his antiretroviral medication: "[my specialist] does all that, that's all controlled by him and I don't have a problem".

Another participant, describing the lengths to which he may have separated himself from his disease, though in a less determined way than Participant One, said that his management of his HIV status was not to think about it:

I've got a medical condition and I take one tablet ... when I go to bed, but I never worry about it, I never think about it, especially comparing with other people who have got a lot worse medical conditions.

(Participant Eleven)

A life lived in secrecy and separateness helps describe what a life lived with HIV meant for some of these participants and how that may inform how their lives may be lived into the future.

Reflecting on the deeper meanings in what participants said about their experiences of a diagnosis of HIV, I felt that some participants experienced alarm and fear at being diagnosed with a previously unknown illness, an illness that contributed to the deaths of



many worldwide, including their friends and associates. This was, for the majority of the participants, a fearful life-changing event.

These participant stories place this data historically. It helps to position their stories and their reflections at a particular point in time. It gives a sense of who these participants are and their history of a life lived with HIV. Moreover, it sheds light on how that life may influence their outlook as they consider a life lived in aged care.

### *Theme One summary*

The reflections of these participants were included in this theme to help understand their individual histories, and the ways they adjusted to and managed their illness. This potentially says a great deal about how they will manage the next stage of their lives – a life well lived in aged care. Phenomenologically speaking, the historicity of the participants is an important element to consider. Their individual histories position where they have come from. Their thought processes are reflected in how they have expressed themselves. The time of the participants' HIV diagnosis has informed their attitudes and their responses.

Some participants were diagnosed with HIV at the beginning of the epidemic, a time when the pathology of the virus was not well understood and when treatment was either not available, or when it was, it was just one agent. There was much discrimination and stigma, which ended relationships, marriages, family connections and employment. Some participants were advised by their doctors to consider retiring from their employment to access and spend their superannuation, as their prognosis and life expectancy were poor. Other participants were diagnosed in more recent times, when the pathology of the virus was better understood, when therapy had advanced and when one's longevity was more probable. These participants' responses were reflections of that time period. This combination of different periods of time at diagnosis and different experiences of living with HIV has added great colour and meaning to the sentiments expressed by these participants. I will now discuss the second major theme.

## **Theme Two: HIV today**

Much has changed in the lives of those living with HIV today (Kidd, 2017). Continuing advances in therapy and research around early testing, diagnosis and commencement of therapy have improved the health outcomes and well-being of those diagnosed with HIV.

Throughout the interviews there was constant reference by many that a life lived with HIV for them had changed. The management of HIV, the treatment and the prospects for longevity were all different from before; things had moved on, had changed. More succinctly, the landscape of a life lived with HIV had changed. This sentiment developed into the sub-themes “A changed landscape” and “A life experienced in a new world”.

### *A changed landscape*

As discussed in the literature review, HIV today is not the disease it once was (Kidd, 2017). Approaching the fourth decade since the initial diagnoses, the issues around HIV are not as they were. Improvements in HIV therapy and other measures in treatment, with today’s emphasis on and encouragement of more people being tested earlier, therefore being diagnosed earlier and commencing therapy earlier than was once believed appropriate, have resulted in better health outcomes. Therefore, HIV today is no longer considered the death sentence after a short illness that was often the case for those diagnosed in earlier eras.

In most regions of the world, PLHIV today who are receiving and doing well on therapy are living longer, healthier lives than once thought possible. Therefore, the participants in this research felt that issues and attitudes around HIV had changed in varying important degrees. These positive changes in the landscape of PLHIV will, it is hoped, be present in the aged care sector when or if the participants make the transition to aged care. Thus, I believe that those living with HIV, while acknowledging the remaining challenges that exist, are now experiencing a life lived within a changed landscape. The following participant quotations refer to some of these changes.

Diagnosed in the 1990s, Participant Two reflected that he felt that he is living in a changed landscape from one he remembers from the past: “I think that’s changed a lot”.

The earliest of the participants’ HIV diagnoses occurred in 1983. When this participant described how he felt attitudes had changed, in particular within the hospital sector, he told the following anecdote:

Back in the early days I remember visiting a friend of mine who is now dead ... [he] went out to one of the cleaners and asked her if she would come and clean up something on the floor which had been done by the person who slid the tray ... [dinner tray] and she said, “No, no, no. I no go that room”, because she didn’t understand. So, he took the mop off her and cleaned it up himself and said, “No problem”. She was more frantic that he’d just dirtied her mop. (Participant Twelve)

This participant also spoke of a conversation he had with a nurse who had been caring for him while he was an inpatient in hospital a year prior to his interview. That conversation was around how he and the nurse each felt that attitudes and education about HIV had changed since the initial years of the epidemic. Participant Twelve said in this conversation: “she ... [the nurse] remembered the ... [dinner] trays on the floor and the red crosses on the doors and things”. Bewilderingly, and indeed worryingly, Participant Twelve went on to say that during the conversation with this nurse she confided that her husband, to this day, does not know where she works: “[her husband] still believes ... [she] work[s] in the maternity, because if ... [her husband] found out ... [she] worked with AIDS patients ... there would be a problem with [her] marriage”.

Conversely, remembering observing how others with HIV were treated many years ago, Participant Three said: “but, of course, that was twenty years ago. The world has moved on.”

In reference to HIV being a changed landscape, the conversations during the interviews included discussions around participants’ experience of their antiretroviral treatment. These stories told of the different eras of antiretroviral therapy and the effects that had

on their experiences then and now. Similar to experiences of those diagnosed many years ago, Participant Six said that when he was diagnosed:

From the beginning ... nineteen tablets a day... and some of them were like horse tablets ... I think the first couple of months I spent living in the bathroom and I had a massive panic attack at work over it and I went back home and thought to myself, "I can't go on like this, this is ridiculous." ... So I went to see ... [my treating specialist] and he introduced me to some clinical trials that were going on. I think initially we started on a three-combination therapy ... There was a drug holiday, probably five years later, because of my liver function reacted quite dramatically to the medication ... Well, we had a drug holiday for twelve months, allowed my viral load to go ... its merry way and it got to about 12,000 ... [copies per millilitre] plus, and we ... [my doctor and I] thought let's go back on ... and eventually became one tablet. So, I only take one tablet now.

Many participants felt their life living with HIV was one lived in a new world, a life much different from and better than the one they had previously experienced. This led me to formulate the following sub-theme.

*A life experienced in a new world*

Reflecting on his experience of times past and present one participant said:

But living with it [HIV] over time ... I've seen my friends die ... my three best friends die within six months of each other and it left me void as the years went by ... I thought, "My God, I'm on my own."

(Participant Six)

Describing the various challenges, medical and emotional, that he has lived with since his diagnosis, this participant added: "To be where I am now and the age I am I feel absolutely wonderful" (Participant Six).

Reflecting on his antiretroviral therapy experience, Participant Twelve said:

Now it's brilliant ... The early days they gave you double, triple doses ... gave you peripheral neuropathy ... it was the amount they were giving back then ... [one of them was similar in appearance to] big horse pills. Yep, got through all that. A few times I thought I wasn't going to.

On the topic of how attitudes towards HIV and PLHIV have changed over time, the earliest of the participants diagnosed with HIV (Participant Twelve) remarked: "Well, you would only hope that it would. But in my point of view and the way I see things the way they've [the community] come along in twenty, thirty years, it's changed a lot".

In a similar vein to the above participant, Participant Eleven remarked:

Yeah. It's like years ago when people found out about my sexuality, there wasn't much talk about it. Today, I can say to anybody, "my partner or our gay relationship". Everybody has got a story to tell, "Oh my nephew's got a boyfriend, or, my niece has got a girlfriend, or my son is gay." Everybody has got someone gay in the family and they are so anxious to tell you all about it. And time will come when people will talk about HIV like they talk about diabetes or high blood pressure.

The point this participant was making is that conversations amongst family, friends or neighbours about homosexuality and HIV have changed to varying degrees and have become more commonplace today.

Reflecting on the deeper meaning derived from this last section, in which the participants described how they have observed the changes in attitudes and issues surrounding HIV over time, it is clear that the landscape of HIV has changed. They are living a life with HIV informed by the past, but one which is markedly and positively changed, a life they feel is now better; a life lived with more hope. This hope may assist these participants to confront a life lived in older age and may inform their considerations about a transition to aged care.

### *Theme Two summary*

Based on these participant stories, I decided to include HIV today, a changed landscape and a life experienced in a new world as a major theme and sub-themes in this analysis. I found clear validation of the inclusion of “HIV today” as a major theme and “A changed landscape” and “A life experienced in a new world” as sub-themes for this analysis.

The history of HIV, as it relates to the participants in this research, is relevant to understanding the data. It says a great deal about what the participants of this research experienced when they were diagnosed, what their life prospects may have been like then and how things have changed with their illness and the real potential for their own life trajectories now. As described in relation to the last theme, phenomenological research is interested in exploring the history of the individual and the issues that are paramount to that individual. The management of HIV was understandably of paramount importance to the participants in this research. Therefore gaining a deeper understanding of how they managed this period is extremely important and worthy of inclusion in this research. HIV is now categorised as a chronic manageable illness in this changed environment, and this is critical to how participants will manage their future life in aged care. I will now discuss the third theme.

### **Theme Three: Considering a transition to a life well lived in aged care**

When I introduced the topic of the participants’ potential transition to a life well lived in aged care in the interviews there was a mixture of responses. Some participants had given no previous thought to the notion, some had given some thought, while others rejected it outright. For those who had given some thought to a transition to aged care, their responses ranged from having no concerns, to a number of concerns, to a clear rejection of this transition. For a small number of participants, euthanasia was their preference. The following are some of their responses to the topic of a transition to aged care, including associated themes that emerged during conversations about what participants foresaw for this transition. To begin, the following quotations stood out for the researcher as examples of their initial responses to such a transition.

When asked what he would say if his doctor said to him it was time he considered a transition to aged care, Participant Four said he would say “get nicked”. This response was said with such spontaneity and forcefulness that it engendered much laughter from both the participant and interviewer. When asked to elaborate he said, “Doing the job I did I’ve seen plenty of this ... seeing people go into aged care ... people seem to deteriorate ... I don’t want to get to that, well, at this stage” (Participant Four). This participant’s response reflected his experiences from his previous employment where he worked with and observed those who had made this transition to aged care.

Other participants’ responses to this topic ranged from a hope that this transition would occur some time, or many years, hence, to total rejection, with another saying that transition to aged care for him would occur only once he had completely lost his cognitive function. The following are some examples of these responses:

I hope it isn’t anytime soon. (Participant Five)

What an awful thought. No one wants it, do they? (Participant Thirteen)

Well for me, it’s not for me. (Participant One)

I don’t ever want to go into a nursing home ... I’ve always said, I will take a dash of pills and go to sleep and that’s what I want. (Participant One)

Put it on record. I’m a strong advocate and supporter of voluntary euthanasia. I think it is everyone’s right to determine how much suffering they wish to contend with. (Participant Six)

I am a member of Euthanasia Society. I believe in it and when my dogs get old and uncomfortable in their life, I put them down and why can’t I put down myself. (Participant Eleven)

I would have to lose all my scruples to be in that state. (Participant Eight)

In my reflections the key elements I identified in these statements can be summarised as: “Into the future, far far away”, “Euthanasia”, and “Only if/once all faculties have failed”.

While these were the initial responses from some participants, it needs to be stated that these would most likely be common responses and concerns that would be raised by all those considering a transition to aged care, regardless of their medical condition and sexual identity. There were, however, elements from the data that were unique to PLHIV, pertaining to their life history, their HIV status, their sexual identity and their concerns about transitioning to a life lived in aged care. Some of these were: choosing the right aged care facility, connectedness with other residents, stigma, assumptions made, aged care workforce readiness, and aged care as a welcoming environment. I felt that these elements were unique to PLHIV considering a transition to aged care. However, before speaking about these more unique elements mentioned above, one issue raised by all participants, universally, when this topic was raised, was the sense of the loss that they would feel about such a transition. This will now be discussed.

Most participants in this research discussed at length the sense of loss that they would feel in a transition to aged care. Examples of loss articulated by participants were loss of one’s partner/loved ones, one’s home, possessions, surroundings, one’s bed, independence, autonomy, privacy, food choice and quality thereof, and indeed choice in its many forms. Essentially, they were concerned about the loss of what they considered to be their quality of life. The loss of the many important, life-affirming elements mentioned by these participants, while profoundly felt, would be, as mentioned above, not dissimilar from what would be felt by the majority of the non-HIV population facing a transition to aged care.

That said, I will now proceed to an analysis of the major question of this research. That question is exploring what participants said would be their concerns related to their HIV status, and which perhaps may be concerns of others living with HIV as well, as they consider a transition to aged care. The following elements that participants spoke about in relation to this question are: finding the right place for a life well lived in aged care, with the right people within – staff and residents, finding a connection with other residents, and whether participants felt that aged care would be a welcoming



environment for them. To begin, finding the right place and the right people within will be described.

### *The right place*

Finding the right place for participants included, fundamentally, finding the right people within. This includes workforce readiness, with care staff who are knowledgeable and empathetic to the care needs of PLHIV and residents within the facility with whom they could develop a sense of connection. The right place for participants also meant that the facility would feel like a welcoming environment; an environment where, as one participant stated, they would feel embraced.

Some participants mentioned that they would want to research broadly so that they found what they described as the 'right' facility. Finding the right facility would be paramount for all considering a transition to aged care, regardless of one's medical condition or sexual identity. For the participants in this research, finding the right facility was of immense importance. Finding an aged care facility where they would receive the same high quality of care and respect for dignity as other residents was more keenly felt as a concern, they believed, for PLHIV entering this previously rarely trodden, unfamiliar environment. As one participant said:

I don't know a lot about aged care. I hear some stories that are really good and I hear stories that are horrific as well. So, I guess, for me, I'd want to, if I had to go into aged care, I'd want to be researching thoroughly what's available, because I just wouldn't want to get plonked into any establishment where you don't get cared for really. (Participant Two)

A key element of this statement was the participant's sense of control. He would want to be in control of his decision.

Another participant expressed the following sentiment in regard to finding the right facility:

Making sure I picked the right one. Because you hear a lot of stories out there, don't you? I mean, let's face it right, they're on *A Current Affair* all the time and you think to yourself, "Shit! When it comes the time I hope I'm smart enough to pick the right one." (Participant Ten)

Reflecting on the deeper meaning of the above statements, I found that "Control over decision making" and "Having the nous to choose the right one" were common themes.

The following section will describe a connection to other residents.

#### *A sense of connection*

When the discussion focused on the transition to aged care and how participants would feel in that environment, one participant remembered a dinner party conversation many years ago with a group of his gay friends about how they felt about a move into aged care.

Even in my early gay years there was always a concern with the gay community as to where they're going to end up. Because could you imagine a lot of these gay people going into old folks homes and trying to be straight? (Participant Fourteen)

This participant chuckled at this story, adding, however, that he was a very sociable person and had no doubt that he would develop a connection with other residents easily:

I could adjust to anything. If I have to play ping pong I will. If I have to go to the football I will, it doesn't matter ... [he would like the aged care environment to be] just a happy environment I would think.

Another participant had a greater concern about finding a connectedness to others in residential care. In relation to his concerns about a transition to the aged care environment, one participant said:

the ability to find people you can relate, finding people you have relatedness to. Which means ... men are very few and far between in nursing homes ... my partner's father was the last man standing amongst all the women, so he had no men to talk to. So you would have to find a nursing home with men, men you can relate to ... [I]t is very important that the type of people match each other up ... [to be with people] that reflects your life closely as possible to what you were used to ... I mean, to spend the rest of my time with people who are sports-minded, or watching football, I'd go and hang myself. (Participant Five)

Moreover, on the topic of relating to others, or the obstacles placed in the way of being able to relate to others, this participant spoke of an experience he had observed many years ago, during his social work studies, when he visited some residential care facilities. This participant said that he observed residents within the communal area: "the television was on loud all day, nobody was watching and the staff put it on to act as a distraction. Well, it was torturous, because there were a lot of people didn't speak English" (Participant Five).

The key elements I identified in the above were: "the need for, or the ability to have a connection with others in the aged care environment" and "The need to not be placed in an environment where connection with others is inhibited".

The following section will now focus on what participants said would be their concerns about the attitudes of the staff within the aged care sector regarding caring for PLHIV.

#### *Attitudes of staff*

Reflecting on what their lived experience might be while finding the right place as they transition to aged care, many stressed the importance of the attitudes of staff within aged care facilities. Some believed that the attitude of staff towards both the participant's HIV status and, for some, their homosexual or heterosexual status, would impact on the quality of their life within this environment. The participants had different views on the attitude of the aged care workforce to caring for PLHIV, with some expressing no concerns, believing the nursing care they would receive within the

aged care sector would be the same as for non-HIV residents. This expectation was expressed by the following responders.

Providing a personal anecdote to demonstrate his thoughts on the above question of the attitudes of the aged care sector caring for PLHIV, Participant One replied:

we had a HIV positive person come in for respite and I was watching with great interest to see how the staff reacted ... I was pleasantly surprised to say that I saw no discrimination anywhere and I felt he was well accepted and he was a well-liked resident there.

In response to the above question, another participant dismissed out of hand the notion that he would encounter any discrimination or feel stigmatised as a result of his HIV status, saying: “Well, I would hope that [discrimination and stigma based on a resident’s HIV status] would not raise its ugly head ... I can’t imagine it ... in this day and age being an issue” (Participant Five). This was repeated by another participant: “I wouldn’t be [concerned about discrimination] Not now. Twenty years ago yes, but not now ... the way I see things, they’ve [the health sector] come a long way ... it’s changed a lot” (Participant Twelve).

Other participants had differing responses to the above. With his experience working in allied health care over many years, one participant said: “Well, of course, I haven’t mentioned that one at all have I? And I think that’s a huge issue ... [discrimination on the basis of my HIV status]. I’m still to be convinced [otherwise]” (Participant Thirteen). Later in his interview, he added on this topic: “I just wonder the level of ignorance still there, the level of prejudice ... I would assume is still there” (Participant Thirteen).

In response to this topic another participant replied:

I would be very concerned about my care. If I would disclose my condition to the wrong person, I would prefer not to disclose because I would fear ... I could be treated differently to other clients ... in a nursing home. And I believe that could easily happen because people are

not educated enough yet out there that we are no danger to them ... I hope when I'm ready to go into nursing home people are more educated.  
(Participant Eleven)

This participant said that his response was coloured by his attendance at a conference held interstate (run by an LGBTI organisation) several months prior to his interview. One of his anecdotes from this conference was the following:

there were people ... [nurses] from nursing homes ... who had experience with their staff that they were treating gay couples differently than heterosexual couples and how to address ... and how to deal with that issue ... there were some interesting quotes. One nurse said that she's not going to look after these two because they are homosexuals, so the nurse was told, then you'll have to go and work somewhere else because we look after everybody. (Participant Eleven)

The point this participant was making, as he ruminated about this anecdote, was that if there were some nurses who had issues with caring for homosexual couples within the aged care sector, then how might those nurses feel towards caring for PLHIV in this environment? It is a question worthy of further exploration in future studies.

Some participants said they were aware of the existence of laws in Australia that preclude discrimination by healthcare workers based on a person's sexual identity or health status, and felt comforted by this. Despite knowledge that laws exist governing health care in general, some participants still were to be convinced that they are universally followed by all health care workers, with one participant responding: "I know it's illegal [to treat people differently depending on one's sexual orientation and medical conditions] ... there are many things that are illegal, but are still done" (Participant Eleven). And another participant said: "I know, but people break laws" (Participant Fifteen).

Some participants felt that the attitudes of staff within aged care facilities are usually moulded by, or mimick, the attitudes of those at the management level or shaped by the organisational philosophy. One participant said his deep concerns were in relation to

staff not always consulting with him or not having the time to spend listening to his desires and wishes:

Yes, I think that is a great fear of mine. And it's not just the system. It's just the day-to-day staff with whom you have contact and perhaps that's where I'm coming from. It's the people. The system can promote one thing, but the people that you've actually got on the ground, one to one, does it come down and does it seep through and are they implementing what the organisational system wants them to implement? I think it's extremely difficult. I think it's very difficult because they do come across people where to consult and to work with people to make decisions as collaboratively as possible takes a great deal of time and effort and having the right sort of conversations and I don't know that that's so easily obtainable. (Participant Thirteen)

This participant expressed his hope that, when it became necessary for him to transition to aged care, the staff would have the time to engage with and get to know him and his wishes, just as they would engage with and get to know other residents they admit into their facility. This would be an integral first step. Staff need to be mindful of what is needed for all people they are admitting into their facility, especially the potentially more vulnerable PLHIV, to ensure that they live with respect, dignity and happiness within the facility.

One participant stated that he believed the quality of care that he would receive in the aged care sector and the attitudes of the staff there might be dependent on the staff's level of nursing education:

Depends on the attitude of the staff doesn't it? Most of these people, or I would say a majority of them are nurses; however some would probably be like nurses' aides or just in aged care without actually having RN or EN [qualifications]. (Participant Ten)

Similarly, a participant who formerly worked as a Registered Nurse raised concerns about nursing qualifications and the level of supervision and staffing in aged care, and

how it might dictate the level of care he received: “It depends on the supervision, doesn’t it? I mean, if there’s good supervision. Because lots of nurses ... [in aged care facilities] only have enrolled nurses or carers, don’t they ... with one RN on the floor?” (Participant Fifteen).

Reflecting on the deeper meaning of the above, I summarised the key elements as follows: attitudes of staff are reflections of the organisational philosophy of the aged care facility and those of the nurses’ educational and qualification levels; laws exist to protect against discrimination; and these laws give comfort to some, while others remain to be convinced.

The following will discuss whether the participants believed that the aged care environment would be welcoming.

*Aged care: A welcoming environment for PLHIV?*

The participants found it interesting to consider whether the aged care environment would be a welcoming one for PLHIV, with some saying that it was a very thought-provoking question. The following are some of these responses from differing viewpoints.

Believing that the aged care environment would be welcoming for PLHIV, one participant replied:

I think that’s beyond doubt. I think the value that has been put into this specific condition ... [HIV] and the research ... the medical profession, you would hope this would go along with carers and aged care ... that they would follow the same culture ... not to discriminate on the basis of any fear factor. (Participant Six)

The opposite response was articulated by another participant, whose past working experience impacted on his reply. This participant responded:

Welcoming? Deep down, honestly, if I was to give an honest off the top of my head answer, I'd say no. No, I don't think, I worry about that, I guess ... I just wonder, the level of ignorance still and the level of prejudice, I think I would have to assume is probably still there. I would love to be proved wrong. (Participant Thirteen)

This sentiment was coloured by his working experience some fifteen years prior when he was engaged with finding aged care facilities for PLHIV. He remembers that time and the difficulties, discrimination, stigma and the level of resistance from those aged care organisations that he faced in this mission. While no longer working with this client group nor in this endeavour, this participant wondered, hoped, but doubted that things have changed significantly in that space. Later in his interview, returning to the theme of his concern that the aged care environment may not be a welcoming one for PLHIV, this participant added: "I didn't bring it up as a major concern [earlier in the interview] but it's always there".

Another participant, who felt the aged care environment would be welcoming, replied:

My sense is that they would be. I mean, they're a health service and, other than in the early days of AIDS when health services were just as frightened as everybody else so they treated people differently, I think that's changed a lot. (Participant Two)

Another participant said: "I think so, in this day and age. I think the environment comes down to the staff, doesn't it? ... And that comes down to the person who's above them and the way they're treated" (Participant Twelve).

Reflecting at a deeper level, these findings about the right place, the right aged care and the right people within, and the concerns of some participants, extend the theme of aged care being a welcoming environment for PLHIV. This will now be further explored.

The difference between a welcoming environment and one that is merely accepting was explored in some depth by one participant. In his response to this question one participant described what he felt would be the difference between feeling accepted and



feeling embraced, and hence feeling welcomed or not. He spoke eloquently about the difference between these concepts from both the perspective of his homosexuality, and also his HIV status. This was an important distinction for him:

when I came from a country where it [homosexuality] was not an issue, but coming to a country [Australia at the time] where it was illegal and then of course how important it is to me that everybody is embraced, not accepted, but embraced. You accept a bill for electricity and water, because you have no choice, but to embrace, that is a choice. (Participant Eleven)

The point this participant was making was that one accepts the bill and pays it, whereas when one feels embraced, that is a more worthwhile acknowledgement of whom one is in relation to the other person. Participant Eleven felt that simply being accepted on the basis of his sexuality and his HIV status was not enough for him to feel welcome. Feeling that he was embraced, that his HIV status and his homosexuality were not an issue, would make him feel welcomed into the aged care environment. Feeling welcomed, for this participant, would go a long way towards him enjoying a life well lived in the aged care environment.

The concept of feeling embraced was an interesting one that caused much contemplation, pause for thought and discussion from Participant Eleven and, it must be said, caused much reflection for me. Thus, I considered that it was worth describing the nuances of these elements more deeply in this analysis.

My reflections on the above sentiments led to the key points: “PLHIV need to feel embraced, not simply to be accepted, in order for them to feel welcomed when transitioning to aged care” and “There is a difference, as expressed by one participant”.

### *Theme Three summary*

The participants in this research hoped that a transition to a life lived in aged care for them would not occur any time soon. They would rather end their days in their own home surrounded by their loved ones and treasured belongings. However, if this

transition was necessary, then they would undertake thorough research to find the best, most suitable and most welcoming facility or, as some participants said, the 'right place' for them. The right place for them was described as a facility that was peopled with what they termed the right staff whom they hoped would be appropriately qualified and educated, with attitudes that were non-discriminatory and residents with whom they could form connectedness. The participants believed that, as time has progressed over the past nearly forty years since the start of the HIV epidemic, education, knowledge, and societal and workplace attitudes have changed in a positive direction. The participants in this research, in general, with all things considered, believed that a transition to a life lived within aged care would not only be not an issue for them, but would indeed be plausible.

Speaking from an hermeneutic phenomenological standpoint, the responses from the participants reveal their sentiments regarding a transition to aged care, for them, in thought-provoking ways. Their responses reflect deeply their different life histories: their backgrounds, their work histories, some of which were within the health/allied health care sectors, and their sexual identities. These histories and the language they used to express the issues raised have hopefully added great colour, context and depth to their responses and to this analysis.

## **Summary**

This chapter has brought together the analysis of each major theme. As described above, the participants in this research exhibit a broad range of differences and similarities. They have lived a different number of years since their HIV diagnoses; therefore they have experienced different periods or eras of living with HIV. The participants revealed differences in the ways they reacted to a diagnosis of HIV and differences in the ways they choose to live their lives with HIV, with some choosing to live in secrecy and others separating themselves from their HIV status. These participants also described their experiences related to advances in therapy over time and how they felt that, for the majority of them, they were doing well and getting on with their lives in active ways. These participants reflected upon and appreciated that, for them, life with HIV today is a changed landscape, and they took each day as it comes optimistically. When the topic of considering a transition to aged care was

raised, the participants expressed a variety of views. Some rejected the notion totally as something they would not consider, while others were more amenable, with the hope of finding what they considered to be the 'right' place with the 'right' people within and, as a consequence, an environment that was welcoming and embracing. The following chapter will discuss some of the most pertinent themes that emerged from this analysis.

## **Chapter Six: Discussion**

### **Introduction**

In the preceding chapter I discussed the findings which I gathered from the in-depth interviews held with the participants. In presenting and exploring the participants' life stories and immersing myself in their lived worlds further, I was able to add to our understanding of what a future life well lived in aged care means to them and what measures they would need to consider for this transition to occur.

In this chapter, I consider all the information that I collected from the initial thoughts that instigated this research and the literature review, through to the final analysis, theme identification and interpretation. I will briefly summarise the themes, discuss them in relation to the scholarly literature, where available, and suggest recommendations for future activities, including potential further research. This chapter will discuss the most resonant and relevant reflections that emanated from the analysis to achieve the aim of the study – to empower PLHIV to transition well into the aged care environment – and also to answer the research questions:

What are the concerns of PLHIV considering a future life well lived in aged care?

What issues do PLHIV perceive need to be addressed to facilitate a life well lived in this transition?

I identified from the review of the literature in Chapter Two that, while research in the field of HIV and ageing has been undertaken, there is a general scarcity of scholarly literature pertaining to and focusing on PLHIV transitioning to and accessing aged care, especially from an Australian perspective.

An interpretive hermeneutic phenomenological approach was used as I was keen to understand, at a deeper level, the meaning of the lived world experiences expressed by the participants in this research. I used this approach to find the essence of those lived

experiences to better understand the phenomenon at the centre of this research, which is the consideration of the transition to aged care and a life well lived in aged care for older PLHIV.

In using a hermeneutic phenomenological approach, guided by Heidegger's ontological philosophy, I remained conscious of my own background and perceptions – my historicity. When carrying out the data analysis, as I moved between listening to the interviews, reading the interview transcripts and reading and documenting my decision trail and reflective diary, following Koch's writings (Koch 1994; Koch & Harrington 1998), I had to be cognisant of the fact that my personal experience as a Registered Nurse working in the field of HIV for a number of decades could potentially influence how I interpreted the participants' words, sentiments expressed and behaviours. I had to understand that my lived world is very different from the lived experience of the participants on a number of levels, including my professional world being one of nursing and health care. Acknowledging this, my being in the world links particularly to van Manen's relationality and his lifeworld existentials – in terms of how I related to the participants and how their rich life experiences influenced my perspectives and therefore this analysis. Moreover, as described in the methods chapter, using van Manen's (2017) research activities and lifeworld existentials was enabling for me. It kept me focused on the phenomenon under question, allowed me to reflect on the essence of what the participants expressed and allowed space for my own reflections. These processes provided me with a deeper understanding of what a life lived in aged care would mean for the participants in this research.

### **PLHIV considering a transition to aged care**

Perhaps an important, or even a pivotal, starting point for this discussion should be why this research exploring PLHIV considering a transition to aged care is important. As outlined in the Introduction, there is a population of older PLHIV who are either already residing within aged care or who are approaching the need for that transition. As they are considering this transition, it is hoped that this research may more broadly open up the reflections and discussion of this group to assist in these considerations. I thought it was important to learn what issues were so different from the non-HIV population who are undergoing similar considerations of transitioning to aged care.

Were sexual identity, HIV status or fears of experiencing stigma and discrimination central to the concerns of the participants in this research when considering a transition to aged care? I was keen to explore what might be the differences in this experience between PLHIV and the non-HIV population entering the phase of considering a transition to aged care.

I posit that we all experience a range of experiences as we proceed through life's trajectories from birth to old age. These experiences may pose challenges that may be mitigated based on one's family structure and beliefs, educational abilities, the degree to which one lives in poverty, or wealth, sexual identity, health conditions, ageing, to name but a few of the experiences and challenges one faces through life. We all share these to varying degrees in a relatively straight line, diverging off kilter as a result of those myriad factors or challenges. We also all share that time in life when considerations about our future in old age occur. It is at this point that thoughts around ageing and aged care, and our various life trajectories, merge. I make the claim that PLHIV facing this stage of pondering ageing and a transition to aged care are different from members of the non-HIV population as a result of their HIV status. This said, I also acknowledge, and do not diminish the uniqueness of, those of the non-HIV community who are considering their own transition to aged care. They may well have concerns unique to their own life trajectories. The focus of this discussion, however, is to present the lived experience of the PLHIV in this research as it pertains to their lives lived with HIV and their attitudes to aged care.

As I have previously stated in this thesis, with a growing population of ageing PLHIV it is only in relatively recent times that PLHIV transitioning to aged care was even considered a possibility. Today, a relatively new and growing population of ageing PLHIV has emerged, and some of this group may require a transition to aged care. Therefore, there is a need for research on this burgeoning topic. This discussion will hopefully unravel the challenges these participants perceive may present themselves in a transition to a life lived well in aged care and answer the research questions at the centre of this research.

This chapter will discuss in more depth the findings that stood out from the data analysis that may bring forth what a life well lived in aged care would mean to the

participants in this research. To be discussed will be the various stages of a life lived with HIV as experienced by these participants: their past, present and thoughts of their future. These experiences may inform and assist them in this transition and, as a consequence, inform and give meaning to this research. To structure this discussion, the following headings will be used: the past, the present and the future.

### **The past**

As described in the analysis chapter, the life histories of the participants from the time of their HIV diagnosis to now, and what that life was like for them, may reveal how that life history has equipped them for a successful transition to a life well lived in aged care. I argue that the ways the participants managed their life journeys and their tenacity to survive and prosper to this older stage of their lives may assist them as they consider a future life, one that may see them live in aged care. The discussion will now focus on the participants' experiences of their past living with HIV in order to make meaning of their lives in the present and their thoughts about a life well lived in the transitions ahead.

As discussed in the analysis chapter, the experiences described by the participants of their lives lived with HIV from the time of their HIV diagnosis were varied. Participants who were diagnosed in the early years of the HIV epidemic described their diagnosis and a life lived with HIV at that time as a shock and traumatic; a time of much anxiety about a previously unknown illness, a life with a poor prognosis and fears of their imminent death.

When asked about his experience of an HIV diagnosis, a participant with one of the earliest HIV diagnoses replied: "what ... [my family and I] envisaged was all too horrible to contemplate and I think, well, I'll just see what happens ... [and then] thirty-two years later" (Participant Five). The point this participant was making was that, once diagnosed with HIV, you continue until suddenly you realise that a significant period of time has elapsed and you surprisingly and happily are still here. The expression 'still here' will be further discussed in the section titled "The present".

The experience described by the above participant and by other participants of a surprisingly long life living with HIV, after what was envisaged as a shorter time span, correlates with those commonly articulated in the literature by other members of the HIV community diagnosed during the early stages of the HIV epidemic. One person diagnosed with HIV in the first decade of the epidemic said:

When I was diagnosed in 1988 I was told I'd be lucky to live three months – six months at the most. I couldn't believe I made it through that first year. My attitude for many years was, "Well, look, there's another day gone." So, I feel unbelievably blessed to be here. (Positive Living 2014–2015, p. 9)

Another person diagnosed with HIV in 1984 reflected on that period and his concerns: "It was a scary and volatile time in the public's understanding of the virus" (Positive Living 2015, p. 8). A treating physician at that time stated: "Many who became ... [HIV] positive at the peak period of the mid-1980s were becoming sick. There were so many lives cruelly cut short so young" (Positive Living 2015, p. 8).

Some of the participants in this research, diagnosed at the beginning of the HIV epidemic and given a poor prognosis at that time, also commented on the fears they felt witnessing friends, associates and celebrities succumbing to the virus, wondering when this would happen to them. Other participants in this research, who were diagnosed in more recent times, when therapy had improved and there were greater prospects for longevity, expressed fewer concerns. Some participants mentioned other ways they managed their life with HIV in ways somewhat removed from their illness. These alternative ways of managing their life with HIV are discussed under the sub-theme of standing outside, from a distance – a life in secrecy or in separateness from their illness.

*Standing outside, from a distance: Secrecy and separateness*

The participants expressed a mixture of feelings about a life lived with HIV in secrecy, with the majority of participants not articulating the same level of concern as others. But, as described in the findings, there were some who did express real concerns about these issues and lived in great fear of disclosure. Of interest, the findings of a project



conducted by the Australian Research Centre in Sex, Health and Society (ARCSHS) titled *HIV Futures 8* (Power et al. 2016) corroborate those feelings. In that study, of the PLHIV who replied to the topic of feelings of stigma, 42% said that they “worked hard to keep my HIV a secret” (p. 1). These concerns raised in that project correlate with those of some, though not all, of the participants in this research, illustrating that concerns around secrecy about one’s HIV status are shared by many PLHIV. Fear leading to a life of secrecy may well have an impact on the ways they lived their lives in the past and present, and may well frame their lives into the future, including their transition to aged care. Or, more pertinently to this research, to what extent do the participants consider that living in secrecy in their transition to aged care would be a life well lived in that environment? Would those feelings of the need for secrecy help or hinder that aim?

A life lived for some participants in secrecy and separateness, as described under the sub-theme from Theme One – “Life lived from diagnosis of HIV” – illustrates what a life lived with HIV means for these participants today, and how that may inform how that life may be lived into the future. Societal attitudes with regards to homosexuality and HIV have become more positive over the years, in many regions of the world. Society today has a greater awareness of and concern for those identifying as homosexual and for those living with HIV (Crock 2013). However, some participants, especially those in the older age bracket, described remembering a time in their lives when that was definitely not the case. These memories similarly have been expressed by many others within the homosexual and HIV communities. Those memories and histories of a life lived with concerns about not being accepted for who they are may linger to this day for many in that age group.

Diagnosed with HIV later in life and now aged 69, Lillicrap (2014) describes his ‘coming out’ as a gay man, which took a number of years. After leading a life of being gay in secrecy, “in the closet”, as he describes it, he considered the likelihood of his own need to transition to aged care. His concerns relate to entering the aged care environment as a gay man, but, as well, as someone with HIV. He wonders, after finally disclosing his sexuality, whether in aged care he may need to return “back into the closet”. This writer, I presume, would share the concerns of some of the participants in

this current research. Some in this research were living lives in secrecy, and one might say ‘in the closet’, and therefore may carry this secrecy with them into aged care.

As discussed previously in the literature review chapter, in the not too distant past, many who identified as homosexual lived in great fear of being ‘outed’ and scorned. Society for many years in Australia, and still today in certain regions of the world, was intensely homophobic and antagonistic towards those who were homosexual (Altman 2013). A diagnosis of HIV at the beginning of the epidemic was considered, to put it mildly, grim, with a poor outcome, with a life expectancy measured in a small number of years, with many dying or witnessing those around them dying (Positive Living 2015). Moreover, those identifying as both homosexual and living with HIV were subject to stigma and discrimination.

Today, those identifying as homosexual are, in most cases, living a life with greater societal acceptance and less discrimination (Crock 2013). This has been demonstrated by the same-sex marriage poll conducted in Australia in 2017, in which 61.6% of the population voted ‘yes’. While acknowledging some regional differences within that percentage, it illustrates the level of acceptance of those identifying as same-sex attracted in this country. As well, today, PLHIV, with the advances in treatment, are enjoying healthier, longer lives with brighter future prospects. As a consequence, the general non-HIV population witnessing those living with HIV leading healthier, productive, contributing lives has perhaps helped to promote improved public perceptions around HIV within the broader community (Crock 2013). The combination of these events, it is proffered here, has perhaps fostered the de-stigmatisation of PLHIV in the eyes of members of the non-HIV broader community.

In the analysis of the data, I found that the vast majority of the participants in this research described their lives living with HIV, generally, as initially a frightening, traumatic experience. Over time, due to the advances in therapy, their lives, apart from a few road bumps along that journey, continued on in most regards positively. The majority of participants simply got on with life, while a small number managed their lives standing outside, from a distance, in secrecy and separateness, from their condition. These various elements of a life lived with HIV from diagnosis resonated with me, resulting in the inclusion of these past experiences as a sub-theme. These past

experiences, as described by the participants, may influence their assessments of the prospect of a life well-lived for them as they consider a transition to aged care. As a way to further develop and find answers to this question, the following discussion will focus on what living with HIV means today for the participants in this research. Living with HIV today, in the present, will now be discussed.

### **The present**

Today, for many PLHIV and for those working in the HIV sector, the improved health outcomes and improved longevity of many living with HIV demonstrate that today HIV is a life lived in a changed environment. Some refer to this environment as a changed landscape (Kidd 2017). Today, PLHIV are taking treatment regimens that are markedly improved, with fewer long-term side effects. Today, there is greater emphasis on those in high-risk groups undergoing more frequent HIV testing. Those diagnosed with HIV are encouraged to commence therapy sooner than was once previously advocated. These changes have improved the long-term outcomes for those newly diagnosed, as well as for the long-term survivors. Long-term survival and ageing with HIV will now be discussed.

### *Ageing with HIV*

HIV has been recognised as a diagnosis for close to four decades. It is now considered a chronic but, for many, a manageable illness, where life expectancy is not dissimilar to that of the non-HIV population. Research has shown that today there are many living with HIV into their old age, and indeed many are diagnosed with HIV after the age of 50. In many regions of the world, including Australia, by 2020 close to 50% of PLHIV will be aged 50 years and over (Ecosta et al. 2018; Carter 2014; Jansson & Wilson 2012; Kearney et al. 2010). Today, the long-term survivors, or as Ecosta et al. (2018) term them “HIV positive veterans” (p. 57), as well as those diagnosed later in life, comprise an older population of PLHIV who are reaching ages that were once unimagined. Indeed, some participants in this research were in their 80s at the time of their interview.

Some participants in this research, when the issue of ageing with HIV was raised, mentioned experiencing fatigue, and some had been diagnosed with various common age-related conditions such as hypertension, high cholesterol and loss of bone density. These conditions, they said, were being monitored by their treating physicians. The experiences of age-related conditions described by the participants correlate with reports in the literature around ageing with HIV.

Reports illustrate that older PLHIV are some years older, in terms of health and age-related conditions, than their non-HIV cohorts; some writers say ten or so years' difference (Ecosta, et al. 2018; Carter 2014; Jansson & Wilson 2012; Kearney et al. 2010). Conditions such as osteoporosis, frailty, diabetes and diseases of the liver, kidneys and cardiovascular system have been reported at a higher incidence than the non-HIV population (Ecosta et al. 2018; Deeks 2011). These conditions need to be identified early and treated accordingly. Thus, older PLHIV need to form a close connection with their HIV-experienced doctors so that such conditions can be well monitored and managed, and decisions around antiretroviral therapy can be made accordingly. These reports give credence to participants' responses to questions about their perceptions of ageing with HIV and, moreover, to their thoughts about a life lived in aged care. These concerns are gaining prominence for these participants.

In general, though, while the participants acknowledged that they were ageing, or at least some more than others were paying heed to signs of various aged-related conditions, the concept of ageing with HIV did not feature as a major concern for them. One participant flippantly said: "I'm getting older. Full stop! Nothing to do with HIV. I'm just ageing as I am" (Participant Four). When asked his thoughts on ageing with HIV, Participant Three said:

I didn't think about it. I'll just get on with it. Whatever will be will be ...  
Having my recent stroke I was faced with my own mortality. Since then it has influenced decisions that my partner and my thinking about the future ... My partner says I'm indestructible.

In relation to ageing with HIV the response from another participant was:

Ageing, well, seeing as the onset ... [his HIV diagnosis] in 1993, I thought I might be dead by 1998. I feel very fortunate to be here in 2016 ... I think we're a bit of a privileged bunch because we've got all that wonderful life to look back on and think we did our best. We're still here. We must be doing something right.

The participants, as mentioned above, expressed varying feelings about living with HIV at the time of their diagnosis. These experiences were coloured by levels of fear, and concerns that often reflected the era of their diagnosis and what the general view of their prognosis was at that time, which was often grim. As their lives continued, thoughts of ageing were not at the forefront, as getting on with life took greater precedence. The participants in this research, many of whom had lived with HIV for a considerable number of years, felt that their lives had been lived with greater or lesser degrees of anxiety and periods of illness, but that they had now reached an older age where thoughts of the future, for some, were now taking more prominence. This may see some participants considering the prospect of a transition to living their lives in aged care. The discussion will now focus on their views about the future.

### **The future**

When the participants in this research reached the point of discussing their views about a life lived in aged care, they expressed a variety of opinions. Their views on this topic were varied and colourful. Some participants expressed horror at the thought, stating a preference for suicide, while others were more circumspect. The participants who were more willing to engage in this conversation and not to dismiss it out of hand were more reflective. Their view was that, as they had successfully aged and were now considering their future, in general, they could now foresee more positive prospects for a life lived in aged care if this were required. Some, however, did express real concerns around this topic, as will now be discussed.

Diagnosed with HIV later in life, in his late 70s, at an older age than some others in this research project, Participant Fifteen raised deeper feelings and concerns as he reflected

on his life history (personal and working life) and how he felt that history, his journey, and his views on life would impact negatively on a future life for him lived in aged care. When asked to speak about his experiences of his diagnosis and life lived with HIV subsequently, Participant Fifteen stated that at diagnosis he felt ashamed, angry with himself that he had become infected, adding, “wished I had never been born homosexual”.

It needs to be remembered that this participant had lived through a time when a homosexual was considered by society as someone who was a “sexual deviant ... an object of ridicule and contempt” (Altman 2013, p. 49). As discussed in the literature review, for many years being homosexual placed one in enormous fear of being ‘outed’, where discrimination and abuse, both verbal and physical, often occurred. Engaging in a homosexual act was a criminal offence, and imprisonment was a distinct possibility (Altman 2013; Carbery 2014). As discussed in the literature review, it also needs to be remembered that homosexuality was not fully decriminalised in all Australian states and territories until as recently as the late 1990s. In some regions of the world homosexual behaviour is still a criminal act, or a religious ‘sin’ to be punished (Pickles 2015; Altman 2013; Carbery 2014). In reference to his homosexuality and his marital status, Participant Fifteen said that marrying “is what you did at that time”. This participant is from a time when men who were homosexual, but did not want to accept it, or wanted to hide the fact, married women because that was what was expected. They conformed to a heterosexual persona because of the fear they felt of discrimination, ostracism and persecution for being identified as homosexual. This participant also articulated that he felt ‘shame’ at his HIV diagnosis. Shame was also felt by some participants in the ARCSHS ‘Futures 8’ study conducted in 2016. In that study 35% said they felt ashamed of having HIV (Power et al. 2016, p. 1). That said, the vast majority of those interviewed for this research did not express feeling shame. The concerns of the participants will be further explored and discussed below in the section titled “Attitudes of staff within aged care”.

This discussion relates to the views of participants about living with HIV in a changed landscape, specifically as it applies to the potential of living within aged care. Notwithstanding the sentiments of some, other participants spoke with greater optimism. They felt that the landscape of HIV today had changed markedly for the

better for them. With the advances in treatment options, their prospect of longevity was encouraging. In addition, they believed that the nursing workforce is now more informed about caring for PLHIV. For all of these reasons they felt that, when it became necessary for them, a life well lived in aged care was a distinct possibility and not to be feared. The participants' considerations about their futures will now be discussed under sub-themes, beginning with a discussion of finding the right aged care place.

### *Finding the right place*

As described in the findings chapter, when considering a transition to aged care the participants felt it was paramount for them to find what they termed the 'right' place. What the right place meant for them was one where those within the facility, both the nursing workforce and the residents, were the 'right' people. That meant that the nursing workforce would not have negative attitudes of stigma and discrimination and the participants would feel welcomed and embraced. The 'right' residents were defined as those with whom the participants could form a sense of connection and relatedness. This meant the participants would find other residents with whom they might share similar interests such as music, the arts, movies, games and travel. The presence of these components, which participants felt were essential, defined what would be the right place for them to live a life well lived in aged care.

The expression 'the right people', as articulated by the participants in this research, reminded me of an earlier Australian study. As discussed in the Literature Review, the report generated from this study was titled *Permission to speak* (Barrett, Harrison & Kent 2009). In a background publication, which these authors describe as the first stage of their research, titled *My people* (Barrett 2008), the LGBTI participants in that research said that for them 'the right people' was defined as 'my people'. For them 'my people' included their family, friends and aged care service providers with whom they could be themselves. In the second stage of this research (Barrett, Harrison & Kent 2009), one anecdote was from a participant named 'Tom' who was previously introduced in the literature review chapter of this research. Tom's experience of living as a gay HIV-positive man in aged care was challenging and dispiriting, and it was an environment where he felt he was not necessarily surrounded by the 'right' people: "I

can't talk to the staff about being gay because ... some people think gay is disgusting. I keep my mouth shut. I have to be careful how I act and be careful what I say" (2009, p. 20). From this anecdote, it is clear that Tom did not feel he could be himself with the people around him.

Tom's story, and the anxieties he expressed, completely resonated with the anxieties that some of the participants in this research articulated. The difference, of course, is that Tom is now living this experience, whereas the participants in this research are in the contemplation phase of his lived reality. In Tom's story there is a sense of vulnerability as well as a sense of loss of who he is, a loss of his selfhood. He depends physically and emotionally on others who provide his care and consequently feels a sense of his selfhood being diminished living in an environment which feels alien to him. These feelings were not articulated by the participants in this current research. These participants drew from a history of a life lived with courage, tenacity and strength of spirit, which were cornerstones of their success in living with HIV to the age they are. That is not to say that Tom did not also possess these attributes before his transition to aged care. The point I am making here is, after considering Tom's story, with his feelings of vulnerability as discussed above, one wonders if, once the participants in this research are living within aged care, and perhaps experiencing similar physical, cognitive or emotional difficulties, their own sense of feeling vulnerable and their sense of loss of selfhood may overwhelm their self-determination to thrive. These components will now be discussed further under the heading "Attitudes of staff within aged care".

#### *Attitudes of staff within aged care*

The majority of the participants felt that the attitudes of the staff within the aged care sector would be positive towards them and that they could envisage no concerns. Those who thought there may be problems with their care as a result of their HIV status would not hesitate to discuss this with the management of the facility. There were, however, some participants who did express concerns, which will now be discussed.

One participant declared in his interview that he would not be going into aged care by his own volition, but if that were to happen, he said he would feel deeply embarrassed



about being known to be HIV positive in aged care. He believes that in aged care he would be treated with suspicion, “and maybe disgust amongst the older ... [nurses] and the Christians”. These fears have been reported in the literature. In one journal article on the topic of religion and caring for PLHIV the authors state:

Since the beginning of the epidemic, HIV has been associated with religious beliefs such as moral failings and sinful behaviour ... Research with Catholic, Lutheran and Pentecostal churches highlighted how people still interpret HIV/AIDS as a punishment from God attaching PLWHA with immoral behaviour. (Reyes-Estrada, Varas-Diaz & Martinez-Sarson 2015, pp. 49–50)

Notwithstanding the findings of this report, it needs to be acknowledged that religious institutions around the world have also helped PLHIV. Anecdotally, in Adelaide, where this current research was undertaken, I have observed that the Catholic Church and other denominations, especially at the beginning of the HIV epidemic, were fulsome in providing a variety of services for PLHIV.

The religious beliefs of some, along with social and cultural beliefs, were also potential barriers for providing care to PLHIV, as Pickles (2015) found. In his research involving a group of nursing students from a variety of cultural and religious backgrounds which focused on caring for PLHIV, he found that those whose societal and cultural belief systems were strongest believed caring for PLHIV would for them be more problematic. One participant in my research, whose work experience had been in aged care, said that, while he felt that those who worked in aged care would have no problems caring for PLHIV, there might be some from particular regions of the world whose religious and cultural beliefs may have negative attitudes and cause them problems caring for PLHIV.

The conversation about aged care workforce readiness, their attitudes and preparedness to care for PLHIV, is one that I believe should commence with the expression that Jo Harrison (2010) cites: “nothing for us without us” (p. 10). This precept, which Harrison has borrowed from earlier writers, relates to older members within LGBTI and PLHIV communities contemplating transition into the domain of residential aged care, hoping

that that domain will be non-discriminatory and will accommodate their special needs. To assure this is the case, Harrison argues that this group should be “in a position of self-determination, so that they are involved as decision makers and recognised as the experts on their own situation and needs” (p. 10). In order for this to occur, Harrison believes, it is crucial that these communities galvanise, to become more visible and vocal about their needs and wishes: “the voices of older [LGBTI and PLHIV] themselves are central to the changes taking place” (p. 10), especially as this relates to issues of ageing and transition to aged care.

Harrison (2010) found, especially in Australia, a dearth of literature around the acknowledgment and attention to issues of ageing within the LGBTI and PLHIV communities. She states: “The deficit in Australian gerontology is reflected in an almost complete lack of mention of GLBTI and HIV-related ageing in aged care policy, education and training” (p. 11). Harrison argues that, due to this lack of attention to this issue, there is a need for older people from these communities to be “a part of delivering, guiding and enhancing the success of projects that seek to educate and drive change” (Harrison 2010, p. 12). Harrison acknowledges the need for the attitudes of those working within the aged care sector to be addressed and acted upon in order to appropriately cater for the growing emergence of people in aged care from what have been termed ‘special needs’ groups. In conjunction with this, Harrison also advocates that there equally needs to be more active involvement by people from within these special needs groups to assist in this change and to act as experts and change agents in this endeavour. The work of Harrison and others helped accelerate action by the federal government in setting out aged care guidelines that focus on non-discriminatory, equitable care for LGBTI and PLHIV in aged care (Australian Government, Department of Health and Ageing 2012).

Possibly as a result of this work and the subsequent legislation recognising PLHIV as potential future recipients of aged care, the participants in this research were in the main optimistic. The findings demonstrate that the majority of participants had no concerns about the aged care nursing workforce not being adequately educated and attitudinally equipped to cater for their needs. These participants did not feel that they would be cared for differently from others within that setting. Moreover, these participants added that when they needed to consider a transition to aged care, they would be actively

engaged in a search for facilities that would be appropriately equipped to cater for their needs. From what these participants said, they would take control of their own destiny, as they had done throughout their lives, when it came to finding the quality of care they deemed they would require. This assertive attitude to taking control of their destiny, as articulated by these participants, echoes the sentiments expressed and advocated by Harrison: “nothing for us without us”. Harrison, I feel confident, would be proud of these participants, who expressed that when it came time to make the transition to aged care they would be expert change agents in their mission.

From the above discussion, I can attempt to answer the research question about the concerns of PLHIV considering a future life well lived in aged care. While there were qualifications or differences in the views of some, who did not believe that that life could be achieved, in large part, other participants believed that a life lived well in aged care could be achieved.

#### *Stigma and discrimination*

Connected to the sentiments expressed by participants about being active in their search for the right aged care facility when this was needed, was the concerns of a small minority of participants about the potential for stigma and discrimination within this environment. It must be stated, however, that the majority of participants said that they did not expect they would experience this today in any environment including in aged care. One participant, totally rejecting the notion that this would occur, said:

I have never encountered it ... [and in the potential transition to aged care] I would hope that that ... [stigma and discrimination] would not raise its ugly head ... I can't imagine in this day and age this being an issue. (Participant Five)

Other participants who equally did not expect to be confronted by stigma and discrimination within the age care sector said that, if they were to experience this, they would be forthcoming and not hesitate to express their disquiet. In acknowledgment of the participants who did raise stigma and discrimination as being concerns for them in relation to a life well lived in aged care, and to acknowledge that for many PLHIV

stigma and discrimination have played a significant part in their lives, I believe it would be remiss not to devote time here to address these concepts.

Stigma and discrimination against PLHIV has existed since the beginning of the HIV epidemic throughout many regions of the world (Wodajo, Thupayagale-Tshweneagae & Akpor 2017, Reyes-Estrada et al. 2015; Pickles 2015; Crock 2013; Thupayagale-Tshweneage, Mgutshini, & Moleki 2012; Neuman et al. 2013; Monjok, Smesny & Essen 2009; Nyblade et al. 2009, Herek 2002). Stigma and discrimination targeted towards PLHIV has had detrimental effects on many, both emotionally and physically. For some PLHIV the fear of suffering stigma or discrimination, or indeed the actual experience of such, has made them reluctant to seek care and treatment, thus it is deleterious to their health. Not seeking care and treatment for fear of suffering stigma and discrimination not only affects the health of the person living with HIV but also, more broadly, “jeopardises the fight against the epidemic” (Wodajo, Thupayagale-Tshweneagae & Akpor 2017, p. 1; see also Kidd 2017). As a result much research has been conducted to identify and address these issues. This is especially pertinent within the healthcare sector for PLHIV who sought and continue to seek care and treatment (Wodajo, Thupayagale-Tshweneagae & Akpor 2017, p. 1; Pickles 2015; Thupayagale-Tshweneage, Mgutshini & Moleki 2012; Neuman et al. 2013; Monjok, Smesny & Essen 2009; Nyblade et al. 2009).

To better comprehend the effect of feeling stigmatised it is best to review Goffman’s (1963) definition of stigma presented in Chapter Two. Originating from ancient Greek, Goffman explains that the term stigma

referred to bodily signs designed to expose something unusual and bad about the moral status of the signifier ... signs were cut or burnt into the body and advertised that the bearer was ... a blemished person, ritually polluted, to be avoided, especially in public places. Today, the term is applied more to the disgrace itself than to the bodily evidence of it ... the term stigma, then, will be used to refer to an attribute that is deeply discrediting. (pp.1–3)

Macionas (1991) defines stigma as “a powerful negative social label that radically changes a person’s social identity and self-concept” (p. 210). In relation to PLHIV, research has shown that feeling stigmatised has a significant negative impact on people’s psychological well-being and health (Rojas Castro et al. 2010; Beals et al. 2009; Herek 2002). Crock (2013) remarks that “Stigmatisation leads to discrimination, or being treated less favourably than other people on the basis of a personal characteristic; in this case, on the basis of a person’s HIV status” (p. 48). As stigma is applied to those living with HIV, fear and reluctance to seek care, as I have observed during my many years of working with PLHIV, can lead to a extremely poor prognosis and the potential for an early death.

In this section I have described the concept of being stigmatised and discriminated against and its potential deleterious consequences when this has occurred and where this may sadly continue to occur. The majority of the participants in this research, while they may have in the early years of their lives living with HIV experienced stigma and discrimination on the basis of their HIV status and the mode of acquisition, do not feel this now, or are less concerned. Indeed, some participants said they were never concerned about these feelings. As a result, encouragingly, these participants have not succumbed to an aversion to seeking medical care, saying at interview that they regularly attend their medical appointments and adhere to their therapy.

Following on from the above discussion about fears of experiencing stigma and discrimination within the healthcare setting, and especially the aged care environment, the discussion will now focus on the laws surrounding this that aim to protect PLHIV from stigma and discrimination.

#### *Legality in caring for all: Basic human rights*

There exist laws to protect against discrimination on the basis of a person’s medical condition or sexual identity in society and within organisations that provide services, including the healthcare sector. PLHIV are a group in society who have in the past experienced stigma and discrimination on the basis of their sexual identity or mode of HIV acquisition. Thus, there is need for protection against this. The following will

discuss the laws that exist to protect those experiencing, or at risk of experiencing, stigma and discrimination.

As discussed in Chapter Two, members of the LGBTI community transitioning to aged care are recognised in the *Aged Care Act 1997*. However, PLHIV requiring transition to aged care were only recognised many years later. In 2012, the National LGBTI Ageing and Aged Care Strategy was released. The following is a statement from this document: “Aged care services provide appropriate policy structures to ensure that, at a minimum standard, a welcoming, inclusive, confidential and culturally appropriate environment is created for LGBTI. This includes responding to the needs of older people living with HIV” (Australian Government, Department of Health and Ageing 2012, p. 11). As previously stated this was the first time recognition was given to PLHIV who may require admission to aged care and then form part of the aged care population. The legislation that exists must be backed up by appropriate monitoring.

As nurses are the predominant sector of the aged care workforce, core principles, rules and regulations apply to all for whom they provide care, regardless of the physical, mental or medical condition, or sexual identity of that person (Nurses and Midwifery Board Standards of Practice for Registered Nurse, 2016). To illustrate this, the following are the core principles by which the nursing profession is registered and legally bound to deliver: recognising the universal human rights of all people, safeguarding dignity and equal worth, valuing and respecting diversity, providing quality nursing care for all people (International Code of Ethics, (2012).

The feelings of vulnerability and the loss of selfhood that Tom expressed when he was admitted to aged care, as related earlier in this chapter, were resolved after his admission. Tom received visits from advocates from the local AIDS Council of that city who became involved with his care. This advocacy group visited him and educated the aged care staff at his facility. These education sessions “changed the way staff treat me” (Barrett, Harrison & Kent 2009, p. 1). With these advocates Tom said “I can be a gay man ... when I am with them I come alive” (p. 1). These efforts made a great difference to his feelings and those of the staff within this environment. It is hoped that the participants in this research would not feel the level of vulnerability and loss of

selfhood that Tom felt. If, however, such feelings were to occur for them, it is hoped agencies in the city of their residence would provide similar advocacy.

The participants in this research, to a large extent, expressed high degrees of optimism about a transition to aged care if and when this was needed. They expect that their transition to aged care will be non-problematic because of what they said was the changed landscape, the support of legislation and their own efforts to find the 'right place' for them. The reality that needs to be considered and acknowledged is that in Australia we have an aged care sector under considerable stress. This stress, as reported and described in the mainstream media in recent years as a crisis in aged care, is the focus of the current Aged Care Quality and Safety Royal Commission. In this Royal Commission examples of vulnerable and marginalised groups residing within aged care being the subject of abhorrent behaviour by staff are being heard. This aged care crisis notwithstanding, the participants in this research have expectations that a life lived within aged care will provide for them a life well lived.

In the endeavour of providing an answer to the research questions, from the above discussion, new knowledge has emerged. It appears that many of the participants in this research believe that stigma and discrimination on the grounds of their HIV status or sexuality (acknowledging strong caveats from some, as expressed in the findings and discussion chapters) would not feature as a barrier to them living a life well lived within aged care. This sense of assurance may stem from the legal and structural safeguards that surround caring for all, including PLHIV. Such safeguards will counteract the feelings of vulnerability that some participants expressed earlier and feelings of apprehension about the potential for stigma and discrimination when living within aged care. These participants had expectations that aged care would be an environment where anti-discrimination legislation and standards of care are adhered to and upheld. This environment would be one in which the workforce within the facility were educationally and attitudinally prepared to care for PLHIV, and would follow codes of nursing ethics by providing respectful, non-discriminatory care. Finally, many participants expressed their wish that the aged care service which provided their care should be one in which they felt welcomed and embraced. However, it should be acknowledged that not all participants shared this faith that the above provisions and expectations would be achieved. For those participants, the aged care workforce must

demonstrate that they will step up to expectations and provide the care that they are obliged to provide.

A successful transition to aged care means the inclusion of all the elements that have been discussed above. For PLHIV as they transition to aged care, the inclusion of all the elements would assure them of a life well lived in that environment.

## **Summary**

The focus of this discussion chapter is to address the key points that emanated from the analysis of the participant data and, most fundamentally, to answer the research questions. What did the interpretation of this data mean to me as the researcher and how might that meaning translate to answering those questions? What has this data achieved in answering what some may call the ‘so what’ questions of this research? What new knowledge has emerged that was not previously known? I will now outline the answers to these questions.

There were commonalities and differences in opinions expressed by participants on the topic of their lives lived with HIV from their past and present experiences and their thoughts about their future. The majority, however, did consider these optimistically. Ageing with HIV, or indeed ageing in general, was not high on the list of concerns for these participants, with the majority taking each day as it comes. While some participants definitely expressed strong concerns about a transition to aged care and the possibility of negative attitudes from aged care staff, as articulated throughout the discussion and analysis chapters, the majority view was largely optimistic with minimal concerns. When it came time for more serious consideration of a transition to aged care they felt confident that that environment would be populated with what they described as the ‘right people’ and that consequently it would be the ‘right place’ for them to reside.

I will now answer each of the research questions, to determine what a successful transition to a life lived in aged care would entail for these participants.



**Question 1** What are the concerns of PLHIV considering a future life well lived in aged care?

As just discussed, some participants expressed negative views about a transition to aged care. They believed they would experience stigma and discrimination on the basis of their HIV status. This group believed that knowledge about PLHIV in the community and in the aged care workforce was still lagging behind. This group had strong concerns about a successful transition to aged care and were uncertain about whether or not they would experience a life well lived in aged care.

However, a sizeable number of the participants were positive about a future in aged care. They believed that knowledge and attitudes around HIV, especially within the medical and nursing workforce, and the care and longevity for PLHIV, had markedly improved. These participants believed they would receive well-informed and empathetic care and would receive the same quality of care as others within aged care settings. This group believed they would not experience the negative effects of stigma and discrimination on the basis of their HIV status and therefore they had no concerns. They believed, with optimism, that their life within aged care would be one they would describe as a life well lived.

**Question 2** What issues do PLHIV perceive need to be addressed to facilitate a life well lived in this transition?

When considering a transition to aged care, participants said they would be active and engaged in finding what they termed 'the right place'. The right place for these participants meant that, supported by the legislation and aged care standards of practice, staff within the aged care facility would be educationally and attitudinally equipped to provide optimal, respectful, non-discriminatory care. The right place also meant for these participants that the facility would be populated with residents with whom they could connect. These participants believed and had confidence that, with the above conditions upheld, a transition to a life well lived in aged care would be a success. It would see them living within a welcoming and embracing environment with their identity and selfhood maintained. This would be a life well lived. Indeed, in response to

this question, one participant laughingly said: “Well, at least I won’t have to make my bed. And I can just ask for more gin please.”

## **Chapter Seven: Conclusion**

I have explored the lives of older PLHIV and their thoughts on their future as they pertain to living, if and when needed, within the aged care environment. PLHIV are an ageing group in society who may one day require aged care services. Research on the topic of PLHIV and aged care has not been vast. This is especially so in the geographical location of this research. With an ageing population of PLHIV who may one day require aged care services, in most cases a forgotten population, I considered this an important endeavour.

This chapter will outline my reflections on the paradigm and methodology used to explore this topic, including a discussion of its strengths and weaknesses as applied to this research. It will also review the limitations of the research, the significant issues that were found and suggest other research activities on this topic in the future.

### **Reflections on the research paradigm and methodology**

The qualitative interpretative hermeneutic phenomenological methodology, chosen as the framework in which to explore this topic, I believe was the appropriate one. This framework provided the opportunity for me to delve more deeply and understand with more clarity what was expressed by the participants about their, in many ways, diverse and rich histories. It also enabled me, as the researcher, to be part of, in fact a contributor to, their stories and the data collected for analysis and interpretation. I feel privileged that the participants accepted me as the collector of their stories on this topic. For some there may have been moments of stressful memories, but also, as some said, it was an opportunity for them to speak of and contextualise that life history, a history they said they had not fully felt able to express with others. I feel humbled, respectful and honoured to be part of this research.

Fifteen participants volunteered for this research. Their experiences of living with and ageing with HIV provided rich, heartfelt, meaningful histories. They recounted their experiences during significant times in their lives. These different eras, which captured the history of the HIV epidemic in Australia, mirrored the experiences of those who

lived with HIV throughout the world. This time span captured the stories of those participants who were diagnosed at the beginning of the epidemic to those diagnosed in more recent decades. In this research I wanted to gain an understanding of this history from the participants' perspectives and what that experience had meant to them. The fifteen participants in this research were a high-functioning, engaged group of people, some of whom were still in the workforce. The majority were living with partners or spouses, some had families and the majority of them were living in their own homes. This participant demographic is significant, as will now be discussed.

These participants, it needs to be acknowledged, were not those I had originally envisaged might be involved in this research. The group I thought I would be interviewing would be those whose life histories might have been different from and perhaps more problematic than those articulated by the participants in this research. The group I originally envisaged interviewing would largely be single, isolated from family, friends and community, with minimal support structures and not managing optimally and independently for reasons either physical, cognitive or psychological. Their lives would not necessarily be lived in a safe environment and the need for care and support, it would be assumed, would be looming. It is members of this demographic whom I see, or whose care I am involved with, in not insignificant numbers on a daily basis in my work. That particular group, however, for one reason or another, were not those who volunteered to participate in this research. Therefore, it needs to be acknowledged that there may well be different life stories, experiences and perspectives given by this group, and other older PLHIV living in the geographic location of this study, that were not captured in this research. The experiences, lives and views of some in the group who did not participate in this research may likely be diametrically different from those whom I did interview.

A strength of this research methodology was its ability to capture and explicate the essence of what those interviewed articulated in their life histories and their stories. However, caution was paramount for me. This caution was crucial for me, so as not to over-interpret what the participants said from my own perspective. I did not want to minimise what the participants said and interpret the data to 'fit' my own historical understandings and beliefs. Cognisant of my recognition of myself as a participant in the collection of and interpretation of this data, and therefore as part of the hermeneutic

circle of this data, I was crucially aware not to ‘bracket’ myself out completely from this process. In doing so, I followed the advice provided by Gearing (2004), Horrigan-Kelly et al. (2016), and Koch (1996), as described in the methodology chapter. Following that guidance enabled me to be transparent, and true to and respectful of the data collected and interpreted.

Another strength of the choice of an interpretative hermeneutic phenomenological methodology was it provided the framework around which to explore what the prospect of a life lived in aged care meant for older PLHIV. This was achieved by way of one-on-one, face-to-face interviews that enhanced the opportunity for the participants to discuss their past and present lives lived with HIV and to share their thoughts about the future and what that would mean for them. I considered that an interpretative hermeneutic phenomenological methodology was the most appropriate framework in which to understand that meaning from the perspective of the participants and from my perspective.

In considering any weaknesses of the research design, there may have been other methodological choices I could have selected to explore this topic. One choice of methodology that I originally thought I might have used was one focusing on achieving socio-political change for older PLHIV considering a transition to aged care. That choice would absolutely be justifiable if indeed I had found that the hopes and wishes of the participants in this research, or of the larger older PLHIV population, for a life well lived within the aged care environment was not a possibility. This has not yet been proven and thus I did not select this methodology.

## **Limitations**

The limitations of this research are the following. The participants were all male. Despite the research recruitment flyer being worded in a non-gender-specific form, with the inclusion criteria simply requesting those living with HIV aged 60 years and over, no females volunteered to participate. There may be a number of reasons why the female population of PLHIV did not participate. One reason may be the fact that there are low numbers of PLHIV females living in the city of this research who are in the 60+ age group. That low number may also be another reason why they did not wish to

participate, as they may have been more easily identifiable. The female voice and viewpoints, I believe, may well have added different perspectives to this research.

A second limitation was that there was no representation of PLHIV from countries where HIV had higher prevalence than Australia. For example, in the city of this research there are a number of PLHIV who have migrated from these high-prevalence regions, some of whom are in the age bracket for this research. One reason may be the eligibility criteria for participation in this research that necessitated a fluency in English. As well, PLHIV from other countries may have heightened sensitivities around disclosure and secrecy. This said, participants from those countries may have added further perspectives on a life lived with HIV and their thoughts about a future life lived within aged care.

A third limitation was that not all centres and clinics providing care for PLHIV in Adelaide were represented. Two sites considered for inclusion communicated to me that their clientele did not meet the selection criteria. Both these centres provide care to considerably lower numbers of PLHIV. With this limitation acknowledged, however, it needs to be recognised that the centres from which participants were recruited for this research were sites that provided care to the largest number of PLHIV in Adelaide. Potentially, the inclusion of all sites in the city of this research that provided care for PLHIV may have generated different viewpoints on older people's experiences of living with HIV and their thoughts on their future transition to aged care.

A fourth limitation of this research is that, to a large extent, many participants in this research were well connected and supported. By that I mean that they were well linked in with their healthcare providers, they were responding well to therapy, and were living with their partners or spouses. As discussed, there are many PLHIV whose life situations are not as thus described. They are people whose stories have not been told and therefore this is a loss to this research and its findings. Further research on this topic will hopefully include some of those not represented in this research.

## **Significant findings**

Based on the analysis of the data collected, and my subsequent reflections and interpretations where I endeavoured to delve deeply into and find the meaning of what the participants expressed, I state the following significant findings and make the subsequent conclusions.

After years of combating the many hurdles that presented themselves to PLHIV and to reach the current phase of their lives, the sentiment of ‘we’re still here’ is a reality to consider for all – for older PLHIV and for those who will provide care for this older population. This research will hopefully enrich the lives of older PLHIV as they consider a future life well lived in aged care. It will also be informative to the nursing workforce and in particular those within aged care.

The new knowledge found in this research, applicable to both older PLHIV and the aged care workforce, is the following. The environment that PLHIV will be entering must be one that is welcoming, non-discriminatory, informed and educated. It must be an environment where PLHIV do not have to relive their past experience of discrimination, stigma, isolation and fear that they will lose their identity and feel that they have to go back ‘into the closet’. The participants voiced optimism about their future transition, which sends a positive message to others living with HIV. They expressed a hope that their future would be a brighter, more enlightened and encouraging one, in which a life well lived is possible for those ageing with HIV and for those who may require a life lived within aged care.

The aged care environment must meet its legislative and quality standards obligations as outlined in the *Sex Discrimination Act* and the Aged Care Quality Standards (see Appendix 5 for a summary of the standards). These obligations are basic expectations that clearly articulate and define consumer outcomes. These fundamental requirements aim to prevent discrimination and preserve dignity, respect and choice for all. If upheld, this would ensure older PLHIV will feel welcomed and embraced. To achieve this, aged care facilities and the workforce within that environment should be educationally and attitudinally equipped for caring for them. The workforce would follow the codes of nursing ethics that require respectful, non-judgmental and non-discriminatory care

(International Code of Ethics (2012)). Finally, the participants' sense of self, as articulated by the participants, would be upheld.

Even with the above legislation and standards, we must hear the voices of those in this research who expressed real concern that the above criteria would not be met. When conversation turned to the existence of legislation as a safeguard, some participants said, "laws can be broken". While one of the major findings in this research was that a number of participants expressed optimism about, indeed expected, a successful transition to a life well lived in aged care, there were some who wondered whether these expectations would be fully achieved. Though not discussed in detail in the discussion, there were some participants who were resolute in their feelings that, if they needed to transition to residential aged care, euthanasia would be their preference.

### **Implications for further research**

This research was conducted in South Australia, in particular within the city of Adelaide. The population of South Australia is 1.7 million people, and the number of PLHIV in South Australia is estimated to be 1500. Fifteen PLHIV participated in the gathering of the fundamental data for this research. To gather broader experiences and perspectives on the topic of older PLHIV who may be considering a transition to a life lived in aged care, further research on this topic might best be conducted from a country-wide pool of participants. In Australia the population of PLHIV at the time of this research numbers approximately 26,000. Within that group there are approximately 45% aged over 60 years of age. This is a considerable pool of potential recruits for a study on the topic of PLHIV and aged care. Research at the national level, with a larger pool of participants, may reap different perspectives on the topic of PLHIV and ageing and how to address their needs when they require aged care services, including those who may already be residing within aged care. I encourage future study and advocate for much more work to be done in this under-researched field.

Future researchers on this topic also might choose other methodological approaches. They may wish to explore this topic from another qualitative approach, perhaps one that focuses on a socio-political framework in order to influence change. That research methodology may well be appropriate if in the future, contrary to this current research,



it is found that a life well lived in aged care for PLHIV has not been realised. For this research I did not choose a socio-political framework because, at the time of this research project, there was insufficient evidence to say that the aged care environment was not already providing the right care to PLHIV. This research aimed to explore and understand the concerns of older PLHIV considering this transition. At this time, it is hoped that my research will at least lay the groundwork for future research in this area.

Also needing further research is the female perspective on a life well lived in aged care. For reasons previously described, in this research the female voice was not heard or explored. Hearing and understanding the concerns expressed by the older female population of PLHIV on the topic of a life lived in aged care is imperative for future research on this topic.

### **Recommendations and implications for practice**

This research has identified the need to engage those providing aged care services in their preparation for the care of older PLHIV within that sector. If we are to respect the voices of these participants and to acknowledge that for some, they have lived a life in fear of discrimination and ostracization, then there is a need to engage those providing aged care services in their preparation for the care of older PLHIV within that sector. In particular, the findings of this research raise a question about the preparation of aged care services to fully understand the disease process of HIV and the risk and mode of transmission. The worst-case scenario would be aged care facilities having policies that include clients with HIV being 'locked' in their rooms and not allowed to mix with other residents due to a misunderstanding of the risks.

Recommendations.

- 1) That there is a national approach to policy development across aged care services that is part of their accreditation standards that demonstrates an understanding of the nuances of all infectious diseases relevant to their population. This would include all communicable diseases such as influenza, HIV, hepatitis, tuberculosis. The policy must include a sound evidence based education process of all levels of staff on communicable diseases, the risks of transmission and process of care. This must ensure that the residents' rights are

respected and that staff bias/ignorance/religious beliefs do not inflict on the resident's freedom. It cannot be assumed that in this day and age that HIV is fully understood. The aged care workforce needs to be adequately educated around HIV and PLHIV to provide safe, respectful, non-discriminatory care. An aged care workforce that is educationally and attitudinally informed around issues related to the care of PLHIV is of fundamental importance.

- 2) That education must be part of any certificate courses in vocational education centres for aged care workers and must include education on communicable disease, risk of transmission and process of care.
- 3) All orientation programmes for aged care facility new staff must include information about communicable diseases, transmission risks and process of care.
- 4) Furthermore, education to the Boards and Management of aged care facilities must be in accordance with the above recommendations and incorporate these into their Policy and Procedure manuals.
- 5) That PLHIV organisations should consider, if they have not already done so, to develop a system of rating aged care facilities about the quality of care and delivery of service provided to all their residents, including those who identify as LGBTI and PLHIV.

### **Respecting those who participated in the research**

With the utmost respect and gratitude, I thank the participants in this research, some of whom sadly passed during the process of the research. These participants took the time to contribute, speaking about their life histories lived with HIV intimately in open and heartfelt memories which, for some, would have conjured deep feelings and degrees of distress. Their voices and sentiments live today with me and forever in this research.

My sincere thank you to them.

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## Appendix 1: Central Adelaide Local Health Network ethics approval

Approval Date: 18 March 2016



Government of South Australia  
SA Health

Central Adelaide Local Health Network  
Research Office  
Level 4, Women's Health Centre  
North Terrace, Adelaide SA  
Australia 5000  
T : 08 8222 3333

Dr Lynette Cusack  
School of Nursing  
UNIVERSITY OF ADELAIDE

Dear Dr Cusack

**Project title:** PLHIV considering transition into aged care – an emerging phenomenon

**CALHN Ref:** R20151213 HREC/15/RAH/550 SSA/15/RAH/551

### **RE: Governance authorisation**

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to commence at the Royal Adelaide Hospital, and The Queen Elizabeth Hospital, SA.

The following conditions apply to the authorisation of this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval to this project:

1. Authorisation is limited to the site/s identified in this letter only.
2. Project authorisation is granted for the term of your project outlined in Section 9 of the SSA, or until the project is complete (whichever date is earlier).
3. The study must be conducted in accordance with the conditions of ethical approval provided by the lead HREC, SA Health policies, and in conjunction with the standards outlined in the *National Statement on Ethical Conduct in Human Research (2007)* and the *Australian Code for the Responsible Conduct of Research (2007)*.
4. Proposed amendments to the research protocol or conduct of the research which may affect both the ongoing ethical acceptability of the project and the site acceptability of the project are to be submitted to this Research Governance Office after a HREC decision is made.
5. Proposed amendments to the research protocol or conduct of the research which only affects the ongoing site acceptability of the project, are to be submitted via email to this Research Governance Office;
6. For all clinical trials, the study must be registered in a publicly accessible trials registry prior to enrolment of the first participant.
7. A copy of this letter should also be maintained on file by the Coordinating Principal Investigator as evidence of project authorisation.
8. Notification of completion of the study at this site is to be provided to this Research Governance Office.

All future correspondence regarding this study must include the CALHN reference number in the subject header.

We wish you every success in your research project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Bernadette Swart'.

Bernadette Swart  
Manager, CALHN Research Office  
Ph: 8222 3890

## Appendix 2: Recruitment flyer



 THE UNIVERSITY  
of ADELAIDE

 Government  
of South Australia  
SA Health

# Are you HIV+?

## Are you aged 60 years or over?

Are you thinking  
about your care and  
living arrangements  
into the future?

If so, would you like to  
take part in a study on  
this topic?

Contact Michael on **08 8222 5816**  
or email me on **Michael.Curry@sa.gov.au**

Study approved by the Royal Adelaide Hospital Human Research Ethics Committee and SA Health

## Appendix 3: Participant information sheet and consent form



*People living with HIV (PLHIV) considering transition into aged care – an emerging phenomenon*

### Participant Information Sheet

**Non-Interventional Study – Adult providing own consent**

Royal Adelaide Hospital

<b>Title</b>	PLHIV considering transition into aged care – an emerging phenomenon
<b>Protocol Number</b>	[Protocol Number]
<b>Coordinating Principal Investigator</b>	Dr Lynette Cusack, University of Adelaide, Professor Erik Sorensen, Alborg University, Alborg, Denmark
<b>Principal Investigator</b>	Mr Michael Curry
<b>Location</b>	Royal Adelaide Hospital ID Unit OPD Queen Elizabeth Hospital O'Brien Street Medical Practice Riverside Family Medical Practice Centre Pharmacy, Central Market

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## **Part 1      What does my participation involve?**

### **1. Introduction**

You are invited to take part in this research project, People living with HIV considering transition into aged care – an emerging phenomenon. This is because you are HIV positive, aged 60 years or over, you are fluent in the English language and you are considering your future care and living arrangements. The research project is aiming to explore and understand the feelings or concerns you may have around your care and living arrangements as it applies to a move into the residential care environment.

This Participant Information Sheet tells you about the research project. It explains the research involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend, or your doctor.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. You will receive the best possible care whether or not you take part.

If you decide you want to take part in the research project, you will be asked to sign the Consent Form. By signing this you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to the research that are described
- Consent to the use of your personal and health information as described, but that this information will be not be identified as yours

If you decide to take part, you will be given this Participant Information Sheet to read and the Consent Form to sign and you will be given a copy to keep.

### **2. What is the purpose of this research?**

The result of this research will be used by the Principal Investigator Mr Michael Curry to obtain a Doctor of Philosophy degree.

This research has been initiated by the Principal Investigator Mr Michael Curry. This research is not receiving any funds as it is being conducted as part of a PhD thesis through the auspices of the University of Adelaide.

### **3. What does participation in this research involve?**

If you are interested in participating you will make contact with me and we can discuss the research project over the phone or we can arrange a meeting to discuss the details of this research. At our first contact we can arrange how best to inform you further about the research and ways to give you this Participant Information Sheet – by post, email, or in person. This initial contact or meeting will be an opportunity for me to describe to you the purpose of the research, the type of questions you will be asked and the time commitment for your research interview with me.

The Participation Information Sheet will be yours to keep and will provide you with contact details of all parties involved with whom you may wish to make contact throughout the duration of this research. These will include the Coordinating Investigator, the Principal Investigator and other contact details of counselling service, if this were needed, and the Human Research Ethics Committee's complaints department.

The interview will be one on one between yourself and me and will be audiotaped. Our interview can proceed once the Consent Form is signed by both parties. The interview questions will be semi-structured but where you are free to elaborate and tell your story. The interview length will be determined by you, but please allow up to two hours. There will be no follow-up meeting unless you have further comments you wish to add to your interview.

Your participation will be voluntary and there will be no payment to you for your participation. However, in extreme circumstances, where travel costs are a problem for you, reimbursement can be provided in the form of a ticket for metropolitan public transport.

This research will be monitored through the University of Adelaide Higher Degree Research Unit, Ethics Committee and through the supervisors of this research thesis.



#### **4. What do I have to do?**

Your participation in this study will involve initial contact by you and attendance at the interview. Prior to signing the Consent Form and the interview you will be provided with the reasons that underpin this study and the opportunity to ask questions of me. This discussion will also describe the nature of the questions you will be asked. These questions will be around your life living with HIV and your thoughts about your future care and living arrangements and what your thoughts are about a move into residential aged care if this were needed.

#### **5. Other relevant information about the research project**

- This research will only be conducted in South Australia.
- This project involves myself as the Principal Investigator and two university supervisors.

#### **6. Do I have to take part in this research project?**

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participation Information Sheet to read and the Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with the Royal Adelaide Hospital.

#### **7. What are the alternatives to participation?**

You do not have to take part in this research project to receive treatment at this hospital.

#### **8. What are the possible benefits of taking part?**

Participation in this research may not be of immediate benefit to you. If there are benefits at all, this will be into the future. It is hoped, however, that the findings of this

research may help and guide the future for those who are faced with transition into aged care to reduce any concerns felt by them around this transition.

### **9. What are the possible risks and disadvantages of taking part?**

The research topic and questions will be discussed with you in detail prior to your commitment and consent to participate. It is hoped that with this advance notice of what will be discussed you will not find reasons to become distressed during or after our meeting. If however, this was to occur, you are welcome to contact a dedicated counselling service, the MOSAIC Counselling Team on 8223 4566 and ask to speak with the Duty Counsellor. They will be happy to assist you. This counselling service will be provided free of charge.

### **10. What if I withdraw from this research project?**

If you decide to withdraw from this research project all information that you have provided will be discarded. Your audiotape interview will be deleted as will the transcript of your interview also be deleted.

### **11. Could this research project be stopped unexpectedly?**

There are no foreseen reasons why this research project should be stopped. However, if unexpectedly, this research project was to be stopped the reasons for this to occur may include: insufficient number of participants, or illness of the Principle Investigator. You will be given immediate notice if this research project was to stop unexpectedly.

### **12. What happens when the research project ends?**

Once the research has been completed the findings and any recommendations will be presented in the Positive Life SA Newsletter or a small public forum in a relevant setting.

## **Part 2      How is the research project being conducted?**

### **13. What will happen to information about me?**

Your participation in this research will be anonymous. Your information will not be identified as yours. You will be allocated a number and not a name. The only person who will be able to link you to your data will be me. Your interview will be recorded by audiotape by me. The recorded interview, which will use your allocated de-identified research number rather than your name, will be written out in full as a transcript by me. This transcript will be kept confidentially stored in a locked drawer in my private office within the School of Nursing of the University of Adelaide. Your transcript will be kept in this location for a period of five (5) years. At this time the data you provided will be destroyed as per University of Adelaide protocol. I will be the only one who has access to your information.

By signing the Consent Form you consent to me and relevant research staff collecting the use of your personal information for the purposes of this research project. Any information obtained in connection with this research project that can identify you will remain confidential. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your permission.

Your confidentiality will be maintained as you will have been allocated, at time of your signing the Consent Form, a number instead of your name.

Information about your participation in this research project will **not** be recorded in your health records. There will be no need for this to occur.

### **14. Complaints**

The study has been approved by the Royal Adelaide Hospital Human Research Ethics Committee (approval number: .....). If you have any questions associated with the

practical aspects of your participation in the project please contact the project's Supervisor, Dr Lynette Cusack on 8313 3593.

If you wish to raise a concern or complaint about the project, then you should contact the Royal Adelaide Hospital Research Committee via the Human Research Ethics Committee contact person Ms Heather O'Dea, phone: 8222 4139, or email: Heather.O'Dea@sa.gov.au, if you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant.

If you suffer any injuries or complications as a result of this research project, you should contact the study team as soon as possible and you will be assisted with arranging appropriate medical treatment. If you are eligible for Medicare, you can receive any medical treatment required to treat the injury or complication, free of charge, as a public patient in any Australian public hospital.

#### **15. Who is organising and funding the research?**

This research project is being conducted by the University of Adelaide as part of a higher degree. There is no research funding.

This research project does not require commercial sponsorship.

#### **16. Who has reviewed the research project?**

All research in Australia involving humans is reviewed by an independent group of people called the Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of the Royal Adelaide Hospital and the University of Adelaide, Human Research Ethics Committee.

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect the interests of people who agree to participate in human research studies.

## 17. Further information and who to contact

### Clinical contact person

Name	Michael Curry
Position	Principal Investigator
Telephone	8222 5816
Email	Michael.curry@sa.gov.au

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

### Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	Heather O'Dea
HREC Executive Officer	Heather O'Dea
Telephone	8222 4139
Email	Heather.O'Dea@sa.gov.au

## Consent Form – *Adult providing own consent*

<b>Title</b>	People living with HIV (PLHIV) considering transition into aged care – an emerging phenomenon
<b>Protocol Number</b>	[Protocol Number]
<b>Project Sponsor</b>	University of Adelaide
<b>Coordinating Principal Investigator</b>	Dr Lynette Cusack, Professor Erik Sorensen
<b>Principal Investigator</b>	Mr Michael Curry
<b>Location</b>	Royal Adelaide Hospital ID Unit OPD Queen Elizabeth Hospital O'Brien Street Medical Practice Riverside Family Medical Practice Positive Life SA Centre Pharmacy Central Market

### **Declaration by Participant**

I have read the Participant Information Sheet in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I understand that my interview will be audiotaped and transcribed but that the transcript will not identify me.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print)

Signature

Date

**Declaration by Study Doctor/Senior Researcher†**

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Study Doctor/ Senior Researcher† (please print) _____	
Signature _____	Date _____

† A senior member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

**Form for Withdrawal of Participation – *Adult providing own consent***

<b>Title</b>	People living with HIV (PLHIV) considering transition to aged care – an emerging phenomenon
<b>Protocol Number</b>	[Protocol Number]
<b>Project Sponsor</b>	University of Adelaide
<b>Coordinating Principal Investigator</b>	Dr Lynette Cusack and Prof Erik Sorensen
<b>Principle Investigator</b>	Mr Michael Curry
<b>Location</b>	Royal Adelaide Hospital ID Unit OPD Queen Elizabeth Hospital ID Unit OPD O'Brien Street Medical Practice Riverside Family Medical Practice Positive Life SA Centre Pharmacy Central Market

**Declaration by Participant**

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine treatment, my relationship with those treating me or my relationship with the Royal Adelaide Hospital nor the University of Adelaide.

Name of Participant (please print) _____
Signature _____ Date _____

*In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher will need to provide a description of the circumstances below.*

--



**Declaration by Study Doctor/Senior Researcher†**

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Senior Researcher <sup>†</sup> (please print) _____	
Signature _____	Date _____

† A senior member of the research team must provide the explanation of and information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.

## Appendix 4: Interview questions

This document provides a guide for the information that will be collected during the interview.

### Demographic profile of participant

**Gender:** Male  
Female  
Transgender

**Your age:**

**Country of Birth:**

**Education level:**

**Partner/Spouse** Yes No

**Do you live: With your partner** Yes No

With your partner and other/s Yes No

With other/s Yes No

By yourself Yes No

Do you own your own home Yes No

Do you live in a rental property Yes No

**Do you identify: Homosexual** Yes No

Heterosexual

Bisexual Yes No

Other Yes No

Define other:

**Are you currently: working full time** Yes No

working part time Yes No

unemployed Yes No

working shift work – full time Yes No

working shift work – part time Yes No

volunteer work Yes No

retired Yes No

**HIV diagnosis - Year:**

**Are you taking antiretroviral therapy?**

Yes/No

**Recent immune function:**

**CD 4 count**

**Viral load**

### **Trigger questions**

#### **Experience living with HIV**

Tell me about your experience living with HIV. *Or, tell me about your life living with HIV.*

#### **HIV treatment**

Tell me about your experience (*or life*) with antiretroviral therapy. Are you doing OK on these tablets now?

#### **Disclosure**

Tell me about your feelings around disclosure. How prominent a factor has this been in your life?

If you have disclosed your HIV status tell me about any feelings of discrimination, or fear of stigma that you may have felt.

#### **Ageing with HIV**

Can you tell me about your experience ageing with HIV? What are your feelings or concerns?

Can you tell me about your current health?

Please tell me about your thoughts of ageing with HIV. Can you tell me about any feelings of signs of frailty – physical, mental?

#### **Support network**

Tell me about your support networks and how do you think they can be relied upon?

How would you describe your current health?

Have you given thought to ageing with HIV?

Are you noticing any signs of frailty – physical, mental (forgetfulness)?

Have you given thought to your living arrangements into the future?

#### **Transitioning to aged care**

Tell me about your feelings about aged care.

Have you given thought to your living arrangements into the future?

Tell me about some of your concerns in relation to transition into aged care if your doctors or you yourself felt this was needed for you.

These concerns you raised, tell me what would concern you most.

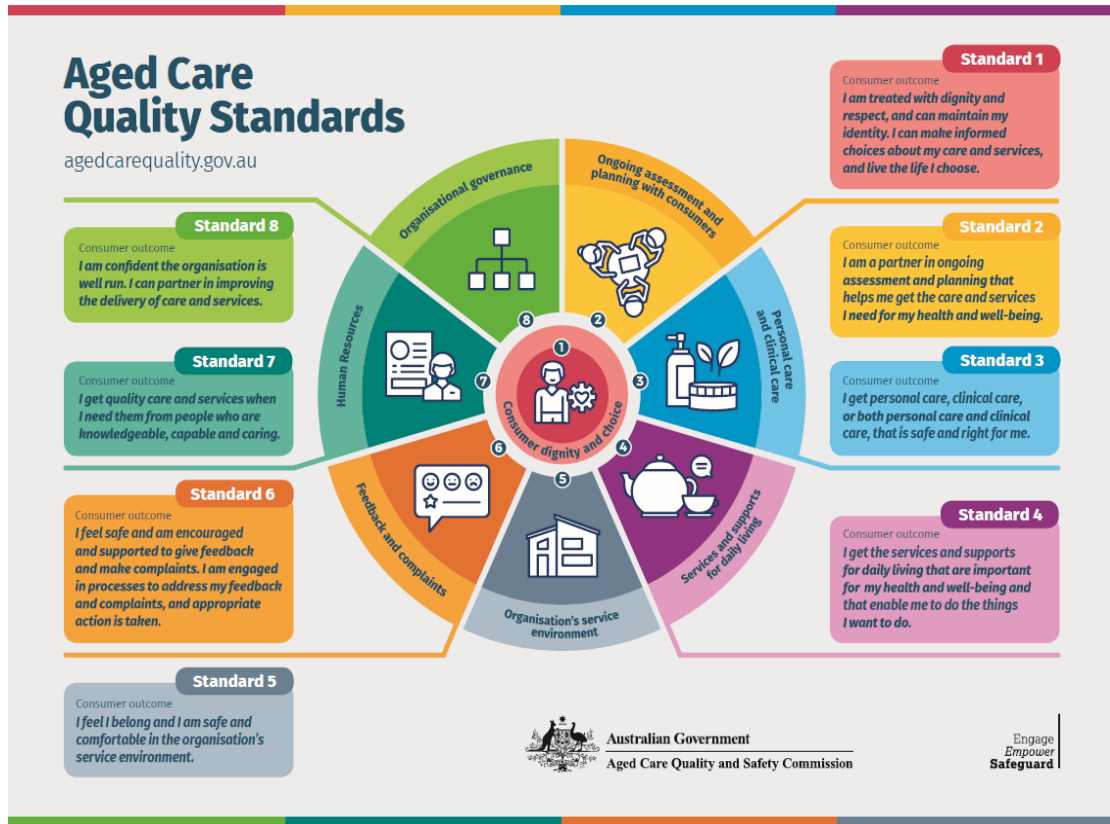
Tell me about what would concern you least.

Would you think the aged care sector would be welcoming to someone living with HIV?

Would you think your HIV care – medications/attending appointments – would be impaired by living in the aged care setting?

Do you have any further comments re the above questions?

# Appendix 5: Australian Aged Care Quality Standards



## Appendix 6: Aged Care Transition Project Protocol

Table 1	
Aged Care Transition Project Protocol	
<b>Preparatory phase</b>	
1.	ACAT assessment completed
2.	Identification of aged care facility
3.	Meet with client, carer's and/or guardian to discuss ongoing support needs
4.	Negotiation of HIV and other health care treatment with the identified nursing home
I.	Identification of health care services
II.	Identification of NGOs and other services
III.	Formulation of timeframe for transfer to nursing home
IV.	Explore potential issues with care/support within the nursing home
5.	Liaison with health care professionals, NGOs and other support services
I.	Collation of reports, medical history, discharge summaries, other relevant information/documentation
II.	Coordination of appointments
III.	Negotiation of roles
6.	Timeframe of service support from HIV community teams.
I.	review and develop exit plan with client, carer's and/or guardian
<b>Implementation Phase</b>	
7.	Completion of Community HIV Aged Care and Transition Project transition plan
8.	Implementation of exit strategies for HIV community services
9.	Completion of care
10.	Evaluation of transition to aged care

Source: Murray, Cummins and Bloom (2014, p. 35).

