The ‘Lazarus Experience’: People with HIV Making Sense of Their Lives in the Post-Treatment Era

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Statement of Authentication

The work presented in this thesis is, to the best of my knowledge and belief, original, except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.
# TABLE OF CONTENTS

Table of Contents ............................................................................................................................................ i

Abstract .............................................................................................................................................................. v

CHAPTER 1: Introduction to Thesis ...................................................................................................................... 1

1.1 Why this Research ........................................................................................................................................ 3

1.2 Research Questions ..................................................................................................................................... 6

1.3 Organisation of Thesis .............................................................................................................................. 7

CHAPTER 2: The Changing Times: Temporally Situation the Research ................................................................. 13

2.1 Introduction .................................................................................................................................................. 13

2.2 Emergence of AIDS ..................................................................................................................................... 14

2.3 Social Meanings of AIDS .......................................................................................................................... 17

2.4 My Vested Interest – My Story and a Version of HIV Social History ....................................................... 21

2.4.1 “The Free Fall” ....................................................................................................................................... 22

2.4.2 “The Slow Progress” ............................................................................................................................. 24

2.4.3 “The High Hopes” ................................................................................................................................. 26

2.4.4 Disease Progression ............................................................................................................................... 28

2.4.5 “The Global Crisis” .............................................................................................................................. 30

2.5 The ‘Miracle’ of Effective Anti-HIV Treatments .......................................................................................... 33

2.6 The Implications of Living with HIV and AIDS as a Chronic Disease and Illness .................................... 39

2.6.1 The Privileging of Clinical Markers ....................................................................................................... 41

2.6.2 Treatment Doubts, Uncertainties, Concerns & Side Effects ................................................................. 43

2.7 Quality of Life and HIV Living ................................................................................................................... 50

2.7.1 Quality of Life: Conceptual and Definitional Issues ............................................................................. 52

2.7.2 The Meaningfulness of Quality of Life ................................................................................................. 56

2.8 The Post-Treatment Era ............................................................................................................................ 60

2.9 Summary ................................................................................................................................................... 65
CHAPTER 3: Methodology: Theoretical Framework ........................................67

3.1 Introduction ...............................................................................................67

3.2 Why Use Qualitative Research Methodology .............................................68

3.3 The Epistemological and Ontological Positions .........................................71

3.3.1 The Difference Between Postmodernism/Poststructuralism Is? ..........76
3.3.2 Poststructuralist Informed Research ......................................................80

3.4 The Analysis Material – The Stories People Tell .........................................84

3.4.1 Stories as Social Constructions ..............................................................85
3.4.2 Stories as Analysis Materials .................................................................89

3.5 Summary .....................................................................................................94

CHAPTER 4: Methodology: Research Protocol ...............................................96

4.1 Introduction ...............................................................................................96

4.2 Research Design .........................................................................................97

4.3 Participant Group Size ..............................................................................97

4.4 Research Method .......................................................................................98

4.4.1 Participant Selection Criteria .................................................................98
4.4.2 Recruitment Process ............................................................................99
4.4.3 Data Collection .....................................................................................101
4.4.4 Interview Questions .............................................................................103
4.4.5 Follow-Up Interviews .........................................................................105

4.5 The Research Participants ..........................................................................108

4.5.1 Participant Profiles – Pen Portraits .....................................................108

4.6 The Analysis of the Materials – the Stories ..............................................113

4.6.1 Transcription .........................................................................................113
4.6.2 Coding ..................................................................................................117
4.6.3 Analytic Strategy ..................................................................................119

4.7 Trustworthiness of Research Analysis ......................................................122

CHAPTER 5: Living with HIV in the Post-Treatment Era: Now That I’m Not to Die, How am I to Live? .................................................................126

5.1 Introduction ..............................................................................................126
5.2 Drawing on the Past to Make Sense of the Present and the Future .............. 127
   5.2.1 Reconstructing a “Life Interrupted” ......................................................... 129
   5.2.2 The “Live Now, Live Today” Story ............................................................ 139
   5.2.3 The “Completely Different Life” Story ..................................................... 146

5.3 Constructing a ‘Normal’ Life Context ............................................................. 157

5.4 Summary ........................................................................................................... 167

CHAPTER 6: The Use of Metaphors in Making Sense of Anti-HIV Treatments ......... 169
6.1 Introduction ....................................................................................................... 169
6.2 Treatments as ‘Life Savers/Restorers’ .............................................................. 171
6.3 Treatments as a ‘Political/Moral Obligation’ .................................................... 177
6.4 Treatments as ‘Feared Objects’ ....................................................................... 185
6.5 Treatments as ‘Necessary Evils’ ..................................................................... 192
6.6 Treatments as a ‘Safety Net’ and the ‘Last Resort’ ........................................... 197
6.7 Summary ........................................................................................................... 206

CHAPTER 7: Medicalisation of the Experience of Living with HIV: The Medicalising of Wellbeing ................................................................. 208
7.1 Introduction ...................................................................................................... 208
7.2 Medicalisation ................................................................................................ 210
   7.2.1 Medicalising HIV Living and Subjective Wellbeing ................................. 212
7.3 The Numbers Game ......................................................................................... 217
7.4 Clinical Markers as Surveillance Devices ....................................................... 225
7.5 Compliance / Adherence: “Do as you’re told because it’s good for you!” ....... 233
   7.5.1 The Reward for Adherence .................................................................. 236
   7.5.2 Adherence as a Regulatory Practice ..................................................... 238
7.6 Contesting Adherence: “I don’t have to do what I’m told.” ............................ 242
7.7 Summary ........................................................................................................... 255
CHAPTER 8: Living a Subjectively Constituted Meaning and Ethical Life in the Post-Treatment Era ........................................................................................................... 256

8.1 Introduction ........................................................................................................ 256

8.2 Living a Subjectively Constituted Meaningful and Ethical Life ...................... 259

8.3 Constructing Survivor’s Guilt as an Subjectively Ethical Experience .......... 260

8.4 The “De-Sickenising” Act .................................................................................. 272

8.5 The Act of Living as a Piece of Contemporary Art ............................................ 282

8.6 Summary ......................................................................................................... 291

CHAPTER 9: Conclusion ......................................................................................... 293

9.1 Introduction ...................................................................................................... 293

9.2 My Argument in the Thesis ............................................................................ 294

9.3 Implications of this Research .......................................................................... 304

9.4 Methodological Implications .......................................................................... 308

9.5 Present Research Limitations and Directions for Future Research .............. 313

9.5.1 Where to From Here? .............................................................................. 316

9.6 Concluding Remarks ...................................................................................... 320

REFERENCES ...................................................................................................... 322

Appendix 1 Information Sheet for Project Participants ........................................ 364

Appendix 2 Confidentiality and Participant Consent Agreement ......................... 365

Appendix 3 Prompt Questions to Participants ...................................................... 366
ABSTRACT

The medico-scientific advances made in the treatment of HIV and AIDS, which emerged in the mid 1990s, were significant. The Highly Active Anti-Retroviral Treatments (HAART) or anti- HIV treatments have been positioned as resources that changed the way HIV is now medically and socially constructed. Although HIV remains incurable, it is now constructed as a chronic disease that is treatable, manageable and people are no longer positioned as living with a ‘death sentence’. The research on which this thesis is based explores the subjective lived experiences of people with HIV living in urban Australia in the context of this change. The effects that the treatments have had on corporeality have also changed the ways people are now living with HIV in the post-treatment era. It is an era in which treatments for HIV are taken-for-granted, but issues, doubts and concerns relating to treatment use are firmly embedded in the everyday life of people with HIV.

This research is qualitative and is informed by postmodern epistemology to facilitate the examination of this topic. The research materials are the participants’ stories produced in individual semi-structured interviews that took place between 1999 and 2003. The participant group consists of 5 men and 3 women aged between 33 and 51 who were living in Sydney when they were first interviewed. Each participant was interviewed twice except for one who was interviewed three times. The findings suggest that whilst AIDS-related mortality has decreased since the availability of effective treatments, the notion of ‘quality of life’, as subjectively constituted and defined, is an ongoing negotiation that is predicated on people locating meaningfulness in their everyday lives. Despite the decreased threat of failing health
and death, the findings also suggest that people are continuing to be confronted by, and therefore positioned as, having to make sense of complex issues embedded in living with a disease for which there is no cure.
Chapter 1: Introduction to Thesis

Some time ago, when I was in conversation with a man who has lived with the Human Immunodeficiency Virus (HIV) for over 15 years, he declared he was unhappy with his life and was “tired” of the debilitating adverse side effects experienced from the anti-HIV treatments. He reduced his experience with the anti-HIV treatments that had prolonged his life to a provocative binary statement of either “be alive or be happy”. This aroused my curiosity and evoked a number of questions. The most intriguing of the questions, for me, was: how does he make sense of his life in such a way that makes him think being alive is the opposite of being happy? Is he suggesting that he has to choose either survival or happiness? How does the use of treatment compromise his subjective sense of wellbeing? These questions intrigued me and provoked an interest in wanting to explore the issues confronting people with HIV in the era of effective anti-HIV treatments.

The advances made in anti-HIV treatments and HIV medico-scientific monitoring technologies, which occurred in the mid-1990s (Carpenter et al., 1998), have resulted in effective means to treat and manage HIV infection. Surviving HIV and its related condition, the Acquired Immune Deficiency Syndrome (AIDS)\(^1\) is now not only possible but probable (Gushue & Brazaitis, 2003; Holtgrave, 2005). People with HIV

\(^{1}\) AIDS is not a disease but a set of signs, symptoms or diseases that is useful for health surveillance purposes (Horton, 1989). AIDS is an illness condition resulting from HIV infection.
are no longer positioned as living with a fatal disease. In this context, people are expected to live with, rather than die from, HIV. This is a meaningful and noteworthy shift when it is framed within the context of it being a disease that had caused negative and destructive changes in people’s lives. It is a disease that was so long synonymous with death (Juengst & Koenig, 1989; Menadue, 2003; Selwyn & Arnold, 1998).

This thesis is about the lived experiences of people with HIV and AIDS in the era of effective treatments. It seeks to contribute to knowledge about the ways in which people negotiate the experiences of living with HIV as a treatable chronic disease (Aranda-Naranjo, 2004; Baer & Roberts, 2002; Chou & Holzemer, 2004), and their negotiation with anti-HIV treatments and medical practices on which they rely in order to prolong survival. In spite of HIV being constructed as a chronic disease, the treatments for HIV, with their beneficial and adverse effects, have produced a situation for people with HIV in which they have the potential to live longer by using treatments, but at the same time, have to endure possible adverse side effects that might diminish their subjective experiences of wellbeing. This is an important issue in understanding the experience of living with HIV in the era of effective treatments because it highlights a dichotomous experience of living a longer life or living a desired life. In their examination of psychosocial implications associated with changes in HIV treatment and management, Catalan, Meadows and Douzenis (2000) suggested that there is a “flip side of the good news” (p.336), which suggests that the promises of effective treatments have to be considered within the frame of the individual’s lived experiences. In this context, it is important that the ‘quality of life’
of people with HIV, as subjectively constructed, be explored. This is the focus of this thesis.

1.1 Why This Research?

An important factor that led me to develop an interest in the experiences of living with HIV and AIDS is my subjective experience of living through the period when the disease produced an intense mortal fear for many people, particularly gay men. The impetus for me to pursue my interest through this research was the result of conversations I had with people living with HIV in professional, academic research and social settings. People whom I met in these settings told stories of fear when treatment options were limited, as well as stories of struggles and difficulties experienced when effective treatments became a taken-for-granted part of their everyday lives. When they recounted their experiences with HIV, particularly in terms of the treatments, their subjective needs were at times in conflict with medical discourses and practices. Medical discourses position individuals as rational subjects when they engage in practices that are beneficial to the body. The practices of taking medication and adhering to treatment plans are constructed by medico-sciences as ‘best practice’ for health maintenance. However, people with HIV do not always do what is ‘best’ for them nor do they always comply with expert advice on treatment use (Cooper et al., 2002; Gellaitry et al., 2005; Veinot et al., 2006). This suggests that in their endeavours to live with HIV and AIDS, people can act in ways that are not predicated on recommended treatment use.
In examining the experiences of living with HIV and AIDS as a chronic disease and illness, some social researchers, as the titles of their works convey, are addressing issues of “rebuilding life” after facing imminent death due to AIDS (Trainor & Ezer, 2000), or “restructuring life to face the future” (Sowell, Phillips, & Grier, 1998). People are positioned as being able to live longer (Pitts, Grierson, & Misson, 2005) and able to lead ‘normal’ lives (Gregonis, 1997; Maticka-Tyndale, Adam, & Cohen, 2002) as asymptomatic or improved periods of wellness can now be extended (Goldstone, 2003). The attention given to “rebuilding” or “restructuring” life could be interpreted as an indicator of the change in the social construction of HIV in the everyday lives of those who are infected. The treatments have renewed hope (Kalichman, Ramachandran, & Ostrow, 1998), and hope for a productive future is a novel experience for many individuals who lived with the disease when a shortened life was the predicted outcome of HIV infection.

In spite of the breakthroughs in HIV treatments, which have “caused a drop in AIDS deaths that is more precipitous than would have otherwise been predicted” (Holtgrave, 2005, p.780), the treatments cannot eradicate HIV or cure the individual from HIV infection. Notwithstanding the availability of effective treatments, it has been argued that improved physical health is not correlated with improved psychological health, (Siegel, Karus, & Dean, 2004) and although there have been significant HIV medico-scientific advances, there continue to be health and social disadvantages experienced by people living with HIV (Grierson, Pitts, & Misson, 2005). Indeed, the difficulty of the HIV treatment regime, acknowledged as being the most rigorous, demanding and unforgiving of any outpatient treatment (Ingersoll & Heckman, 2005; Matthews et al., 2002) and which requires stricter adherence than
any other types of treatment regimes (Halkitis, Shrem, Zade, & Wilton, 2005), has produced difficulties in the form of adverse side-effects and drug toxicity (e.g., Remien et al., 2003; Yeni, 2006). Nevertheless, since HIV can now be effectively treated, the experience of living with HIV and AIDS has been medicalised and there is a proclivity “to dwell on quantitative aspects of HIV management and complex algorithms of antiretroviral therapy” (Selwyn & Arnold, 1998, p.900). A corollary of this is “the threat that in this process somehow the whole patient – and importantly, the patient’s personal history or narrative – may be lost” (Selwyn, 2000, p.264). The importance of personal history or narrative is also noted in chronic illness research (e.g. Thorne, 1999) and cancer research (e.g. Bishop & Yardley, 2004; Thomas-MacLean, 2004).

Whilst the health of the body is important, it could also be argued that the notion of health is useful when it encompasses the quality of lived experiences as subjectively constituted and defined. Schönnesson and Ross (1999) problematised the privileged positivist approach to health and disease in the health care system, and argued that “the concepts of health and disease are themselves existential, as disease represents the possibility and reality of life’s distortion, and health may be seen as the conquering of disease. Thus, health/disease should not only be equated with longevity but should also include existential well-being” (p.105). Given that treatments are not a panacea enabling people to live disease-free and unproblematic lives, living with HIV since the emergence of effective treatments has produced an ambiguity between wellness and illness. Living with HIV as a chronic disease, and AIDS as an illness experience, could now be argued as living with uncertainty (Brashers et al., 2003; Brashers et al., 1999; Siegel & Lekas, 2002). The ambiguity
and uncertainty embedded in living with an incurable but treatable disease underscores many issues confronting people in their endeavours to make sense of their experiences and their lives as they engage with a disease that is not only a remarkable medico-scientific phenomenon, but also a social phenomenon (Chapman, 2002; Herek, 1990; Herek & Glunt, 1988; Herzlich & Pierret, 1989). From this perspective, the notion of health is contestable as people continue living with a virus that has the potential to cause both physical and psychological harm. Conrad (1986) suggested that “[d]isease and illness can be examined on different levels” (p.51). A disease can be understood as a materiality that affects the body and produces tangible consequences. By contrast, illness, or our experiences of it, can be constructed as social and psychological phenomena related to the disease. He further suggested that “the world of illness is the subjective world of meaning and interpretation; how a culture defines an illness and how individuals experience their disorder” (p.51). This delineation of disease and illness is the one I am adopting in this thesis, as I am interested in the illness experiences of living with HIV. The delineation draws attention to the subjective need to construct meanings which might help individuals make sense of their illness experiences, meanings which are socio-culturally and historically specific.

1.2 Research Questions

The preceding issues have led to four key questions that the research, on which this thesis is based, aims to address. They are:
1) How do people with HIV living in Sydney, Australia and who have had previous engagement with the HIV/AIDS sector, make sense of their lives and their illness experiences with HIV, in an era when effective treatments for HIV are available?

2) How do people in this group make sense of these treatments in their lived experiences with HIV?

3) How do people in this group negotiate the medicalisation of their lived experiences with HIV, especially the negotiation between doing what is best for them as medically constructed and what is best in terms of how life is subjectively constructed and meaningfully lived?

4) How do people in this group constitute a meaningful life in their everyday practices and experiences in the era of effective treatments?

1.3 Organisation of the Thesis

This thesis does not contain a ‘traditional’ literature review section. Rather, relevant literature is cited and referred to as appropriate throughout the thesis. That is, I use the literature in a contingent way to give my interpretations depth and context. It is an approach to literature review that draws “on the relevant work of others on a when-and-as-needed basis” (Wolcott, 2002, p.95). I will draw on pertinent literature to present and examine the HIV and AIDS phenomenon from a socio-historical perspective, to clarify the medico-scientific advances made in HIV treatments and monitoring, and the physical and psychosocial implications associated with treatments. Relevant literature, together with interview materials, will be used to examine and contextualise the lived experiences of HIV since the availability of effective treatments. The contingent way that the literature is used facilitated my
understanding and informed my analysis of the interview materials, which in turn enabled me to theorise the material through which the four key thesis questions are answered.

This thesis has eight chapters following this introduction. Chapter Two situates my research in terms of how HIV is medically and socially constructed at the present time. In it, I explore my subjectivity and locate my subject positions as a researcher and as a gay male. My ‘gay-ness’ is pertinent, for HIV and AIDS have caused profound psychosocial devastations in the gay male population, particularly in Australia (Menadue, 2003; Sendziuk, 2003), the United States, Scandinavia, and Western Europe (Schönnesson & Ross, 1999). I detail the history of HIV and AIDS, and the medico-scientific advances made in treatment and management. I will describe the treatments that have shown to be effective in managing HIV, and will introduce and explain relevant medico-scientific terminologies and technologies frequently referred to in subsequent chapters. In my endeavour to elucidate the advances made in HIV treatments, I will examine the benefits and adverse side effects associated with their use, and the implications of adverse side effects in the everyday lives of people with HIV. It is in this context that I will interrogate the ‘quality of life’ concept and will argue that it is the meanings embedded in the concept that would better serve my exploration of individuals’ lived experiences. At the end of Chapter Two, I will clarify the ideas which informed and underpinned ‘post-treatment era’ as a theoretical concept, and the manner it will be used in this thesis.
Chapters Three and Four focus on methodology. Chapter Three introduces the theoretical framework which informed my research in order to clarify the manner in which the research materials are engaged with and analysed. Chapter Four explains the procedural aspects of conducting this research. It addresses the methodological issues of recruitment and ethics, and provides descriptions of the research participants (five men and three women) using ‘pen portraits’. The chapter includes my thinking and ideas about how and why certain steps were taken or issues considered, as informed by the theoretical framework. I detail participant selection criteria and present issues that I found to be important when recruiting the participant group. I also present some reflections on the process of qualitative research and analysis.

Chapters Five to Eight focus on analysis. Each of the four key thesis questions is responded to separately in these chapters. Chapter Five examines the research participants’ stories of how they made sense of their lives in the post-treatment era. It presents and examines the experiences of the participants who now have “the luxury of stepping back, out of the constant “crisis mode,” to reflect on the experience of those long and difficult years” (Selwyn, 2000, p.263) when living with HIV and AIDS was associated with a fatal consequence. The way they made sense of their experiences with HIV is temporally contextualised in that their past experiences inform and shape the way they make sense of their present circumstances and situations as well as their future prospects. The discursive (re)construction of HIV and AIDS as being treatable and manageable is positioned as an impetus for people to construct a ‘normal’ life context and to reconcile with the experience of a ‘life interrupted’ that forced them to confront mortality when it was least expected.
The opportunity to reconcile and to make sense of their experiences with HIV is made possible by the availability of effective treatments. The constructed meanings participants ascribe to treatments are explored in Chapter Six. Although participants acknowledged the importance of treatments as means with which to prolong their lives, I will argue that the treatments are not uniformly or unconditionally favoured. Treatments are acknowledged as ‘life restorers’ but their use is also constructed as a ‘political/moral obligation’. Not all participants were taking treatments at the time of the interviews as some participants positioned the treatments as ‘feared objects’ while others positioned them as ‘necessary evils’. In spite of the treatments being positioned as effective in treating HIV, they were also positioned as having adverse side effects that diminished the quality of lived experiences. Nevertheless, the potential of treatments to preserve life has meant that they were positioned as ‘safety nets’ on which individuals could rely if and when their use became necessary. From this perspective, treatment use underscores the challenges confronting people with HIV and the prominence of treatments in HIV discourses.

The medical advances made in HIV treatment and monitoring has produced a situation in which the experiences of living with HIV are medicalised. This issue is examined in Chapter Seven. The advances in HIV treatments are supplemented by medico-scientific technologies developed to monitor the physical health of individuals. The ‘numbers game’ of achieving desirable results, as determined by clinical indicators, has meant that health is externally measured, under the medical gaze and not predicated on reports by individuals. If ‘good’ clinical results are achieved through treatment use, individuals are positioned as ‘healthy’ in spite of the
subjective difficulties experienced due to adverse side effects. Participants narrated stories of the conflict produced by the privileging of clinical markers over their subjective experiences. The privileging of clinical markers is reflected in the emphasis on adherence, the practice of taking treatments promptly and correctly as prescribed. Living with HIV in the era of effective treatments could be interpreted as an act informed by medical practices. The medicalisation of living with HIV has marginalised the notion of subjective wellbeing and thereby fuelled the debate on what constitutes a good and healthy life, that is, the quality of their lives.

Chapter Eight draws on the analysis of the previous three chapters to argue that the way participants constitute a good and healthy life is subjectively informed. The effective management of HIV and longevity achieved by treatment use are meaningful only if the effects of the medical advances complement and enable people to live in a manner they desire. The opportunity to live longer but needing to accommodate unwanted side effects from treatments is a situation that demands consideration. How participants make sense of their lives with HIV is predicated on the meanings they construct in terms of how they want to live. For some participants, living longer does not connote a better life. The chapter examines the importance of the subjectively constructed ‘meaning of life’. This meaning guides people in their everyday endeavours and their projects of producing a subjectively constituted meaningful and ethical life.

Chapter Nine summarises and consolidates the knowledge produced by the responses to the four key thesis questions. This chapter also discusses some of the implications of my research in the understanding of lived experiences with HIV and AIDS, the
contribution that I hope it has made to psychotherapeutic and research work with people with HIV, limitations of this research and suggestions for future research.
Chapter 2: The Changing Times: Temporally Situating the Research

“The sick human body does not need some new spiritual magic, but it does, as always, need something made by human beings, namely a certain kind of practice which, in part, constitutes what we mean by healthy, normal or natural.” (D'amico and Layon, 1988)

2.1 Introduction

In this chapter, I will provide an exposition of the social and medico-scientific milieu in which this research is situated. The aim is to temporally situate this research and to clarify the manner in which HIV has been constructed before and after the availability of effective treatments. The chapter will detail the history of HIV and AIDS, in terms of the social and medical changes that have occurred since the early 1980s. In detailing the social and medical changes, I will reflexively explore my subjectivity and my experiences with HIV and AIDS. I will clarify the manner in which the currently available treatments have come to be constructed as ‘effective’ as well as the adverse side effects associated with their use. In doing so, I will explore the varied effects that treatments have on people’s lives by introducing and interrogating the concept of ‘quality of life’ as a theoretical frame from which to examine people’s lived experiences in the era of effective treatments. In clarifying the temporal context for this research, I will introduce and discuss the referent ‘post-treatment era’ in which the exploration of lived experiences of people with HIV is located.
2.2 The Emergence of AIDS

The conditions and symptoms associated with AIDS were noticed as early as 1979 when gay men in New York and California were experiencing and dying from illnesses unexpected in young healthy people. The first indication of the emergence of what later became known as AIDS was formally noted in a medical science publication in 1981¹ (Gottlieb, 2001; Steinbrook & Drazen, 2001). The median survival rate for people with AIDS in 1981 was eleven months (Jue, 1994) and there was an identified time frame from infection to death (Siegel & Krauss, 1991).

Despite limited knowledge about the condition, AIDS discourses in the early years shaped the view that it affected homosexuals, it killed, and it spread rapidly (Alcorn, 1988).

Surviving AIDS was not considered to be a probable outcome in the early years. Although there were people who were described as ‘long-term healthy seropositives’ (1997) or ‘long-term survivors’² (Jue, 1994; Remien, Rabkin, Williams, & Katoff, 1992; Remien & Wagner, 1995) or ‘HIV non-progressors’³ (Barroso, 1999; Kovacs & Connors, 2004; Madhavan et al., 2004; Troop et al., 1997), the expectation was that people infected with the virus will eventually succumb to a range of illnesses and health conditions that constituted AIDS, and to confront the ‘reality of death’ (Tross & Hirsch, 1988). This expectation was fortified by the commonly used term

¹ According to Gottlieb (2001), the 5 June 1981 issue of Morbidity and Mortality Weekly Report, the bulletin of the Centers for Disease Control in the USA, published a report on five individuals who were diagnosed with what later became known as an AIDS-related disease (pneumocystis carinii pneumonia), this publication signalled the beginning of the AIDS epidemic in the USA.

² “As of 1990, the Centers for Disease Control (CDC) defined a long-term survivor as any person living for more than three years following a diagnosis of an AIDS-defining opportunistic infection” (Remien & Wagner, 1995, p.180).
‘AIDS virus’ (Varmus, 1989) to signify the material virus that produced AIDS. The conflating of the virus with the terminal phase of its infection produced the grand narrative of ‘infection as death’. The term ‘AIDS virus’ was more projective than descriptive (Grover, 1988) and the implication was great for it imposed a mortal sentence on the individual infected with the virus. This expectation formed an illness progression, which was perversely predictable and commonly fatal; what was uncertain was the length of time before the person became unwell after infection (Carricaburu & Pierret, 1995).

The disease and its associated condition were not always known by the acronyms HIV and AIDS. The disease and condition were initially referred to as a ‘gay disease’ (Rofes, 1996; Ross, 1989; Smith, 1989) or ‘gay plague’ (Conrad, 1986; Lupton, 1994; Murphy, 1989). However, these terms were not neutral but were imbued with prejudice and discrimination. The use of the term ‘plague’ was to position individuals as morally culpable for their infections (Murphy, 1989). The act of connecting the illnesses observed with gay men led to a more ‘scientific’ descriptor, gay-related immunodeficiency (GRID) (Oppenheimer, 1992) or gay-related immunodeficiency syndrome (Padgug & Oppenheimer, 1992). The notification of infections in non-gay people led to the adoption of a different name, AIDS, selected in 1982 for its descriptive feature and non-pejorative connotation (Treichler, 1988b). Several names, such as the Human T-Lymphotrophic Virus type III (HTLV-III), the Lymphadenopathy Associated Virus (LAV) (Oppenheimer, 1992) and Immunodeficiency-Associated Virus (IDAV) (Treichler, 1988b) were used by

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3 The term ‘non-progressor’ refers to individuals who remained disease free for more than 5 years after HIV infection (Madhavan, Mahajan, Hewitt, Whitney, & Schwartz, 2004); or individuals who have restricted HIV replication for up to 20 years without ARV therapy (Kovacs & Connors, 2004).
different research teams at the time to refer to the retrovirus which was identified as having caused AIDS\footnote{I am aware of Peter Duesberg’s challenge against the virus-AIDS hypothesis which assumed prominence when knowledge about AIDS was limited. His hypothesis was that AIDS was brought on by recreational drug use or the drug AZT which was used to treat the condition at the time (see Adams, 1989). His theories were published in academic journals but have since proved to lack credibility.}; HIV was officially adopted as the name for the virus in 1987 (Treichler, 1988b). It should be noted that the discovery and naming of the virus was controversial. According to Cochrane (2004), there was a claim that LAV (named by the French researcher Luc Montagnier) was appropriated and renamed by the researcher Robert Gallo in the United States as HTLV-III; this controversy was addressed by the International Committee on the Taxonomy of Viruses by naming the isolated retrovirus that caused AIDS as HIV. From this perspective, as with all historical accounts, the specifics of the historically contingent circumstances surrounding the discovery of HIV are contested and thus other accounts can be given.

Names and language are important to our understanding of AIDS as both a medico-scientific and a social construct. AIDS is not just a physical malady or a serious medical condition but is also a social product (Grover, 1988) and a complex social issue (Cree, 2004). AIDS was a social phenomenon constructed through medical knowledge and in public opinion (Herzlitch & Pierret, 1989). From this perspective, just as important as it is to be knowledgeable about the material virus, it is also critical for us to understand the social construction of it in the everyday life.
2.3 Social Meanings of AIDS

“AIDS is not just a biomedical phenomenon but a syndrome with a set of social meanings... (it is) a morally repugnant disease” (Miles, 1997, p.481)

Cochrone (2004) argued that knowledge about a disease or an illness is “not apolitical and biomedical assertions about the causes of illness and the characterization of symptoms denoting distinct disease entities are not, and have never been, value-free” (p.137). In this section, I want to examine the social meanings for AIDS when it first emerged as a health issue, and the manner in which people were constructed and positioned as a result of being infected by this “morally repugnant disease” (Miles, 1997, p.481).

Herzlich & Pierret (1989) analysed the construction of AIDS as a social phenomenon and found that the news media acted as a conduit in relaying information about the then new disease from the medical sphere into the public domain. The reporting of medical information and knowledge in the social had meant that social meanings about AIDS were produced. The role of the news media in constructing social meanings was examined by Lupton (1994) who framed news as a social construction. She argued that accounts produced by the news media are like any other cultural products in that they reflect societal norms, values and ideologies as well as constituting them. She asserted that “the media tell people not only what to think but what to think with” (Lupton, 1994, p.26-27, italic original). The reporting of issues, particularly those that are contentious or controversial such as AIDS, are imbued with prejudice; not malevolent prejudice necessarily but ‘the angle’ that the news producers deemed to be meaningful or provocative. News accounts thus do not
reflect reality but construct a version of it. This is an important point because of the privileged position that news, and the act of reporting of news, is given, for it is in our reliance on news that we are informed and connected with our worlds, both globally and locally (Herzlich & Pierret, 1989; Lupton, 1999). However, this reliance also means that people are influenced by the constructed accounts of issues that they have no direct experience, which means that the construction of AIDS in the media informed an understanding that is not necessarily accurate or precise but nevertheless produced definite judgements about the disease and those who were infected. In this context, ‘having AIDS’ became an event which stigmatised and positioned the infected individual as an innocent victim or a guilty pervert by christian/moral or legal discourses depending on the mode through which the person became infected (see Lupton, 1994, 1999; Matic, 2006; Murphy, 1989; Watney, 1989). Stigma is a discrediting social label that affects the manner in which an individual is positioned by him/herself and others and has the effect of disqualifying him or her from social acceptance (Wright, Naar-King, Lam, Templin, & Frey, 2007). HIV stigma is unique in that it is associated with factors that imbue judgment and criticism as well as a conceptual link with morality by associating HIV with sexual promiscuity, sexual deviation, drug use and personal irresponsibility (Wight, Aneshensel, Murphy, Miller-Martinez, & Beals, 2006). HIV stigma produces a social process that results in marginalisation and exclusion of those who are infected (Ware, Wyatt, & Tugenberg, 2006). Effects of HIV stigma are profound, for these effects interfere with prevention efforts, health behaviours, testing for HIV status (Abadía-Barrero & Castro, 2006), avoiding HIV information (Lieber et al., 2006), psychological adjustment and treatment adherence difficulties (Vanable, Carey, Blair, & Littlewood, 2006). The
AIDS was initially constructed as a condition that fell upon the morally corrupted, which positioned people infected as carriers of a deadly disease who should be avoided (Lupton, 1999; Watney, 1989). Treichler (1988b, p.32-33) listed a number of social meanings constructed to account for and to make sense of AIDS, some of which in particular targeted gay men and were imbued with a predilection to moral condemnation. Most damning was that AIDS was “the result of moral decay”, “nature’s way of cleaning house”, “an infectious agent that has suppressed our immunity from guilt” and “God’s punishment of our weaknesses”. If these social constructions of AIDS were not sufficient to make plain the prejudice against and the persecutory activities directed at gay men, this was made most visible by it being referred as WOGS, the Wrath of God Syndrome (Treichler, 1988a, 1988b), a punishment for the depraved activities of homosexuals (Sendziuk, 2003). Referring to it as WOGS signified that AIDS, the physical condition, was conflated with morality, and those infected were positioned as morally corrupted and were stigmatised as their diseased bodies were constituted as objects that needed to be segregated from and controlled by non-infected people. People infected with the virus were constructed as feared objects, for they had a disease that was likely to cause death. AIDS constituted individual subjectivity, for people were constructed as the disease and were positioned in certain defined ways (e.g., ‘the AIDS man/woman’) (Lupton, 1999). The prejudice against people who were identified as carriers of the disease were legitimised and acted on (Sendziuk, 2003) as shown by the proposal of quarantining and isolating all people with AIDS (Nutbeam & Blakey,
AIDS was constructed as a ‘dirty’ disease that was the property of the social ‘undesirables’ as people infected were constructed as “blame-worthy, deviant, and delinquent” (Miles, 1997, p.481). It is as Cree (2004) argued, “AIDS has become a threat to encourage people away from what are perceived to be ‘dangerous identities’” (p.9). This was an issue documented in HIV history by positioning individuals, the ‘victims’ of HIV infection, as either ‘guilty’ or ‘innocent’ (Ross, 1989; Weeks, 1988). The ‘innocent’ were the haemophiliacs, female partners of bisexual men, and children; the ‘guilty’ were the drug addicts and gay men (Weeks, 1988). The risk factor in contracting the disease was ‘who you are’, not ‘what you do’.

The socially constructed meanings to understand and to make sense of AIDS further complicated the lived experiences of people who were infected. It was politicised and was manifested as a reason to marginalise, to discriminate and to position the individual infected as ‘Other’ (Chapman, 2000; Joffé, 1997, 1999; Miles, 1997). The positioning of the individual infected, commonly a gay man (Dodds, 2002; Treichler, 1988b), as ‘Other’ reinforces homophobic discourses which position gay men as not “fully or properly human” (Watney, 1988, p.53). The notion of ‘otherness’ has been historically linked to incurable disease in the past whereby people with the disease are positioned as “out-groups within the society” and who engaged in “practices which are deemed alien and perverse within the culture” (Joffé, 1997, p.136). Treichler (1988b) argued that AIDS was both an epidemic, in the epidemiological sense, and “an epidemic of signification”. By this, she was referring to “the exponential compounding of meanings as opposed to the simpler spread of a

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5 It should be noted that being positioned as ‘other’ was the experience of marginalised groups, for example, women (de Beauvoir, 1961).
term through a population” and “to the way in which language (or any other
“signifying system”) organizes rather than labels experience (or the world)” (p.32).
The epidemic of signification produced “AIDS panic” (Squire, 1997) which signified
the cultural metaphors and uncertainties about the disease which intensified the fear
associated with the observable material consequences from infection.

What I want to do in the next section is to situate the emergence of AIDS, the AIDS
panic, and the AIDS crisis in a subjective context by recounting my experiences with
HIV and AIDS. I will do this by weaving my experiences in with a short account of
HIV social history as a means of contextualising my experiences.

2.4 My Vested Interest – My Story and a Version of HIV Social History

I want to reflexively explore my subject position as both a researcher and as an
individual whose life has been affected by HIV and AIDS. Reflexivity is a crucial
practice in research that is informed by postmodern thought (Mauther & Doucet,
2003). ‘Doing’ social psychological research critically is inherently reflexive
(Henwood & Parker, 1994), and the researcher needs to reflect upon his or her own
position in the research process (Burr, 2003). It is the onus of researchers to
acknowledge how their own experiences and contexts inform the process and
outcomes of inquiry (Etherington, 2004). Drawing on these ideas on reflexivity, it is
pertinent to include my story in the thesis for it illustrates how my experiences have
shaped the way I engage with the research topic. Since I am informed by my
experiences and the constructed meanings I hold for the disease, I cannot deny their
importance in my work as a researcher. The story that I will present here is brief, as
this is not an autobiography, but rather an account which aims to situate myself clearly and openly within the frame of the research topic.

The time period since the appearance of AIDS in 1981 has been usefully categorised by Sepkowitz (2001) into four different periods: “the early years – Free Fall” (the early 1980s); “the late 1980s – Slow Progress”; “the mid-1990s – High Hopes”; and “the late 1990s – Global Crisis”. I will use Sepkowitz’s temporal structures as the frame within which to locate my own story.

2.4.1 “The Free Fall”

AIDS was not yet a concern when I went through the process of ‘coming out’ and coming to terms with my sexuality. I was born in 1963 which meant that by the time I was sexually aware and active as a gay man in the late 1970s, the American Psychiatric Association had already removed homosexuality from its list of mental disorders (Australian Psychological Society, 2001). This, however, did not mean that I embodied my sexuality without the fear of discrimination, as social stigma and bigotry towards homosexuality continued to silence me and labelled my sexuality as a ‘disease’ and a crime. From a legal position, I was committing a criminal offence in New South Wales whenever I had sex up until 1984\(^6\) (Bull et al., 1991). After this time, AIDS was used as a justification for continuing to criminalise and to moralise against homosexual behaviours, for these behaviours could lead to death (Nutbeam & Blakey, 1990). The time period of the late 1970s and the early 1980s was, for me,

\[^6\] Bull, Pinto, and Wilson (1991) offered an informative account of Australian law reforms pertaining to homosexuality. At the time of Bull et al.’s publication, Tasmania was the only state in Australia where all forms of sex between consenting adult males in private was a criminal offence. The law in Tasmania was repealed in 1997.
a period when I experimented and became comfortable with my sexuality through sexual activities. Although contracting sexually transmissible diseases was undesirable, I was told they were largely treatable. I certainly did not think I would die if I were to contract any of them, until AIDS. Initially, not much was known about this ‘gay disease’ and indeed it was not a disease of great concern for me as it had not invaded my own social reality. I was fortunate I was not infected and no one I knew had been infected. Thus, unlike many other gay men in particular, I was somewhat sheltered from the devastation of the early years. In the “Free Fall” period, which was when the disease first emerged and was uncontrolled, people learned of their infection, fatality was common, fear was prevalent, effective treatment was unavailable and knowledge about the disease was limited. The devastation as experienced by individuals in this period, particularly gay men has been well documented (Menadue, 2003; Rofes, 1996, 1998): pessimism and fatalism were omnipresent and the disease was constructed as a “fatal affliction” (Juengst & Koenig, 1989, p.xviii). My situation changed dramatically in the second half of the 1980s when two good friends told me they had AIDS and this prompted me to think more about my own health status given the high risk activities in which I had engaged. Also at this time, news of people I knew being infected entered into my awareness and social occasions became times when news was shared about people who became infected. Conversations which started with “did you hear about…” unnerved me.
2.4.2 “The Slow Progress”

The “Slow Progress” period, which loosely depicts the time from the late 1980s to the mid-1990s, was when we became more knowledgeable about the disease, and about how to prevent infection, as pharmaceutical agents were researched and tested as possible treatments. During this period of the late 1980s, I witnessed the failing health of one of the two friends mentioned earlier, over a very short period. He was prescribed with a medication that was thought to be effective, and when he complained about the negative effects from the medication, all of his friends, including me, encouraged him to persist ‘because that’s what the doctor prescribed’. The medication was called Zidovudine (AZT) (AZT will be examined later in this chapter). He continued to take this medication as prescribed, albeit reluctantly, because of the discomfort it was causing, but in the end, it ceased to be effective and the toxicity from taking it created a whole new set of discomfort and complications. It was difficult to bear witness to his suffering through a drug-induced ordeal that did not seem to end, but at the same time, we did not want him to stop taking this medication for it appeared to be the only one that was available, regardless of its effectiveness. On reflection and with the benefit of hindsight, it was peculiar that we, including my friend, continued to support the use of this medication even when it was suspected to be ineffective; perhaps all of us wanted to have a tangible hope, and this medication signified hope. I believe my reservations about future treatments came from that moment when the confidence I had placed in medico-science proved unjustified. When his once athletic body became emaciated and weak, it signalled to us that he was not going to survive this disease. He did not. At the time of his death, he became one of many. The despair of losing this friend was somehow merged with
the despair of losing others, and grief became non-specific. It was distressing and profoundly confusing to feel this ubiquitous and generalised grief, rather than the grief I would feel for a specific friend. The only comfort in this situation was that I was not alone; others experienced similar events and tragedies of losing friends and lovers. We consoled each other but in the process continued to traumatise each other by hearing each other’s stories. The devastation experienced by others in the “Free Fall” period had caught up with me.

In the early 1990s, I turned my distress into a productive force by actively seeking work with people with HIV; we knew what to call the virus by then. It was both a ‘blessing’ and a ‘curse’. It was a ‘blessing’ for I was constantly in the presence of people who were struggling with the effects of HIV and AIDS, and with the physical signs that revealed their HIV status, which elicited stigma, intolerance and prejudice. From my observation, the trials and tribulations of living with HIV served to make them resilient and to show that they were people with dignity and integrity. I learned a lot from them. It was a ‘curse’ for I was constantly in the presence of death: death of friends; death of colleagues; death of clients. I engaged in the macabre activity of looking through death notices in the gay and lesbian newspapers to find whether or not someone I knew had died in the preceding week. It was also at this time that I started to think about the question of how people make sense of their lives in their negotiation with impending death. This informed my work as a clinician in providing psychological support to people with HIV and AIDS. I remember visiting one client who was in an AIDS specific Sydney hospital ward in 1995, his death was imminent, his body was ravaged by AIDS-related conditions and I was there at his request to hear his story of how he made sense of his life. He was adamant he needed to tell his
story. It seems there is always a need for us to tell stories that help us to make sense of our lives to others, as well as to ourselves. I never forgot the insight I gained from this man.

2.4.3 “The High Hopes”

I remember in late 1996, at a staff meeting at the AIDS Council of New South Wales (ACON), where I was working at the time, the Treatment Officer informed the forum that there were these drugs, the protease inhibitors, which showed encouraging results when used to treat HIV, especially when used in combination with other drugs that were already available. I was excited but cynical. I had heard it all before. Fortunately, as time passed and more information was made available about these drugs, and the outcomes from using drugs in combination, my cynicism proved unwarranted and the social phenomenon of witnessing people recovering from AIDS-related conditions was novel and life changing. HIV was never to be the same again. The good news was ‘infectious’ and the prospect of eradicating HIV was deemed to be a possibility. Friends and colleagues who displayed signs of AIDS-related conditions recovered and resumed paid work. It was a very exciting time. Like many of my contemporaries, I was astonished that effective treatments for HIV materialised after more than ten years of witnessing the same grim script of infection-deterioration-death. The mid-1990s was described as a period of “High Hopes”, for the availability of these drugs and the practice of combining drugs had made it possible to treat HIV and AIDS effectively and successfully. Anti-HIV
treatments, ‘CD4’\(^7\), and ‘viral load’\(^8\) became parts of the HIV lexicon and constituted different HIV medical discourses from those of the “Free Fall” and “Slow Progress” periods.

The attention was now on pharmaceuticals, that is, how to develop more drugs, better drugs, more effective use of drugs which include planned or supervised treatment interruptions\(^9\) (Deeks & Hirschel, 2002; Hirschel, 2001). The enthusiasm of the period was palpable for after a decade of predicted fatality from HIV infection, the apparent linear disease progression could be disrupted, HIV could be treated strategically, and conceivably successfully. The discursive practices of living with HIV were dramatically reconstituted. The living with ‘death’ analogy was abandoned to make way for living with ‘life’. A number of attention grabbing headlines in both general and gay and lesbian specific newspapers in Australia captured the zeitgeist of this period.

“Super Optimism Replaces Early ‘90s Pessimism” (Sydney Morning Herald, 29.6.1996)

“Drugs Provide Hope On AIDS” (The Australian, 6.7.1996)

“Drug Mix Beats AIDS” (The Herald Sun, 10.7.1996)

\(^7\) The CD4 T-lymphocytes also known as CD4 cells or T-4 cells are a critical part of the immune system as they are also a central target of HIV. The CD4 count is a test to monitor the damage HIV has caused to the immune system. A high CD4 count indicates a healthy immune system; the ‘normal’ count for a healthy adult is between 500 and 1350. A count of less than 250 indicates significant immune system damage and the individual is at risk of opportunistic illnesses (Australian Federation of AIDS Organisation, 2003).

\(^8\) Viral loads or viral load assays measure the number of viral copies of HIV per millilitre of blood; a ‘copy’ is what HIV produces when it grows inside a cell (Australian Federation of AIDS Organisation, 2003). The higher the viral load, that is, more copies, the more virus. There are however no strict ranges that define ‘high’ or ‘low’ results (Clark, Maupin, & Hammer, 2004) but it is a guide to possible future damage to the immune system (Australian Federation of AIDS Organisation, 2003).

\(^9\) Treatment interruptions or ‘structured treatment breaks’ or ‘drug holidays’ (Australian Federation of AIDS Organisation, 2003) refer to the practice of stopping treatment use for reasons such as drug toxicity and adverse side effects (Volberding, 2003) or pregnancy (Buccheri et al., 2003) as well as a strategy to maximise the length of drug benefits by not using treatments continuously (Deeks & Hirschel, 2002). Treatment interruption as a medical practice is noteworthy as it signifies that HIV management is a long-term process (Baer & Roberts, 2002).
2.4.4 Disease Progression

At this juncture, I want to briefly describe the ‘disease progression’ as it was identified prior to the “High Hopes” period, for it gives context to the changes that have occurred. The disease progression denoted the stages of corporeal deterioration when HIV is unsuccessfully treated. HIV treatment advances have controlled the disease progression (Starace et al., 2002) by extending the length of the asymptomatic period, possibly for the individual’s lifetime (Clark et al., 2004). The capacity of treatments to disrupt disease progression means that the progression model is less pertinent in HIV discourses as compared with when HIV was ineffectively managed. In Australia, the use of treatments substantially slowed progression to AIDS and increased survival (P. Cunningham & Kelleher, 2001; McDonald et al., 1998; Starace et al., 2002). Moreover, by the use of treatments, individuals who previously had an AIDS defining illness would now be classed at a less severe stage of disease progression (Grierson, Misson, McDonald, Pitts, & O’Brien, 2002) as a corollary of achieving healthier clinical results. The disease progression model was premised on HIV infection being degenerative in that people were expected to progress through the stages until death with little backwards movement (Grierson et al., 2002). The stages were typically described as “transmission”, “acute syndrome”, “AIDS-related complex”, and “AIDS” (Lears & Alwood, 2000). Information distributed by the Australian Federation of AIDS Organisation (2003) delineated the stages as:
Stage 1: Primary infection: This stage reflects the initial infection, when the individual experiences a set of symptoms that are referred to as “seroconversion illness”. The unusual aspect of this stage is that not everyone who is infected with HIV will experience the symptoms associated with seroconversion illness, as some people do not have symptoms, and thus it can be a greater shock when they learn that they are infected with HIV.

Stage 2: Asymptomatic infection: This is the stage when the individual with HIV remains well and free from symptoms or illness.

Stage 3: Symptomatic illness: This stage reflects the progress HIV has made in diminishing the body’s ability to defend itself. The individual experiences a range of symptoms that would indicate a clear compromise to his or her immune system.

Stage 4: Advanced disease (AIDS): This is the stage when the individual has symptoms and there are indications that reflect a significant damage to the immune system by HIV. The symptoms experienced by people in this stage are severe and are at risk of opportunistic illnesses. These are common illnesses or infections to which most people are exposed, but are suppressed when their immune systems are healthy. In extreme situations where the immune system is significantly compromised, the common infections can be fatal.
2.4.5 “The Global Crisis”

Returning to my story, the hope which stemmed from the treatments was momentous, for it constructed HIV as a disease which could be treated. I was also excited and encouraged by the social changes. The hope and excitement was qualified by Sepkowitz’s last category in the HIV history, which he termed “Global Crisis”. HIV remains a threat in many parts of the world, and Sepkowitz (2001) not only regards it as a health concern but also as social and political concerns, for he argued that “by devastating a country’s entire population of young adults, AIDS now threatens the world’s security” (p.1767). In comparison with HIV as experienced in many other countries, particularly developing or resource-poor countries, the Australian experience of HIV in the 21st century, like the experiences of other developed or resource-rich countries, is remarkable; and it highlights the disparity between the developed and developing countries in terms of effective and available HIV treatment and management. The African continent, for example, is one part of the world where AIDS continues to be a major health crisis (Binswanger, 2003; Susman, 2003). An HIV diagnosis in many regions of sub-Saharan Africa, where two-thirds of all people with HIV and AIDS in the world live (Van Den Boom, Catalan, Hedge, Fishbein, & Sherr, 2006), continues to be tantamount to death, as delayed diagnosis undermines survival (Sandström & Birx, 2002). Anti-HIV treatment availability in Africa is an issue of concern (Attaran & Gillespie-White, 2001; Pauls Wohlgemut, 2002), as is in most of the developing countries where over ninety percent of the world’s population of people with HIV live, and where the celebrated treatments are not readily available to the majority of these people (Colebunders, Florence, Lynen, & Bouckenooghe, 2003; Desvarieux, Landman,
Liautaud, & Girard, 2005). Treatment availability issues on a global level are changing. The establishment of the Global Fund is a valuable resource in addressing the AIDS epidemic and the disparity between resource-rich and resource-poor countries (Hosseinipour, Kazembe, Sanne, & van der Horst, 2002). The endeavour of making treatments available to resource-poor countries is also demonstrated by the effort of the World Health Organisation’s “3 by 5 Initiative” that aimed to provide HIV treatments to 3 million people by 2005; an initiative that would provide treatments free of change through public healthcare institutions to people who could not afford treatments (Macklin, 2004). Furthermore, the challenge to patents for anti-HIV drugs as a possible constraint to treatment access has resulted in some governmental initiatives on patent exemptions for anti-HIV drugs (Ahmad, 2005; Tirelli, de Castro, & Awada, 2006).

The acknowledgement of the global context of HIV is important, for it challenged my understanding of issues confronting people living with HIV in this country, where effective treatments were available and accessible. Working as a psychologist in a clinical setting was a privilege because it afforded me the opportunity to gain insight into the everyday life of people with HIV. For after the initial excitement when effective treatments and their availability were accepted as the norm, from the late 1990s onwards and into the new millennium, some people presenting for counselling/psychotherapy surprised me for they expressed ambivalence or even indifference about the longevity extended to them resulting from the treatments. As much as they were grateful for the available treatments from which their corporeal health benefited, they also conveyed anxiety, concerns and dilemmas about having an extended life. I reacted to their ambivalence by recalling the friends and
colleagues who died and wished that treatments had been available to them. I felt slight resentment towards what some of my clients were articulating in our psychotherapeutic sessions. Fortunately, appropriate support from professional colleagues enabled me to continue to be respectful towards my clients through differentiating my own experiences and reactions from those of my clients. I became more aware of my subjectivity and how my experiences influenced the ways I made sense of the changes associated with living with HIV. My experience was different to the experiences of my clients who were confronting issues and circumstances for which they were not prepared.

In 1998, I completed an academic research project, using qualitative methodology, which examined the psychosocial implications of the treatments on people with HIV and AIDS (Wong, 1998). The research findings were consistent with the content of psychotherapeutic conversations I was having with clients at that time. Namely, there were everyday life issues which treatments could not resolve and these issues were constructed as difficulties and dilemmas by the participants of that research. It has been over eight years since I conducted and completed that research and the knowledge I have gained since that time has meant that my thinking about this same research topic, as well as the issues, have changed. In this context, and as noted in the research questions noted in Chapter One, I am now interested in how people with HIV make sense of their lives in the era of effective treatments, for these treatments have produced significant changes in their lived experiences.

The above account of my subjective experiences with HIV illustrated the impact that the anti-HIV treatments have had on the lives of people with HIV. It is apparent that
anti-HIV treatments have been effective but what this means requires clarification. What I want to examine in the following section is the manner in which these treatments are constructed as effective.

2.5  The ‘Miracle’ of Effective Anti-HIV Treatments

In this section of the chapter, I want to elaborate on the history of HIV treatments, and the advances that changed HIV management. There are a number of terms used in literature to denote the currently available anti-HIV treatments: ‘combination therapies’ (e.g., Kalichman, Ramachandran, & Ostrow, 1998); ‘antiretroviral\textsuperscript{10} drugs’ (ARV) (e.g., Visnegarwala et al., 2006), antiretroviral therapy (ART) (e.g., Huff, 2003; Pomerantz, 2001); Highly Active Anti-Retroviral Therapy (HAART) (e.g., Russell et al., 2003; Veinot et al., 2006); and idiomatically, the ‘drug cocktails’ (e.g., Zhang et al., 2003). In this thesis, I will either use the term anti-HIV treatments or simply, treatments. This account on treatments is not intended to be comprehensive but it is an opportunity to explain pertinent terminologies associated with HIV treatments and management. Furthermore, by elucidating the changes effected by the advances in HIV treatments, I will clarify how the currently available treatments have come to be constructed as ‘effective’ as well as to underscore the associate benefits and costs to their use. It is useful to note here also that treatment effectiveness is not the same as treatment efficacy. The difference is in the context.

\textsuperscript{10}The drugs are referred to as antiretrovirals because HIV is a retrovirus. A retrovirus replicates ‘backward’, and it has a unique enzyme, reverse transcriptase (from which the name retro comes) that copies the viral ribonucleic acid (RNA) into deoxyribonucleic acid (DNA). This process enables the viral genetic information to be inserted into the host cell chromosomes and uses their biochemical machinery to replicate itself (T. Cunningham, 1994). These replicant virus particles then infect other cells and this process continues until the infection is successfully treated by the immune system or the infection debilitates or kills the host making it susceptible to other infection, as is the case of HIV (Treichler, 1988b).
Treatment efficacy is asking the question ‘can the treatment work’, while effectiveness is asking ‘does the treatment work in practice, that is, in the everyday life’ (Haynes, 1999; Marley, 2000).

Zidovudine (AZT) was one of the earliest compounds tested as a possible treatment for the virus (Fischl et al., 1987), and in 1987, it became the first drug approved for the treatment of HIV infection (Weidle, Holmberg, & DeCock, 1999). According to Sepkowitz (2001), progress in drug research and development was very slow after AZT and the advances made were in prophylaxis against opportunistic infections as a means to avert rapid deterioration. The history of AZT has been well documented (see Ariss, 1997; Callen, 1990; Lauritsen, 1992; Rappoport, 1988; Sendziuk, 2003) and among the many issues these accounts raised, they highlighted the political struggles in making the drug available for people with HIV. The need for drugs to treat was central to AIDS political activism. AIDS activists played an integral role in demanding drug research and early access to medications for critically ill individuals (Gottlieb, 2001).

When AZT emerged in the mid 1980s and was regarded as a remedy to the AIDS crisis, it was billed as a “new miracle drug” (Sendziuk, 2003, p.209). The supply of AZT to people with HIV was hindered by governmental funding, and when it was supplied to people, it was only within a clinical trial context (Ariss, 1997; Sendziuk, 2003). Large-scale clinical trials were established to test its toxicity and efficacy, and the initial results were promising, for AZT use had been shown to decrease mortality and opportunistic infections for some people with HIV (Fischl et al., 1987).

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11 AZT was first developed as a cancer treatment in 1964 but it was abandoned after it shown to be ineffective.
However, these encouraging outcomes were countered by cautions about its toxicity and concerns about its long-term use and effectiveness (Richman et al., 1987). In spite of noted cautions and concerns, it was demanded that AZT be made available for anyone infected with HIV by political groups such as ACT-UP (AIDS Coalition to Unleash Power)\textsuperscript{12}. This demand for its accessibility was the flashpoint of political struggles for people with HIV against the medical bureaucracy (Ariss, 1997; Vaillancourt Rosenau & Thoer, 1996). Notwithstanding the political struggles that eventually led to its availability, AZT was regarded in HIV history as a drug that caused more damage than it remedied due to its toxicity and poisonous effects on the health of individuals who used it (Callen, 1990; Lauritsen, 1992; Rofes, 1998). Not only did AZT fail to fulfil the promise of it being the “miracle drug” but the AZT saga was positioned as a situation to which people refer when making sense of their fear, caution, scepticism and resistance to treatment use.

Since AZT, the changes effected by the advances in scientific development and medical advancement in the treatment of HIV have been dramatic and monumental. The understanding of the virus and its working in the material body has led to increased knowledge, and improved pharmacological treatments for the virus. The mid-1990s was the major turning point in the history of HIV in terms of medical management and treatment. Carpenter et al. (1996) noted four major medico-scientific advances which improved HIV management and treatment; these advances were: 1) a better understanding of the replication kinetics of HIV throughout all stages of disease; 2) the development of assays to determine the viral load in individual patients; 3) the availability of several new effective drugs; and 4) the

\textsuperscript{12} A grass-roots group originated in New York in 1987 comprised of gay men to fight against the AIDS crisis and to politicise treatment access issues for people with HIV.
demonstration that combination therapy is more effective than monotherapy. These advances were crucial for they were the bases on which innovative ways of treating HIV were developed which until then had not been possible or considered. In developed countries, the availability of effective drugs and the commonly accepted clinical practice of combination therapies have resulted in a significant increase in the number of people who are long-term survivors (Shernoff, 1999) and the treatments have been credited for the decline in AIDS-related deaths (Thomas, 1999). More importantly, the results from these ways of treating HIV confirmed the view that the disease could be medically managed successfully and shifted the emphasis from preparing people with HIV and AIDS to die, to preparing them to live (Westburg & Guindon, 2004). The shift in the discursive construction of HIV living through treatments, that is, from dying to living, positioned people infected as having being brought back from near-death (Persson, 2004; Wheeler & Shernoff, 1999) and thus were given a ‘second life’ (Rabkin & Ferrando, 1997). People who returned from near-death were called the ‘Lazaruses’ (Rofes, 1998), and the phenomenon was referred to as the ‘Lazarus syndrome’ in news media (e.g., France, 1998) and in academic literature (Demmer, 2000; Gregonis, 1997; Gushue & Brazaitis, 2003; Sowell, Phillips, & Grier, 1998). The use of the biblical figure, Lazarus who was raised from the dead, accentuated the dramatic positive changes in the corporeal health of people who were facing imminent death due to life-threatening illnesses. Just as Lazarus’ resurrection was, in biblical terms, a miracle, the treatments were socially constructed as the ‘miracle’ that stemmed the number of deaths and reduced the corporeal anguish frequently witnessed.
The emphasis on pharmacological interventions is not new, as medications were regarded as the means by which the disease was to be treated since the “Free Fall” and “Slow Progress” periods (e.g., Palmer, 2003). However, consistent effective treatments for HIV have only been relatively recent. Until the “High Hopes” period, the practice of sequential ‘mono-therapy’ – the use of one drug at a time, was an accepted treatment approach (Jones & Loewenthal, 1994; Palmer, 2003) but its effectiveness was limited (Australian Federation of AIDS Organisation, 2003).

Initially, there was only one class of drug for HIV treatment, which was called nucleoside analogue reverse transcriptase inhibitors (NARTIs) or nucleoside reverse transcriptase inhibitors. When more NARTIs were developed, the practice of ‘dual therapy’ became widely used from 1992 (Ives, Gazzard, & Easterbrook, 2001), thus establishing the practice of using more than one drug in one treatment regime.

Different classes of drugs were developed after the NARTIs, they were the non-nucleoside reverse-transcriptase inhibitors (NNRTIs) and the protease inhibitors (PIs). Currently, there are five classes of drugs available in Australia. The additional classes are nucleotide reverse transcriptase inhibitors and fusion inhibitors (Post & Kelly, 2005). The development of the PIs, in particular, was vital in altering HIV treatment. Its emergence was venerated as the “Protease Moment” (Rofes, 1998, p.29) in HIV discourses. The “protease moment” refers to the period of the mid 1990s when the unprecedented results occasioned by the use of protease inhibitors were reported widely. Rofes (1998) suggested that it was the “period when all social and cultural changes in our experiences of the AIDS epidemic were explained in light of the new therapies, or ‘the cocktails’” (p.29).

13 The nucleoside reverse transcriptase inhibitors and the nucleotide reverse transcriptase inhibitors are regarded the same (Clark et al., 2004; Post & Kelly, 2005); although the drugs differ chemically, they work on the reverse transcriptase enzyme (Clark et al., 2004).
The introduction of PIs was important as they were used in combination with other drug classes that reduced viral loads (Lucas, Chaisson, & Moore, 1999; Treisman & Kaplin, 2002), increased CD4 counts, and improved immune function (Behrens, Meyer-Olsen, Stoll, & Schmidt, 2003; Treisman & Kaplin, 2002), which led to a reduction of AIDS diagnoses (Ives et al., 2001) and hospital in-patient care (King, 1997). The aim of treatments is viral suppression and to achieve an ‘undetectable\textsuperscript{14}’ viral load (Race, 2001). Research into treatment usage supported combining different drug classes, that is, combination therapy, as more effective than mono-therapy (Hammer et al., 1996; Saravolatz et al., 1996) as each class of drugs attacks HIV at different stages of its replication in the body after infection\textsuperscript{15}. This treatment approach is constructed as ‘effective’, for when used in the everyday life, it is able to reduce the virus to undetectable levels in the blood, to prevent opportunistic infections, which mean people are less likely to present with the physical indicators of HIV infection. In this context, the treatments have made HIV less visible (Persson, 2005). Anti-HIV treatments, or HAART\textsuperscript{16} and the other terms used in literature as noted earlier, constituted different HIV medical discourses which shaped HIV and AIDS as a chronic disease and illness (Baer & Roberts, 2002; Cooper et al., 2002; Hoffmann & Jaeger, 2001; Land & Hudson, 2002; Martínez et al., 2001; Selwyn & Forstein, 2003; Siegel & Lekas, 2002).

\textsuperscript{14} An undetectable reading means that the amount of HIV in the blood is too low to be detected by the test (Henderson, 1997). The sensitivity of current viral load assay is to 50 copies per millilitre of blood; a number less than 50 cannot be accurately identified. Undetectable does not mean the absence or eradication of HIV from the body. Although an undetectable status is coveted, its meaning is socially complex for it affects sexual negotiations and lifestyles (Race, 2001).

\textsuperscript{15} The nucleoside/tide reverse transcriptase inhibitors are faulty versions of building blocks that HIV needs in its replication; this class of drugs stall the replication process. The NNRTIs, which have a similar action to the previous class of drugs but they bind to and disable the reverse transcriptase enzyme, which is a protein needed by HIV to make more copies of itself. The PIs disable the protease enzyme, another type of protein needed for HIV replication. The fusion inhibitors work by blocking HIV entry into human cells (AIDS Info, September 2005; Palmer, 2003).
Living with HIV and AIDS as a chronic disease and illness could be argued as an encouraging and affirming experience when compared with the destructive and mortal consequences embedded in the early years when treatments were less effective. However, there are implications associated with living with a disease for which there is no cure and survival is dependent on treatment use. In the following section, I will examine these implications and the effects that they have on the everyday lives of people with HIV.

2.6 The Implications of Living with HIV and AIDS as a Chronic Disease and Illness

The construction of AIDS as a chronic illness is not a recent phenomenon (see Fee & Fox, 1992). The term ‘chronic illness’ was used as early as 1991 (Siegel & Krauss, 1991; Siegel & Lekas, 2002) in reference to some people with HIV and AIDS who lived longer than expected, and were therefore positioned as people living with a chronic illness. The difference I consider to be most salient in delineating the construction of HIV and AIDS as a chronic disease and illness since effective treatments is that the individual’s corporeal health can now be improved and maintained strategically, which is in stark contrast to the “Slow Progress” period when treatments were less effective and survival was improbable. More pertinently, living with HIV is now positioned as a long-term proposition, a probability rather than an exception. The construction of HIV as a chronic disease is supported by the decline of AIDS defining illness (Hoffmann & Jaeger, 2001) and the observation that people with HIV are living longer (Ezzy, De Visser, Grubb, & McConachy, 1998).

16 HAART is typified by a combination of at least three drugs in the treatment regime (Carpenter et al., 2000; A. Carr & Cooper, 2000).
This should not be taken to mean that AIDS-related mortality ceases to be a constituent of HIV discourses, but that people living with HIV “can realistically hope for longer and better quality lives” (Gerbert, Bronstone, Clanon, Abercrombie, & Bangsberg, 2000, p.410).

Many published research papers begin their introductions into their respective topics by noting that advances made in treatments have reduced morbidity and mortality (e.g., Brinkman, Smeitink, Romijn, & Reiss, 1999; Hirschel, 2001; Powderly, 2002; Pulvirenti et al., 2003; Rathbun, Lockhart, & Stephens, 2006; Saint-Marc et al., 1999; Schönnesson, 2002; Thorner & Rosenberg, 2003; Weiss et al., 2003), which suggest that people are living ‘healthier’ lives. There is support for the view that mortality from HIV and AIDS related illnesses has decreased and been maintained since the availability of effective treatments (Mocroft et al., 2003; Morris, Masur, & Huang, 2006). This is good news, but we need to question whether or not people are living unproblematic, healthier lives given they have to negotiate the complexities embedded in living with HIV in the era of effective treatments that can be challenging and worrying. These complexities include treatment use (Gold, Hinchy, & Batrouney, 2000; Gold & Ridge, 2001), treatments complications (Baer & Roberts, 2002; Fogerty et al., 2003), possible treatment failure (Grierson et al., 2002; Grierson, Thorpe, Saunders, & Pitts, 2004), HIV-related fatigue17 (Barroso, 2002), future planning including resumption of paid work (Maticka-Tyndale, Adam, & Cohen, 2002; Nixon & Renwick, 2003), the quality of lived experiences and

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17 According to Barroso (2002), HIV-related fatigue is the most common symptom reported by people with HIV and their health care providers. It has been associated with functional limitation and diminished survival.
existential issues (Schönnesson, 2002), and the need for regular monitoring and supportive care to reduce the degree of illness (Chou, Holzemer, Portillo, & Slaughter, 2004). From this position, I suggest the reduction in morbidity, as noted in the above literature, is a claim made within the limits of the clinical indicators, and the claim marginalises the struggles and concerns that are located in the social and psychological sphere. I am informed by Basu (2004), who in his examination of medical advances in the treatment of diseases and illnesses argued that a corollary of the inordinate focus on symptom control through treatments, is that the patient as an individual is neglected and “[a]s a result, years have been added to the life of the patient who would not have lived otherwise, but, paradoxically, the patient might have felt that those added years were not really worth living!” (p.35).

2.6.1 The Privileging of Clinical Markers

“The care provided to patients does not always meet patients’ expectations, in particular in the course of serious illness…Physicians may also pay more attention to objective clinical findings than to subjective reports of symptoms experienced by their patients.” (Fontaine, Larue, & Lassauniere, 1999, p.263)

Living with HIV as a chronic disease has meant that results from clinical indicators such as viral load assays and CD4 counts assumed prominence in the assessment of care provision and health. The viral load assay, for example, is regarded as a vital surveillance device by which the prognosis of the individual and the effectiveness of the combination therapy are ascertained (Ho, 1996). The viral load assay and the CD4 count are privileged in HIV medical discourses, for they provide empirical evidence and tangibility to health. However, Selwyn and Arnold (1998) cautioned, “a new temptation has emerged to dwell on quantitative aspects of HIV management
and monitoring” (p.899). The quantification of health disembodies the individual by privileging the numerical indicators, for health is signified by the amount of virus in the blood, and the number of CD4 cells. The health of people with HIV is thus reconfigured as a pharmaceutical relation (Mykhalovskiy, McCoy, & Bresalier, 2003). The privileging of the clinical indicators produces an emphasis on treatment combinations and treating the numbers. Selwyn and Arnold (1998) argued that the “medicalisation of AIDS” has reduced the complexity of living with AIDS to a causal relation between disease and treatments and obscured the lived experiences in which HIV infection continues to be expressed. Moreover, despite its effectiveness against HIV, combination therapy has not alleviated uncertainties embedded in the social construction of HIV, and suffering continues to be experienced by people who have a chronic illness regardless of treatment availability or efficacy (Charmaz, 1999; Frank, 1995, 2001; Öhman, Söderberg, & Lundman, 2003), and this also include people with HIV (Hall, 2003). From this perspective, the notion of health, as medico-scientifically constructed, is confined to the corporeal, and there can be a vast difference between ‘feeling good’, a subjective experience, and having ‘good results’, as indicated by the clinical markers. This difference underpins the question of whether or not people’s lived experiences have improved since the availability of effective treatments.

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18 The use of ‘suffering’ in the context of illness experiences has been problematised, for it is argued that there is an absence of a solid conceptual foundation for exploration of this phenomenon (Rodgers & Cowles, 1997), and what it means to ‘suffer’ (Cassell, 1999). The manner in which ‘suffering’ is employed here is that it is a descriptor with which to account for a subjective experience with HIV.
2.6.2 Treatment Doubts, Uncertainties, Concerns & Side Effects

I want to clarify the tension between ‘feeling good’ and having ‘good results’ as produced by treatment use, for I suggest this is crucial in exploring the ways in which people with HIV make sense of and socially construct their lived experiences. ‘Good results’ cannot be viewed in isolation from the lived experiences as the results need to be considered within the context of whether or not the value of the lived experiences is undermined by adverse treatment side effects.

The assurance produced by the initial results from treatment use is now mitigated by concerns, uncertainties and doubts associated with their use, which has produced a questioning of the privileged status of treatments. Achieving ‘good results’ from treatment use does not inevitably lead to ‘feeling good’ because possible adverse side effects and drug toxicity are associated with all the classes of HIV drugs (A. Carr & Cooper, 2000; Dedieu et al., 2001; Emery & Cooper, 2002; Hsieh, Hung, Lu, Chen, & Chang, 2000). Holzemer (2002) in his aptly titled paper “The Symptom Experience: What cell counts and viral loads won’t tell you” affirmed that despite the improvement in corporeal health as indicated by t-cell count and viral load assay, “values that have taken for years to be indicators of…wellbeing” (p.48), they do not reflect the subjective experience of living with HIV, and more disturbingly, do not take into account the adverse side effects from the treatments. A report produced by The National Centre in HIV Social Research in Sydney (Prestage et al., 2001) found that a majority of people in their research experienced side effects from the use of the treatments, with a quarter of people rating these side effects as severe. The weighing of adverse treatment side effects against treatment benefits has been an important
issue and a troubling dilemma in HIV discourses. The older HIV drugs have known side effects, which include fatigue, headache, insomnia, malaise, nausea, diarrhoea, pancreatitis, peripheral neuropathy, rash and vomiting (Jones & Loewenthal, 1994). The newer ones have not allayed uncertainties and concerns pertaining to adverse side effects for they have been identified as causing lipodystrophy\(^\text{19}\) (Bonfanti et al., 2000; A. Martin et al., 2004; Saint-Marc et al., 1999; Shikuma et al., 2001), which in turn is linked to incidences of cardiovascular disease in people with HIV (Behrens et al., 2003; Leen, 2003). The newer drugs are also associated with hepatotoxicity\(^\text{20}\) (Abrescia et al., 2005; Ena, Amador, Benito, Fenoll, & Pasquau, 2003; Martínez et al., 2001), the aggravation of existing hepatic-disease (Bonfanti et al., 2000; Rodríguez-Rosado, Perez-Olmeda, Garca-Samaniego, & Soriano, 2001) and abnormal liver function (Kawsar & El-Gadi, 2002). The use of PIs as part of the combination therapy is identified to cause nausea, vomiting, diarrhoea, weakness, altered taste and gout (Kawsar & El-Gadi, 2002), as well as sexual dysfunction (Lamba, Goldmeier, Mackie, & Scullard, 2004). Sensory impairment such as hearing loss (Reynolds & Garske, 2001), and adverse psychological side effects include psychiatric syndromes, delirium, seizures and cognitive impairment (Treisman & Kaplin, 2002) are also attributed to treatment use. More significantly, just as the treatments were able to reduce the physical indicators of HIV infection as

\(^{19}\) Lipodystrophy refers to the body shape changes that appear to be associated with anti-HIV treatments (Clark et al., 2004); it denotes conditions such as peripheral lipoatrophy, central fat accumulation and lipomata (A. Carr et al., 2002).

\(^{20}\) Hepatotoxicity refers to damage caused to the liver as a result of chemical use, such as side effects from medications.
noted previously, some side effects, such as lipodystrophy or lipoatrophy, have made the disease visible again by producing a body shape that is now known to be a result from HIV treatment use (Persson, 2005).

The listing of identified adverse side effects is to illuminate the paradox associated with treatment use and to make clear that achieving ‘good results’ as determined by the viral load assay and CD4 count does not always correlate with ‘feeling good’. The paradox is made most visible when the currently available drugs have potentially life-threatening side effects (Jain, Clark, Diaz-Linares, & Grim, 2006; Powderly, 2002; Shibuyama et al., 2006). This paradox places the question of treatment success at the centre and challenges the privileging of treatments in HIV medical discourses. The term ‘effective’ needs to be interrogated, for it could be interpreted in a number of ways. One interpretation that is most salient is whether or not ‘effective’ implies that treatments enable people to have lived experiences which are subjectively valued. I suggest that for many people, averting probable death from HIV infection is valued but at what costs? I want to present passages from Ross’ story about his subjective experiences with treatment side effects which he wittily titled “Snide Effects” (Duffin, 2003, p.25-26). Ross is an HIV educator and his story was in a journal published by the Australian Federation of AIDS Organisation which is the peak non-government organisation representing Australia’s community-based response to HIV and AIDS. The story is in part humorous but mainly provocative in its illustration and problematisation of the benefits from treatment use as shaped by HIV medical discourses. Ross’ story is important for it encapsulates the subjective

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21 Lipoatrophy refers to fat loss. However, it is unclear whether or not lipodystrophy and lipoatrophy are two separate phenomena but one theory suggests that the protease inhibitors contribute to lipodystrophy, and the nucleoside analogues contribute to lipoatrophy (Persson, 2005).
lived experiences relating to treatment use that are often placed on the margins in the examination of treatment effectiveness.

Six weeks ago I was one of those people with HIV who got the rare side effect of lactic acidosis. This condition is often fatal. It was my first HIV-drug-related ‘potentially fatal’ experience. HIV-related illnesses aren’t so common anymore. HIV-drug-related illnesses are. They are politely called side effects – yet strangely with the important word ‘drug’ omitted. A side issue. Not the main game. Yet living with HIV and HIV treatments is, for many of us, mainly about side effects.

As a result of lactic acidosis I am off all my HIV drugs. And I feel fantastic. No wonder treatments breaks have been described as addictive. Not only has the “chemical fog” of my treatments regimen lifted, but I don’t have the shits anymore … By ‘chemical fog’ I mean that vague not well defined feeling of being on ‘drugs’. My impression is that this is the great undocumented side effect of HIV drugs but because neurological (or psychological?) side effects are not well defined and are vague, subjective and hard to objectively measure, well they don’t really happen do they? Mind you, most people with HIV I know with some experience on HAART talk about these ‘mind’ side effects in different ways.

And as for the shits – well they really shit me. If you’ve known the indignity of considering nappies in your forties, of getting half way between home and work and experiencing ‘that feeling’, of the wonderful stench and the gorgeous feel of having to sit on it. You only realise how much it affects your life until it is not there –

22 Lactic acidosis is an increase in blood acid level; people with this side effect may have nausea, vomiting and stomach pain and their blood may show an inflamed liver and a high level of acid (Clark et al., 2004).
and you once again get to luxuriate at the thrill of a solid pooh - and how satisfying they are.

Experiencing a life-threatening side effect certainly changes how you feel about swallowing antivirals … So even though the last three months of my life have been occupied by a HIV-drug-related-illness … I know I am going back on antivirals sooner rather than later. This is because I know what untreated HIV disease looks like. There’s nothing like a shingles attack or an episode of bacterial pneumonia to remind you of the consequences of not treating HIV in the longer term. And there’s no better motivator for taking your HIV pills and complying with your dosing schedule than experiencing HIV-related illness.

Almost every person with HIV has heard the stories of people with HIV trying to raise side effect problems with their doctor, only to be quickly told ‘yes but think how good your laboratory results are’. I’ve never experienced anything close to this story and maybe that story is somewhat mythical. But HIV drug-related side effects have usually been posited against the actual experience of HIV disease – i.e. the side effects may indeed be bad - but – they are sooo much better than HIV disease. There’s been a tendency sometimes not to acknowledge them – unless they are impacting on adherence. Yet as memory of what actual HIV disease looks like fades, and as experience with side effects increases, then side effects become primary…and will no longer be so easily dismissed as ‘not nearly as bad as HIV disease’.

Ross’ story is enlightening and profound for it epitomises the lived experiences that medical research literatures on HIV treatment efficacy rarely place at the centre of their inquiries. Adverse side effects are acknowledged, but as Ross suggested, they are situated within the context of treatment adherence. Ross reinforced the
marginalising of subjective experiences by describing the indignity and misery brought about by having to consider “nappies in your forties” and the “chemical fog” which he argued “is the great undocumented side effect of HIV drugs but because neurological (or psychological?) side effects are not well defined and are vague, subjective and hard to objectively measure, well they don’t really happen do they?”

The challenge presented by Ross embodies the ‘invisible’ difficulties that pervade the range of lived experiences which constitute a life. The paradox of living with HIV in a treatment privileged era is exemplified by Ross who made clear of his preparation to resume treatments even though he felt “fantastic” when he stopped using them.

The positioning of “HIV drug-related side effects” against the “actual experience of HIV disease” could be interpreted as an act of assessment; an assessment which requires individuals to consider whether or not tolerating side effects from treatments against HIV is preferable to being vulnerable to the disease and its destructive consequences. From this perspective, the dilemma embedded in treatment use is that its use, which could prolong survival, could also detract from the experience of ‘feeling good’. The costs and health implications of using treatments to achieve ‘good results’ are noted by Morris, Masur and Huang (2006) who found that people with HIV are now more likely to be presenting at hospital intensive care units with conditions related to the use of the treatments such as drug toxicity, a situation they referred to as “ART (antiretroviral therapy)-associated diagnoses” (p.43). This is a disturbing situation as some people with HIV who are using treatments are being hospitalised, not due to HIV-related illnesses but due to treatment-related illnesses. The treatments for HIV have themselves thus become the causes of health problems.
Ross’ declaration that “living with HIV and HIV treatments is, for many of us, mainly about side effects” could be interpreted as a situation where the attention is on medical technologies and the associated consequences, which means that individuals are still living with discomfort, and continuing to suffer despite improved management and treatment of HIV. This issue is made explicit by the Immune Reconstitution Inflammatory Syndrome (IRIS) which is noted as one of the ART-associated diagnoses for which medical treatments are required (Morris et al., 2006). IRIS refers to inflammatory reactions caused by immune response to pre-existing or sub-clinical infections following restoration of the immune system by treatments (Couppié et al., 2004; French et al., 2000; Shelburne, Darcourt et al., 2005; Shelburne, Visnegarwala et al., 2005). The experience of IRIS is paradoxical to advances in HIV treatments, for the inflammation and subsequent physical distress are associated with the improvement in the immune system as indicated by viral suppression and an increase in CD4 cells. From this perspective, IRIS symbolises the troubling discrepancy between the subjective experience and the clinical indicators in living with HIV in the era of effective treatments.

In this chapter thus far, I have suggested that in spite of the benefits produced by the treatments in managing HIV and the usefulness of the clinical indicators, the treatments and clinical indicators do not necessarily reflect the subjective experience of ‘feeling good’. In the next section of this chapter, I want to examine the subjective experience of living with HIV within the frame of ‘quality of life’. As suggested by Ross in his story “Snide Effects”, living with HIV in the era of effective treatments is about living with adverse side effects. In spite of the buoyancy produced by restored health based on the clinical markers, issues pertaining to treatment doubts,
uncertainties, concerns and side effects as previously discussed, continue to be issues people are required to negotiate, and issues that could diminish their ‘quality of life’.

2.7 Quality of Life and HIV Living

There is a large body of research into ‘quality of life’ issues for people with HIV (e.g., Aranda-Naranjo, 2004; Friedland, Renwick, & McColl, 1996; Holzemer & Wilson, 1995). It has been used in research pertaining to treatment use (Brecht, Breitbart, Galietta, Krivo, & Rosenfeld, 2001; Mannheimer et al., 2005), side effects from treatment use (Bakken Henry, Holzemer, Weaver, & Stotts, 1999; Nicholas, Kirksey, Corless, & Kemppainen, 2005), and mental health issues relating to HIV infection (Lechner et al., 2003; Maldonado et al., 2003). The availability of this body of research suggests ‘quality of life’ is an important and pertinent concept when investigating the effects of HIV and its treatments on lived experiences.

The observed changes in HIV and AIDS related morbidity and mortality in the last decade has produced a view of people with HIV as being able to lead normal lives (Gregonis, 1997; Hirschel, 2001; Maticka-Tyndale et al., 2002). The provision of health care has altered from a palliative care approach that aimed to give comfort, to one that aimed towards normalising life (Davis, 2004). The normalising of HIV infection and the notion that living with HIV is less complicated are reflected in the presumption that the ‘quality of life’ of people with HIV has improved as an outcome from the use of HIV treatments (Cooper et al., 2002; W. E. Cunningham, Crystal, Bozzette, & Hays, 2005; Mannheimer et al., 2005; D. J. Martin, Brooks, Ortiz, & Veniegas, 2003; Phaladze et al., 2005). However, the difficulties embedded
in the practical aspects of treatment use noted in Chapter One and the range of possible adverse side effects noted in this chapter, have the potentiality to diminish ‘quality of life’ as subjectively constituted. The difficult treatment regimes to which individuals are expected to adapt is an added pressure to what is already a challenging situation of living with an incurable disease. So has ‘quality of life’ improved as a result of a decrease in mortal threat or an increase in health levels as indicated by clinical markers such as the t-cell count and the viral load? What about concerns such as: HIV-related stigma, which continues to be experienced by those infected as indicated by recent research (Brown, Macintyre, & Trujillo, 2003; R. L. Carr & Gramling, 2004; Cree, 2004; Poindexter, 2004); the need for people to hide their HIV status from others and the effect of this in the everyday experiences and their subjectivities (Chandra, Deepthivarma, Jairam, & Thomas, 2003; Charmaz, 2002); and the acknowledged detrimental consequences of treatment side effects (e.g., Baer & Roberts, 2002)? From this perspective, despite their capacity to produce ‘good health’ as indicated by the clinical markers, I question whether or not the ‘quality of life’ of people with HIV has improved as an outcome from effective treatment interventions. This is an important question, for Grierson et al. (2002) suggested that people with HIV are having to balance “the (side) effects of treatments against quality of life” (p. xvii, my italic). I am not denying the encouraging and optimistic changes produced by advances in HIV medical sciences; however, I am challenging the unproblematic use of the ‘quality of life’ concept with which to discern the changes effected by the treatments. It is on this basis that I contend that the concept has been narrowly defined which undermines its significance when deployed as a device with which to explore, and to assess, the
overall lived experiences. I will briefly examine issues which contributed to the confusion in its definition and to its narrow usage.

2.7.1 Quality of Life: Conceptual and Definitional Issues

‘Quality of life’ has been used in a wide range of contexts and has become a significant consideration specifically in health care (Meeberg, 1993). Although the concept is often used, its definition is either absent (Farquhar, 1995; Schipper, Clinch, & Powell, 1990), infrequently defined (Calman, 1984, 1987; Haas, 1999) or confusingly, there are numerous but inconsistent definitions (Farquhar, 1995). Consequently, there is not a consensual definition (Hunt, 1997; Katschnig, 1997; Lutgendorf, Antoni, Schneiderman, Ironson, & Fletcher, 1995). In HIV clinical settings, Schönnesson (2002) argued, the definition of ‘quality of life’ is limited to aspects of life directly affected by health status. Hence, ‘quality of life’ is regarded as health-related quality of life (Wu, 2000) and is used as an outcome measure in clinical trials for medication and healthcare interventions (Holmes, 2005; Rosenberg, 1995; Schönnesson, 2002). As a result of this approach to the concept, the subjective evaluation of wellbeing independent of health status is marginalised. An explanation which might account for the delineation of health status from ‘quality of life’ is that ‘quality of life’, as a theoretical concept, is not regarded as an empirical entity. Its abstractness invoked the preference by researchers and clinicians for the “far less existential concept” of health-related quality of life (Robinson, 2004, p.14S), which reflects what Rosenberg (1995) described as a pragmatic approach. This pragmatic approach is problematic, for it devalues the complexity of what ‘quality of life’ as a concept aims to elucidate. Differentiating and privileging aspects of lived
experiences into those that are measurable and quantifiable while marginalising the ‘existential’ aspects, for they are difficult to incorporate into a quantitative paradigm, weaken the philosophical underpinnings of the concept.

The reification of ‘quality of life’ is inappropriate and problematic. My assertion against its reification is reinforced by a suggestion made by Rotheram-Borus et al. (2001) who, in their research into ‘quality of life’ issues for young people with HIV, stressed that “[q]uality of life may play a crucial role in influencing positive health behaviors and reducing or eliminating risk behaviors” (p.227). I found this use of the concept disconcerting, for it implies that ‘quality of life’ as a humanist concept is manifested as a tool by which behaviours of people with HIV are regulated, so that they are expected to attain the desired ‘quality of life’ as externally constructed. The reification of the concept becomes a useful resource for health care professionals to encourage the use of or to endorse certain forms of treatments to their patients. From this perspective, the concept ‘quality of life’ is made problematic when it is constructed as the reason for and an outcome from treatment use. The problematic usage of ‘quality of life’ is illustrated by Halkitis et al.(2005) in which they claimed that while their investigation found that treatment use did affect ‘quality of life’, and this varied from one individual to another, they could not account for this variation. They surmised that their research finding could be related to personality traits for they argued that it has been “suggested that personality traits may be associated with HIV-specific quality of life, and that HIV-specific quality of life may be impacted by HAART (Highly Active Anti-Retroviral Treatments)” and advocated for future research to “disentangle person-level characteristics that may predispose individuals to the type of experience that they encounter while on HAART” (p.354).
Conclusions drawn from this research are provocative, for they positioned subjective dissatisfaction with ‘quality of life’ resulting from treatment use as being related to “person-level characteristics” that need to be “disentangle(d)”, which could be interpreted as an act of problematising the individual. Moreover, I would argue the researchers’ inability to account for individual variation is associated with the absence of an articulated definition for ‘quality of life’ in their research. In spite of the absence of a definition, there appear to be an assumed understanding of ‘quality of life’ implicit in their analysis.

The researcher or clinician centred approach to the defining of ‘quality of life’ and its use as a research topic is typified by the assertion made by Elkinton (1966) who suggested that “what constitutes this quality of life for a particular patient and the therapeutic pathway to it often is extremely difficult to judge and must lie with the conscience of the physician” (p.713); it is a situation described by Holmes (2005) as what the researcher or clinician wants ‘quality of life’ to be. The privileging of the medical gaze is questionable, for it not only assumes that it is through this gaze that ‘quality of life’ is realised but also the “conscience of the physician” implies the presence of a moral imperative determined by the physician towards which the patient has to strive. It could be argued that much has changed since Elkinton’s article was published, but recent articles such as Basu (2004) have argued otherwise. He suggested that the advances in medical science have neglected the individual, as a person, in the quest to control diseases by emphasising symptom treatment and management. The neglect of the individual has produced a paradox in medical interventions in treating diseases and health conditions, that is, survival is assured but the lived experience of the individual is compromised. The issues identified by Basu
are informing, for they make visible the negotiation that is necessary when the individual is having to construct a life(style) that is worth living in the context of needing to take treatments that, conversely, could also undermine the desired life(style).

As I have outlined above, defining ‘quality of life’ is complex. Hunt (1997) argued against the medicalising of ‘quality of life’ by suggesting that if the concept were to have a meaning, it would be “rooted in existentialism, the values of the individual and the fluid dynamics of human attempts to cope with the exigencies of life” (p.209). I embrace this ‘fluidity’ in its conceptualisation for it is its conceptual flexibility which offers a wider scope in terms of how life’s meanings are constructed. Prutkin and Feinstein (2002) argued that “quality of life is a state of mind, not a state of health” (p.79). This is a useful reading as it locates the significance of the concept in the individual’s interpretation, which is unique to that individual and which could not be understood unless the individual has the opportunity to give meaning to his/her lived experiences.

In the next section, I want to shift my attention from definitional issues pertaining to ‘quality of life’ to the meaning embedded in the concept. The purpose for doing so is that the concept ‘quality of life’ could be a useful discursive device with which to explore lived experiences, particularly in the context of an illness experience. However, the absence of a consensual definition would suggest that its meaning is open to subjective interpretation, and the endeavour to locate a precise definition could be less productive than if the meanings embedded in the concept are explored. The facility for the concept to be subjectively interpreted and constituted is valuable,
for this enables individuals to make sense of their experiences in ways that are subjectively meaningful. What I want to do next is to explore the ‘meaningfulness’ of the concept of ‘quality of life’, for it is in its subjectively constituted meanings that a way forward in understanding individual lived experiences can be found.

2.7.2 The Meaningfulness of Quality of Life

“[F]ocus on meaning, understanding and interpretation might guarantee that an exponential growth of medical technology does not lead to an unwarranted dehumanizing practice.” (Rosenberg, 1995, p.1414)

Based on the above examination of ‘quality of life’, I would argue that the activity of defining ‘quality of life’ needs to be shifted from the perspective of what ‘quality of life’ is to one that concerns with the what does it mean subjectively, for it is the subjective constructed and ascribed meanings of ‘quality of life’ that are more useful in the understanding of individual lived experiences than using the concept as a tool to assess outcomes from treatment interventions. According to Cottingham (2003), meaningfulness is a concept which refers to the notion that in order for “something to be meaningful to a (sic) agent, that agent must interpret it or construe it in a certain way” (p.22, italic original). Research has shown (Aller & Van Ess Coeling, 1995; Boswell, Dawson, & Heininger, 1998) that when individuals are invited to speak about their interpretations of ‘quality of life’, and are positioned as experts of their experiences whose knowledge is privileged, a deeper and richer understanding of what ‘quality of life’ might mean to the participants could be found. It is as Boswell et al.(1998) argued, “quality of life means different things to different people at different times in life” (p. 31). The multiple and varied meanings to which ‘quality of life’ is ascribed are more likely to emerge from an intersubjective exploration of the
concept than participants complying to established methodological practices, such as by filling in questionnaires or completing rating scales. For example, Aller and Van Ess Coeling (1995) found that by speaking with their research participants, they found that “caring for oneself” and “helping others” (p.24) contributed to what ‘quality of life’ means to their research participants, and claimed that their findings were not previously identified in the literature.

In this context, the usefulness of the ‘quality of life’ concept is predicated on it being read as a subjective meaningful expression for both existential and corporeal satisfaction. It is a way by which the local, provisional and idiosyncratic stories with all the ‘messiness’, intricacy and complexity that constitute a life is expressed. ‘Quality of life’ is about the subjectively constructed meanings ascribed to subjective experiences, and thus it could be argued that ‘quality of life’ is less useful when it is used as a universal concept that is situated outside of the individual context. When examining the issues pertaining to ‘quality of life’, Mukherjee (1989) drew attention to the objective and subjective dichotomy by attending to the “duality arising from our encounter and experience that the world exists without oneself but one can appreciate the world only by oneself” (p.15). It is the last part of the quote – “appreciate the world only by oneself” which informs my undertaking to clarify the concept.

I want to attend to the importance of subjectively constructed meanings by drawing on an idea of Viktor Frankl (1984) as presented in his book “Man’s Search for Meaning”. In his book, he suggested that the notion of quality of the lived experiences is connected with the meanings found in these experiences. He argued
that the search by individuals for meaning in their lives is an important quest and this meaning “is unique and specific in that it must and can be fulfilled by him (sic) alone; only then does it achieve a significance which will satisfy his (sic) own will to meaning” (p.121, italic original). The significance of meaning is important here, for Frankl suggested that it is by locating a meaning that is acceptable and satisfying for the individual that he or she is able to not only make sense of his or her experience but to be with the experience existentially which gives the individual a purpose in living with ongoing difficult circumstances embedded in his or her situations. In this context, Frankl quoted the words of Neitzsche: “He (sic) who has a why to live for can bear almost any how” (p.126, italic original). He also suggested that the term “existential” could be used in three ways: 1) existence itself, which refers to act of being; 2) the meaning of existence, which I take to signify the subjectively constituted reasons and purposes to the act of being; and 3) the striving to find a concrete meaning in personal existence, it is what he referred to as the “will to meaning”. From this perspective, I argue the ‘quality of life’ concept needs to be about meaning, and to explore lived experiences in the context of the meanings people construct and ascribe to their experiences. Furthermore, by attending to subjectively constructed meanings, it privileges the individual and the story he/she wants to tell of the quality of his/her life.

The stories people tell of their lived experiences are means through which their actions are explained and justified, not only for their own benefit but for the benefit of others. The activity of storytelling, as Widdershoven and Smits (1996) argued, is an ethical endeavour. From this perspective, the existential issues embedded in the everyday living with HIV in the era of effective treatments need to be negotiated and
this means that people have to construct stories that are subjectively authentic and ethical so that these issues are made meaningful to them. The way that I am using ‘authentic’ and ‘ethical’ is to reflect the endeavours of living subjectively responsible and meaningful lives that are informed by participants’ subjective constructions of how lives are to be lived. I am informed by Foucault who suggested that ‘ethics’ in the context of an individual’s relationship with him/herself, “the individual is supposed to constitute himself (sic) as a moral subject of his own actions” (Rabinow & Dreyfus, 1991, p.352). The use of ‘ethical’ has utility in exploring the subjectively constructed notion of quality in lived experiences.

I regard the activity of living a subjectively constituted ethical life to be significant in my exploration of how people make sense of their lives. It could be argued that the aim to construct an ethical life is to achieve existential satisfaction by fulfilling their “existential responsibility” (Schönnesson, 2002) through resolving troubling issues that are significant and meaningful. Quinton (1999) offered a definition of ‘ethics’ that is useful here. He defined ethics as being concerned “with the meaning and justification of utterances about the rightness and wrongness of actions, the virtue and vice of the motives which prompt them, the praiseworthiness or blameworthiness of the agents who perform them, and the goodness or badness of the consequences to which they give rise” (p.284). The way Quinton defined ethics is informing, particularly when it refers to subjective experiences and the manner in which these experiences are made morally coherent by constructing meaning and justification

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23 I am mindful that being ‘authentic’ and ‘ethical’ are mediated by language, and conceptually, they are not fixed with intrinsic values but are socially mediated, negotiated and constructed. The ideas and actions embedded in the stories of the research participants are engaged with the view that they are cultural products. The analysis of these ideas and actions are culturally framed within the Australian context.
that fit with subjective values. It is also about, to use Quinton’s words, the “praiseworthiness” and “goodness” of the individual’s action through which it is made sense of by the way the meaning is constructed.

In my exploration of the illness experience with HIV and the ways people make sense of lives, I am interested in the “individual’s sense of well-being and the degree to which he or she can participate in the human experience” (Zhan, 1992, p.799). I do not consider nor will I be using ‘quality of life’ as a quantitative measure but I do regard it as a useful concept by which people can make sense of their experiences; how it is empirically defined is less pertinent in this thesis than what it means to the people in the everyday life. From this perspective, in addressing the four key thesis questions as noted in Chapter One, I privilege the subjectively constructed meanings ascribed and interpretations given to their experiences. Subjectively constructed meanings and interpretations will inform the exploration and analysis of how people make sense of their lived experiences in what I refer to as the ‘post-treatment era’.

2.8 The Post-Treatment Era

I will start by offering a description of the ‘post-treatment era’ before elucidating the ideas which informed and underpinned this theoretical concept.

I regard the ‘post-treatment era’ as a temporal context in which HIV treatments are positioned differently to when they first emerged with extraordinary results. In using ‘post’ in the referent ‘post-treatment era’, I want to draw on the work of Best and Kellner (1991) who argued that the prefix ‘post’ “signifies an active rupture with
what preceded it…and as an affirmation of new developments, a moving into new terrains, a forging of new discourses and ideas” (p.29). In this context, the post-treatment era signifies new discourses and ideas about treatments; and for this thesis, it signifies a period of critical questioning of treatments and their use. It is also a social context in which I situated my exploration of the ways people with HIV made sense of their lived experiences since effective treatments have became an accepted part of everyday HIV living. The post-treatment era is a period in the history of HIV and AIDS when people are afforded the opportunity to reflect on their past and present lived experiences, which they need to make sense of in order to venture into a future they did not consider was available before the ‘protease moment’. The post-treatment era is a theoretical frame through which HIV and AIDS issues, both familiar and novel, could be examined.

I want to make clear that by the post-treatment era, I do not mean it to be a time when treatments are unnecessary, superfluous or that treatment related issues do not warrant appropriate attention or concern. Given a cure for HIV is yet to be found, it is likely that ongoing pharmacological interventions will be required in order to prevent and to remedy the damage the virus could cause. However, in the post-treatment era, the ways in which treatments are used and the subjectively constructed meanings people ascribed to them are varied and multiple, but more importantly, HIV medico-scientific discourses on treatment use are being questioned by people with HIV.

I want to now clarify the ideas by which I was informed when developing the ‘post-treatment era’ as the theoretical frame for this thesis. Describing the era of available
effective treatments for HIV as ‘post-treatment’ can be unproductive without clarification. The need for clarification is encouraged by the lessons learned from when the term ‘post-AIDS’ was introduced and the ensuing confusion, debates and discussions that took place which were political and divisive. I want to draw on ideas that underscored the construction of ‘post-AIDS’ as a way to delineate and explain my conceptualisation of the ‘post-treatment era’.

‘Post-AIDS’ raised questions and caused disquiet among HIV commentators such as Pickstone (1997) who cautioned against the use of the term and challenged the complacency that the term might imply. There was a view that ‘Post-AIDS’ suggested the diminished importance of the illness and that it does not warrant the level of attention that it once demanded. I want to clarify here how the ‘Post-AIDS’ emerged in public discourses.

When the notion of ‘Post-AIDS’ emerged in the mid 1990s concurrently with the protease inhibitors and combination therapies, it was met with curiosity and concern. The term ‘Post-AIDS’ was accredited to Gary Dowsett who first used it at an HIV and AIDS conference in 1995 (Hurley, 1996) in reference to the generation of young men who ‘came out’ as gay after the AIDS epidemic had begun. Dowsett (1996) proclaimed that by “post-AIDS, I do NOT meant the epidemic is over, nor am I talking about a time when it will be” (p. 21-22; upper case original) and added that post-AIDS is not to ignore people with HIV but to recognise the different relationships that people have with HIV (Dowsett & McInnes, 1996). In the context of his research into gay men’s sexual practices, he identified that for gay men who ‘came out’ after the epidemic had started, HIV knowledge, safer sex practices and
HIV discourses were embedded in their subjectivities as gay men and therefore argued that “for many gay men in Sydney, HIV/AIDS is no longer a crisis…These men are already living as they will for the rest of their lives or until the epidemic is over, whichever comes first. In this sense these men already live post-AIDS” (P.22). Rofes (1998) continued with the examination of post-AIDS after combination therapies by drawing on Dowsett’s work and argued that AIDS as a crisis has ended, but supported the view that this does not mean that the AIDS epidemic is over. This is an important distinction because it clarified, and averted the criticism that was directed at using ‘post’ in terms of AIDS, by acknowledging that the ‘post’ of post-AIDS denotes “the event of AIDS generated by urban gay communities in the 1980s is no longer dominant in men’s social worlds” (p.75). This is critical for it suggests that, perhaps unfortunately, HIV and AIDS will continue to be permanent parts in the everyday life of gay men in particular, despite the availability of effective treatments for the disease. The main thrust of ‘post-AIDS’ is to put forth the view that it is inappropriate or inaccurate to persist in constructing HIV and AIDS as crises (Dowsett, 1996; Hurley, 1996).

I was informed by the ideas embedded in post-AIDS to theorise a ‘post-treatment’ temporal context, and to understand the present period in relation to the social changes produced by the effective treatments. As post-AIDS denotes the acceptance of HIV and AIDS in the everyday life of gay men, post-treatment could be read as the taken-for-granted-ness of treatments in the everyday life of people with HIV and in contemporary HIV discourses. The excitement of the ‘protease moment’ and the elation engendered by the effectiveness of the treatments have passed; the potentiality of treatments to effectively manage HIV is accepted as a given.
Treatments and their use are everyday issues in HIV living in developed or resource-rich countries. Treatment availability is less remarkable in countries such as Australia, where they are readily accessible by those who are infected. Living with HIV in the post-treatment era means that it is possible for people to live with the disease indefinitely, provided that treatments are appropriately utilised and deployed. Just as Dowsett argued that for many gay men, HIV and AIDS are no longer a crisis, I argue that treatments are no longer constructed as the ‘miracles’ they were thought of when they appeared in the mid 1990s and produced a wave of excitement that had not been witnessed previously or since. Not only are the treatments now taken-for-granted, they are problematised and are constructed as objects of concern, for it is now accepted that they have harmful side effects, which are believed to be the causes of diminished health and wellbeing (Baer & Roberts, 2002; Powderly, 2002; Siegel & Lekas, 2002; Treisman & Kaplin, 2002). Although treatments might have assisted in ending the AIDS crisis as argued by Dowsett, the anticipation and enthusiasm of the treatment era has changed. The optimism associated with initial claims of their ability to eradicate HIV has largely been replaced by a more pragmatic understanding and acceptance of their effectiveness (Flowers, 2001). They are not the panacea to HIV and AIDS that they had initially been positioned to be.

Close to a decade after the emergence of effective treatments that changed the construction of HIV from that of a fatal disease to a chronic one, people with HIV are engaging with treatments, not as means for removing the disease from their lives, but as resources with which they venture into what remains to be an uncertain future. In contrast to the time when the use of treatments was viewed as being central to living well, in the post-treatment era, the answer to living well with HIV and AIDS is
not only found in treatments, but also from the ways that people make sense of their lives and their abilities, and opportunities, to lead the life they desire.

### 2.9 Summary

What I have done in this chapter is to provide an overview of the medico-scientific and social background to HIV and AIDS. The history of the disease and the eventual development of effective treatments informed and shaped my questions for this thesis as noted in Chapter One. I detailed my subjective experiences with HIV and AIDS, for these experiences directly or circuitously shaped my understanding and views about the HIV phenomenon, both as a collective experience as well as a subjective one. Locating my subjectivity is important, for reflexivity is important in this research enterprise. I went through the changes in HIV treatments just as the participants of this research did, and this has influenced the way I engage with the research process, from its development, to the analysis of the research materials, and the conclusions drawn. I want to be clear and open about my subjectivity, for HIV and AIDS are as much social constructions as they are medical and scientific concerns in the way they are made sense of.

This thesis examines living with HIV in the social, that is, the everyday subjective experiences of living with a chronic disease. More specifically, this thesis examines the implications of living with HIV in the post-treatment era and the tacit assumption that people could live well given the availability of effective treatments. The attention on HIV in the post-treatment era could be argued as having shifted from the experiences of living with the disease to the experiences of living with side effects.
This shift to living with side effects is made visible by the subjective experiences of people who have to negotiate these effects in their everyday lives. The undesired effects from treatments are crucial when examining the quality of lived experiences, for these effects intrude, disrupt and undermine the value of these lived experiences.

The analysis of participants’ stories will be presented in Chapters Five to Eight. Before doing so, in the next section, which comprises Chapters Three and Four, I will elucidate the methodology by which this research is informed. In Chapter Three, I will discuss the theoretical framework – the epistemological and ontological stance assumed and the postmodernist/poststructuralist approach taken in the analysis. Chapter Four details the research protocol. In this chapter, the process undertaken in conducting this research will be explicated, which includes the research design, the recruitment process, descriptions of the participants and the research materials.
Chapter 3: Methodology: Theoretical Framework

*Dr. Aragon:* Has he asked for anything special?

*Dr. Melik:* Yes, why, for breakfast… he requested something called wheat germ, organic honey, and tiger’s milk.

*Dr. Aragon:* Oh, yes. Those were the charmed substances that some years ago were felt to contain life-preserving properties.

*Dr. Melik:* You mean there was no deep fat? No steak or cream pies or… hot fudges?

*Dr. Aragon:* [chuckling] Those were thought to be unhealthy… precisely the opposite to what now know to be true.

*Dr. Melik:* Incredible!

### 3.1 Introduction

The comical dialogue of the two scientists in the satirical sci-fi motion picture “Sleeper” illustrates several theoretical issues I want to examine in this chapter. The humour arising from the tension of believing certain items to be unhealthy, as compared with those that were, brings to the fore the view that scientific knowledge is socio-historically contextualised. Moreover, what is regarded as knowledge is informed by the theoretical framework and the historical/cultural context in which knowledge is constituted. Dr Aragon’s claim to “know” what is “true” in the year 2173 suggests that knowledge is not ‘fixed’; what we concede to be knowledge is produced by accepted knowledge producing methods that are available at the time, and these methods and the theories which underpin them are specific to particular contexts.

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\(^1\) From the motion picture “Sleeper” written by Woody Allen and Marshall Brickman (1973).
The comical scenario is by way of introducing the aim of this chapter, which is to elucidate the theoretical framework informing this research. I will discuss the utility and pertinence of qualitative research methodology as a means through which an understanding of subjective lived experiences is attained and the knowledge it produces in the endeavour of conceptualising how people make sense of their lives specifically in the context of an illness experience. I will clarify the epistemological and ontological positions, the approach which guides the research analysis and the materials this research uses in its effort to address the research questions.

3.2 Why Use Qualitative Research Methodology?

“Qualitative research takes place in the natural world, uses multiple methods, focuses on context, is emergent rather than tightly prefigured and is fundamentally interpretive.” (Rossman & Rallis, 2003, p.8)

Qualitative research explores meanings (Willig, 2003) by raising ‘how’ and ‘why’ questions (Wisker, 2001) and attending to “propositional data” (Agar, 2003, p.976). Propositional data are research materials obtained through conversations, dialogues or interviews with research participants. Conducting research by interviewing people and engaging them in conversations about their lives and experiences is considered to be the most appropriate approach for gathering rich materials. What I refer to as the rich materials are the complex ideas, issues, conditions and clarifications that constitute subjective interpretations and understanding of lived experiences.

By exploring the subjective meanings and interpretations people construct to account for their actions or behaviours, we are able to understand subjective experiences and
Employing a qualitative research approach is to place people’s interpretative processes at the centre of its inquiry (Liamputtong & Ezzy, 2005). The research approach itself is also an interpretative endeavour, and the materials obtained through interviews require an in-depth understanding of and an insight into the stories presented by the participants. Attending to the participants’ stories “leads the analyst to look beyond, between, and underneath the participant’s words, to understand the social space in which the participant is located and in which the interview took place” (Power, 2004, p.860). This research seeks to explore subjective experiences and as a researcher, I assumed a qualitative stance in this research as it “enables researchers to carve open territory about which they have vague hunches rather than clear predictions” (Kidder & Fine, 1997, p.37).

Qualitative research or inquiry provides an insight into how people make sense of their illness experiences that other methods, such as quantitative research methods, cannot (Liamputtong-Rice & Ezzy, 1999). Although quantitative statistical data are useful in explaining “the cause and extent of disease, they may mask people’s interpretations and understandings, and their interactions with others” (Liamputtong & Ezzy, 2005, p.5). In contrast, qualitative research “explains, defines, deciphers, construes, unravels, uncovers, synthesizes, and summarizes” (Morse, 2004, p.739). Embracing these ideals, qualitative research methods provide strategic ways to analyse, to understand and to “arrange and rearrange the complexities of the reality or realities within which we live and/or study, and portray them in such a way as to connect their various (seemingly unconnected) propositions in a systematic way, thus extending the knowledge base of our discipline and/or producing patterns of
knowledge applicable to our immediate problems” (Mantzoukas, 2004, p.994). The perspective offered by Mantzoukas resonates because it directly addresses and reflects the aspirations and undertakings set out for this research. The lived experiences of individuals with HIV are complex and challenging, and at a glance, the connections that are apparent to people themselves when making sense of their lives are not so equally obvious to an observer, in this instance, the researcher. More notably, it has been argued that qualitative research methodology is better suited to reflect the nature of human experiences (Epstein Jayaratne, 1993), and that it “seeks depth over breadth and attempts to learn subtle nuances of life experiences as opposed to aggregate evidence” (Whittemore, Chase, & Mandle, 2001, p.524). These are important issues, for this research is about the human experience of living with a disease and the exploration of the illness experience by privileging the individual voice. It is in this context that I argue aggregate evidence silences the individual and marginalises the subtle but critically vital differences that are fertile ingredients to a better understanding of social lives and the social world.

I have so far discussed the utility of qualitative research methodology and how it will be useful for my research. However, subscribing to a qualitative research methodology does not necessarily indicate the epistemology by which the research is informed. The epistemological position is established not solely by the method with which the materials are obtained but how the materials are used and the knowledge the research strives to produce, is able to produce, or more precisely, claims to have produced. What I want to clarify in the next section is the epistemological and ontological stance assumed in this research.
3.3 The Epistemological and Ontological Positions

In the modernist view of the world, as Barry (2002) argued, realist ontology asserts there is one ‘true’ reality and therefore the role of the researcher is to uncover this truth. This is in contrast to the relativist ontology of postmodernism, which considers that there is no one true reality but many realities, and that there are multiple perspectives from which to understand any social phenomenon (Cheek, 2000). That ‘reality’ can be represented in different ways is a central theme in postmodern thought, and “the ideal that several voices should be heard” is privileged (Alvesson & Sköldberg, 2000, p.152). The postmodern relativist ontology informs the theoretical framework of this research. A relativist ontological position regards objective knowledge to be unattainable and that each individual “views the world through the lens of their own culturally determined ‘common sense’” (Davidson & Layder, 1994, p.21). In this context, this research privileges the subjectiveness of meaning production and acknowledges the socio-cultural as well as the historical contexts in which the meaning is produced.

The term ‘postmodernism’ was originally employed to denote an architectural movement (Agger, 1991) and later in academic/scholarly pursuits including philosophy, social theory and cultural criticism (Weedon, 1997); it is also a term used in popular vernacular such as in the creative arts to denote a ‘school’ or ‘sensibility’ by way of describing a particular piece of artwork (Bradbury, 1999; Featherstone, 1988). Alvesson & Sköldberg (2000) argued that postmodernist thought resists modernist or structuralist ideas that “there are some rational, global solutions and explanations, some general principles which guarantee progress in the
development of knowledge” (p.148). They further argued that a postmodernist position contests the stability of the structuralist view by arguing that knowledge privileged by structuralist ideas are “myths or grand narratives” which are produced by dominant discourses. The grand narratives serve as absolute truths and assume universality in the explanations given (Alvesson & Sköldberg, 2000). Research projects informed by postmodernism in contrast, as Iseke-Barnes (1997) attests, are concerned with divergence of points of view; more significantly, they attend to the individual and often marginalised voice.

Research informed by postmodern thought treats knowledge claims cautiously and “obscures all versions of truth” (Rosenau, 1992, p.3). Increasingly, postmodern approaches and strategies are engaged in the analyses of health and health care issues owing to their utility to illuminate the complexity of subjective experiences. Although postmodernism is often referred to as the epistemological position on which the research is based, poor explication of its theoretical underpinnings has raised concerns and attracted criticisms to the point where postmodern epistemology is regarded as esoteric and devoid of relevance in the ‘real’ world (Kermode & Brown, 1996). Defining postmodernism is a difficult task as “[it] is a highly contestable and contested term not easily defined” (Cheek, 1999, p.384), so if the task here is to narrow postmodernism to one singular definition then it is at risk of betraying the notion that it is a set of intellectual propositions which underpin the epistemology by which the research is informed. Rosen (1996) asserted that anyone who claimed to have a precise definition for postmodernism is probably mistaken, for it could be argued that postmodernism, by its theoretical underpinnings, defies this practice. The term itself is complex (Weedon, 1997) and its complexity is made
more confounding by the different ways in which the term, its ideas and its relevance are used in competing and varying contexts by theorists, writers and commentators (Cheek, 2000). The situation is made more difficult by the absence of a unified postmodern theory or a coherent set of positions; instead, there is a diversity of theories with conflicting positions that are coalesced under the umbrella term ‘postmodern’ (Best & Kellner, 1991). This does not exempt any researcher from being clear about his/her understanding of postmodernism in the way that it is employed in the research process. Cheek (1999) advised and encouraged the need to provide an adequate explanation of postmodernism as understood by the researcher and its theoretical application within the context of the research. If this were achieved, it could be argued that the credibility of the research is preserved and the knowledge produced could not be dismissed on the grounds that its theoretical framework has been inadequately postulated. Heeding to Cheek’s advice that to prevent esotericism or the falling into the “postmodernist hoax” (Kermode & Brown, 1996), it is necessary to articulate the theoretical position which informs my research, I aim to make clear the understanding I have of postmodernism and the analytic endeavours I will engage in my research.

Postmodernism, or a postmodern approach to research, is not a method but a way of thinking or conceptualising the social world which informs the epistemological and ontological positions underpinning the research. The criticisms that have been levelled at postmodernism are that it is esoteric (Cheek, 1999) and that it resists a clear definition thereby obstructing a clear and easy access to its theoretical postulations (Cheek, 2000; Featherstone, 1988). The view that it lacks exactitude in its definition could be inferred as a lack of clarity in its theoretical formulation.
However, I do not think the situation is as problematic as it has been depicted for the plurality of ideas embedded in postmodernism is suggestive of its strength in making sense of vexing, chaotic, complicated or simply, ‘messy’ events that we call ‘human experiences’. It is not always, if at all, possible to make the experiences we have in the social world rational, as premised by the ‘grand narratives’ assumed by the modernist project. It is, as Parker and Burman (1993) have argued, that a characteristic of the postmodern turn is “the shift from a belief in truth to a celebration of the impossibility of truth, to uncertainty” (p.164). Postmodern thought rejects the notion that human experiences could be “reduced to, and captured by, grand or totalising theories” (Cheek, 2000, p. 5).

Notwithstanding the divergence of ideas in theories with each having particular emphases, there are commonalities in the utilisation of postmodern thought. Cheek (1998; 1999) noted that the commonality in approaches considered to be postmodern is that they hold plurality or multiplicity of truth and reality, or that it is asserted that there is no truth or fixed meanings, and knowledge is regarded as contextual, localised, with a generalised way of knowing rejected. Postmodern approaches challenge the assumption that it is possible to represent reality entirely and accurately. Thus, they reject the way in which reality is represented in modernist approaches by which to make truth claims and to attain universal understandings of the social. This is a salient issue with respect to the ontological position I take in this thesis, in exploring the lived experiences of people with HIV. Best and Kellner (1991) postulated that postmodernism “rejects modern assumptions of social coherence and notions of causality in favour of multiplicity, plurality, fragmentation, and indeterminacy” (p.4). In this context, postmodernism positions the notion of
‘truth’ as multiple, localised, and contextual (Power, 2004). Riessman (1989) contested that in social research where the natural science model is adopted, the researcher controls meaning through the research protocol and inhibits the development of meaning and sense-making activities of the participants. In contrast, the epistemological and ontological positions which inform this thesis privilege the social interactivity that shapes responses and the subjectively constructed meanings. In the research on which this thesis is based, the endeavour was to understand the complex experience of living with HIV and to explore the multiple realities as constructed by the stories people tell, that is, the social and linguistic constructions of their experiences. I am interested in the sense-making activities of participants, to understand the constructed meanings they ascribe to events experienced, by placing the personal stories people tell at the centre of the research.

The manner in which I engage with postmodern thought in this research is to proffer a way of thinking about living with HIV which acknowledges the multiple and varied ways in which people make sense of their lives. The appeal of a postmodernist epistemology emphasises the “everyday life experience, the importance of multiple, relativistic constructions of reality, and the ambiguity and complexity inherent in both everyday life and the research enterprise” (Lowenberg, 1993, p.63). ‘Facts’ are not taken as reflections of a reality “but as empirically based constructions that are always socially mediated and interpreted” (Power, 2004, p.859). The knowledge this research produces is based on my own interpretations and I accept that alternate interpretations are available. I am aware this could be construed as supporting a criticism of postmodernism, which argues that its tenet on multiplicity of truths and realities promulgates the notion of ‘whatever you want it to be’, a criticism based on
postmodernist rejection of structures and belief in knowledge (Kermode & Brown, 1996). However, I would argue that qualitative research informed by postmodern epistemology facilitates a more profound understanding of multiple and varied lived experiences, whilst acknowledging that this understanding is influenced by my subjectivity, my relationships with the participants, and the stories produced in interviews. In exploring the participants’ stories of their lived experiences, I will take a poststructuralist approach in the analysis. A poststructuralist approach accepts that an objectively neutral perspective is unavailable as everyone is located socially and historically, and this context shapes the knowledge we produce. Just as previously I have argued the importance of clarity in the use of postmodernism in my theoretical framework, I want to clarify poststructuralism as is used in the analysis. I will do so by firstly elucidating the relationship between postmodernism and poststructuralism, two terms often used interchangeably in literature, and then I will make clear why I am using a poststructuralist approach in the analysis.

3.3.1 The Difference Between Postmodernism/Poststructuralism Is…?

Although it is accepted that postmodernism and poststructuralism are not the same, their commonalities are considerable and sometimes have been regarded as synonymous (Rosenau, 1992). The problem here, as Rosenau (1992) further argued, is that in spite of the difference between them, few efforts have been made to distinguish the two, for the assumption is that the differences are of little consequences. I question this assumption as it perpetuates a situation pertaining to ambiguity in theoretical understanding that Cheek (1998; 1999) warned against. The examination of the differences and similarities between postmodernism and
poststructuralism is to make sense of these two ideas in a way that would provide clarity to the analysis of the research materials. This examination is not to categorically resolve the complexity and perplexity observed by writers and theorists, as there have been many who have previously exerted great intellectual efforts to decipher these differences and similarities (see Agger, 1991; Alvesson & Sköldberg, 2000; Cheek, 2000).

According to Best and Kellner (1991), not only poststructuralism “forms part of the matrix of postmodern theory” but they also interpreted “poststructuralism as a subset of a broader range of theoretical, cultural, and social tendencies which constitute postmodern discourses” (p.25). Weedon (1997) provided an explanation that illuminates the interchanging use of postmodernism and poststructuralism in scholarly writing. She suggested that the poststructuralist theories and ideas employed by her in her work are often called ‘postmodern’ and “poststructuralism is either conflated with ‘postmodernism’ or seen as a postmodern set of theories” (p.170). The conflating of the two terms could be inferred as they share the same epistemological position thus allowing the fluidity of their reciprocal usage.

Moreover, the interchangeability of the two terms (Alvesson & Sköldberg, 2000; Burman & Parker, 1993; Cheek, 2000) has established the practice of some writers using postmodernism in preference to poststructuralism to denote the broad orientation which Alvesson & Sköldberg (2000) called “postmodernism/poststructuralism” (p.149). The preference for the term postmodernism was interpreted as a move away from positivism of which the term poststructuralism still carries, given its history in structuralism (Burman & Parker, 1993; Jones, 1997). The “postmodernism/poststructuralism” orientation would
suggest that the theoretical connection between postmodernism and poststructuralism is so intricate and entwined that a precise demarcation is perhaps not as useful as an orientation which includes both terms in its designation.

Further reading into this issue revealed some divergent articulations of these two terms. Although Agger (1991) conceded that a distinct discussion of poststructuralism has the implication of it being separate from postmodernism, this is not so as there is substantial overlap between them. However, in his effort to provide clarity between poststructuralism and postmodernism, he suggested that “poststructuralism is a theory of knowledge and language whereas postmodernism is a theory of society, culture and history” (p.112). Denzin and Lincoln (2000a) suggested that postmodernism “is a contemporary sensibility, developing since World War II, that privileges no single authority, method, or paradigm”; whereas poststructuralism, as suggested by the same writers, has its emphasis on language and that “language is an unstable system of referents, thus it is impossible ever to capture completely the meaning of an action, text, or intention” (p.24). This pithy differentiation is useful for it not only attends to how postmodernism and poststructuralism could be distinguished but highlights the similarity which could be surmised by the tenet of multiplicity and variability, that is, the resistance to and contestation against universality and grand narratives privileged by modernism and empiricism. Moreover, poststructuralism, Mumby and Putnam (1992) argued, is one of the many schools of postmodernism, and it attends to “discourse and linguistic patterns as the institutional practices that shape rationality, construct power relationships and enact member identities” (p.467). This particular interpretation concurs with Rosenau (1992) who proposed that postmodernists focus on cultural
critique while poststructuralists emphasise on method and epistemological matters and offered the delineation which suggested that poststructuralists interrogate language, discourse and meaning while postmodernists assume a broader perspective in their projects. Simply put, poststructuralism is a form of textual inquiry and a part of the greater cultural movement of postmodernism (Baxter, 2002). Rosenau (1992) further noted that postmodernism privileges “sense experience, a highly personal individual, nongeneralized, emotional form of knowledge” (p.3). These perspectives suggest that postmodernism is a theoretical “sensibility”, a paradigm in which poststructuralism is located but with the emphasis on language and discourse as resources with which to contest and resist the privileging of a singular, unitary approach to scholarly analysis of events, occurrences and phenomena in the social world. It is as Best and Kellner (1991) noted, poststructuralist and postmodern theorists hold the position that there is instability in everything social, that is, language, culture, practice, subjectivity, and society.

The differentiations presented are useful, as the research on which this thesis is based, on the broad level, could be regarded as being informed by the “theoretical sensibility” of postmodernism. In term of its analysis however, this research could be regarded as poststructuralist as it examines the materials, that is, the stories people tell in textual forms, by which the key thesis questions are answered. In light of this delineation, I want to clarify the poststructuralist informed approach to which this research enterprise adheres.
3.3.2 Poststructuralist Informed Research

Poststructuralism, according to Fuery (1995) challenges two fundamental claims made by structuralism. The first one is that it questions the claim that explanatory structures are present in all human activities, which implies that a sense of ‘truth’ is attainable by understanding these structures; the other challenge to structuralism is that it contests the structure of the linguistic sign (the relationship between the signifier and the signified) as the basis to all meaning production and communication processes. The assumption of poststructuralism is that there is no singular or objective truth aside from the socially constructed-ness of truth and that the sign, that is language, is unstable and variable in meaning and knowledge production.

Knowledge produced through language is not a copy or a reflection of reality, language mediates what we can know. Poststructuralist informed research attends to the way “theories are constructed, their assumptions, their rhetorical strategies and their claims to authority” (Alvesson & Sköldberg, 2000, p.152). These challenges to structuralism are important ideas for they provide a different way of understanding stories people tell of their lived experiences.

Poststructuralist informed research is concerned with the cultural and discursive resources that are available and utilised by people in their efforts to construct meanings to their experiences, for it is through language that people understand and give meanings to their lived experiences (Burr, 2003). What this means is that people can only construct accounts for their experiences, both to themselves and to others, by using concepts embedded in language. Language is formative (Shotter, 1992a) and has the power to constitute social realities by interpreting and negotiating the
meaning of lived experiences (Hare-Mustin & Marecek, 1997; Kvale, 1992). The poststructuralist position premised that all human activities, in the way they are expressed and made sense of, are mediated by language, and language cannot be considered as value free (Cheek, 2004).

Wetherell and Potter (1988) contend that language does not simply act as a neutral, transparent medium through which it is used to convey thoughts and experiences pertaining to the relationship between the individual and his/her world. They consider what is said, the utterance, is action orientated and language is functional. The meaning of what is said is constructed by the local and broader discursive systems in which the utterance is embedded. This emphasis on language is crucial, for language encodes many discourses (Buchbinder, 1998) and the stories we tell are constrained by the available discourses. The manner in which ‘discourse’ is understood here is informed by Hollway (1983) who viewed discourse as “a system of statements which cohere around common meanings and values…a ‘set of assumptions’” and noted that the way ‘discourse’ has been theorised by Foucault is its emphasis on “how these meanings and values are a product of social factors, of powers and practices, rather than an individual’s set of ideas” (p.231). From this perspective, the manner in which people make sense of their illness experiences with HIV within the Australian culture and the post-treatment era is constructed by and through a complex network of discursive relations.

The constellation of socio-culturally available discourses intersect or run alongside one another (Buchbinder, 1998), which enable people to construct and to tell stories about the same issue in what appears to be contradictory ways. This, as West (1990)
argued, could be understood as being the consequence of the discourses with which people engage with at different times, in different contexts and for different purposes. Thus to understand the lived experiences as expressed in people’s stories is to understand discursive construction of these stories. For me, the significant issue here is that by understanding that discourses are socially constructed and meanings ascribed to social phenomena are shaped by discourses, what appear to be fixed and dominant discourses could be interrogated and destabilised so to invoke a different way of understanding subjective experiences.

Research analysis informed by poststructuralism holds at the centre of its inquiry the questioning of claims that a world outside of language could be revealed and of claims that we can experience any aspect of ourselves as outside language (Burman & Parker, 1993). From a poststructuralist perspective, the importance of language as a constitutive process is acknowledged, which means that the constitutive power of culturally available discourses in the production of stories about our experiences that we tell about ourselves, as well as the production of meanings we ascribed to these stories, is recognised. Stories of lived experiences are discursive productions and not reflections – accurate, distorted, or otherwise, of “true” experiences (Gavey, 1997). The shift away from essentialising the individual as the origin and guarantor of meaning and the humanist assumptions that the individual as rational, unitary and autonomous (Weedon, 1997), to the individual and his or her experiences as discursively constituted is the basis on which a poststructuralist approach is regarded as anti-humanist. However, the emphasis on language, as I interpret it, is not de-humanising as it does not negate the existence or significance of the experiences, but the issues here are concerned with how they are understood, articulated or expressed,
which is deemed to be dependent on and connected with the language used and the
constitutive power of available discourses. The implication is that if we are to
understand subjective experiences and the social world, we need to examine the
linguistic space in which people move with other people (Burr, 2003). Moreover,
poststructuralism offers a way of examining individual experience by situating this
experience and its meaning within a socio-historical context through which “an
analysis of its constitution and ideological power” (Weedon, 1997, p.121) is made
available. Poststructuralist assumptions hold that meanings cannot be fixed, they are
contextual and shifting for there are “a range of historically and culturally specific
possible meanings, so researchers/thinkers can never get to the final, ‘real’ meaning
or structure of a society or action or text” (Jones, 1997, p.265). This point is
supported by Gavey (1997) who argued that poststructuralist emphasis on multiple
meanings of texts highlight the particular way texts are read or understood is shaped
by the reader’s location in various discourses, for example, scientific, humanist and
feminist.

The work by Gavey (1989; 1997) and Weedon (1997) on feminist poststructuralism
were thoughtful influences on this research. The goal of the poststructuralist project,
from a feminist standpoint, is to develop “understandings or theories that are
historically, socially, and culturally specific…[r]ather than “discovering” reality,
“revealing” truth, or “uncovering” the facts” (Gavey, 1989, p.463). It is a project that
rejects the possibility of absolute truth and objectivity and is concerned with
disrupting and displacing dominant and oppressive knowledge (Gavey, 1997). The
poststructuralist position is political as it aims to disrupt the universalising of
knowledge about human activities, and to contend that knowledge produced by
modern science is to effect social control (K. J. Gergen, 1985). From this perspective, the research approach I have taken is to privilege the individual voice and to aim for non hegemonic oppressive knowledge, as reflected in feminist research methodologies (Mies, 1983). These methodologies aim to produce knowledge in an intersubjective space, where individuals are afforded the opportunity to share their stories, to connect, and to reveal rather than to answer predetermined, empirically based questions designed to elicit particular responses in the enterprise of locating ‘the’ truth. It is as K.J. Gergen (1985) suggested, a call for attention to the social, moral, political and economic institutions that perpetuate the taken-for-granted assumptions about social phenomena and human experiences. Individual stories are social constructions produced in an intersubjective space between the storyteller and the listener or, as in this instance, the participant and the researcher.

3.4 The Analysis Material – The Stories People Tell

In this section of the chapter, I want to discuss and to theorise the analysis materials, which are the stories people tell. I will draw on social constructionism, as a theory about knowledge, to understand the storied form and its importance for people in their effort to make sense of their experiences. The aim for doing so is to provide a theoretical understanding of stories as social products. A poststructuralist theorising of a constructed story is that it is “an embodiment of various discourses available in the social, cultural, and historical context of the author” (Gavey, 1997, p.55). This idea supports the notion that knowledge is socially constructed and stories can be argued as constructed realities through which people make sense of their
experiences. Constructionism\(^2\), noted by Gavey (1989; 1997), is part of the postmodern movement, which illuminates the connection between poststructuralism and social constructionism as they are both informed by postmodern sensibility.

3.4.1 Stories as Social Constructions

“Constructionism asks one to suspend belief that commonly accepted categories or understandings receive their warrant through observation. Thus, it invites one to challenge the objective basis of conventional knowledge.” (K. J. Gergen, 1985, p.267)

Social constructionism, like postmodernism, is viewed as an epistemological position “principally concerned with elucidating the processes by which people come to describe, explain, or otherwise account for the world (including themselves) in which they live” (K. J. Gergen, 1985, p.266). Here, in his clarification, Gergen gives emphasis to the significance of language in social constructionism (as it is in poststructuralism) by the necessity of the individual to “describe” and to “explain”. According to Phillips and Jørgensen (2002), social constructionist approaches share the poststructuralist premise “that language is a dynamic form of social practice which shapes the social world including identities, social relations and understandings of the world” (p.96). The power of language to organise thoughts and experiences through the ways we speak and write influences our conceptual boundaries (Lather, 1992), and how we talk about our experiences determines what those experiences are for us. The constructionist epistemological stance positions realities as being socially constructed through human interactions and it questions the

\( ^2 \) Constructionism is often confused with constructivism despite their different orientations. “For constructionists, the site of construction is the relationship (language), whereas constructivists typically locate the process of construction in the mind of the individual” (Rehner Iversen, Gergen, & Fairbanks, 2005, p.690).
attribution of reality to phenomena whose existence seems to only have a solid base in our language. Social constructionist theory observes how language works and how meaning is created (K. J. Gergen, 1985; Nunkoosing, 2000; Shotter, 1992b). Language is action orientated, for “people can be ‘moved’ linguistically into treating their circumstances in certain socially recognised and recognisable ways” (Shotter, 1992b, p.148). Subjective views about the world are assumed to be constructed and altered by the interactions and experiences with others, and as Gergen & Gergen (1984) have argued, the stories people tell of themselves are products of social interchange and the act of storytelling is the human activity of generating meaning (K. J. Gergen & Warhus, 2001). In this sense, social constructionism rejects the view that concepts, and lived experiences are absolute and timeless; instead the emphasis is placed on the view that concepts and experiences gain importance through social usage, and meanings are socio-historically specific. To view concepts and experiences as socially constructed is not to suggest that they are not real but to argue that the knowledge and meanings we construct and ascribed to our experiences, and the way we make sense of those multiple realities, is socially and linguistically mediated.

The ‘turn to language’ as another way to understand lived experiences and social realities has brought forth the criticism that social constructionism contends that the materiality of experiences does not ‘exist’. This criticism is fuelled by the emphasis that language is productive rather than reflective as “[r]eality’ isn’t so much mirrored in talk and texts as actually constituted by them” (Edley, 2001, p.435, italic original) and by Derrida’s often quoted idea “that there is nothing beyond the text” (Cromby & Nightingale, 1999, p.7-8). However, as noted by Stam (2001), the social
constructionist position is that it is interested in descriptions of the entities and not
the entities themselves. It is concerned with accounts, and the construction of these
accounts, by the use of socially available discursive resources. Furthermore, Edley
(2001) argued that the criticism is founded on an epistemological and ontological
confusion. He contended that critics mistake the emphasis on language and text, as
epitomised by Derrida’s idea, as an ontological rather than an epistemological
pronouncement. The suggestion that there is nothing (a reality) outside of the text is
read as an ontological claim which is then interpreted as an assertion by
constructionists that only talk is real and all around it is constructed or imagined.
Laclau and Mouffe (1985) provided a useful example to illustrate the misconception
of emphasis on language and text as a rejection of materiality, they suggested that

“The fact that every object is constituted as an object of discourse has nothing to do with whether there is a world external to thought, or with the realism/idealism opposition. An earthquake or the falling of a brick is an event that certainly exists, in the sense that it occurs here and now, independently of my will. But whether their specificity as objects is constructed in terms of ‘natural phenomena’ or ‘expressions of the wrath of God’ depends upon the structuring of a discursive field. What is denied is not that such objects exist externally to thought, but the rather different assertion that they could constitute themselves as objects outside any discursive conditions of emergence.” (p.108, italic original)

A subjective account or a personal story is about how the world as understood by that
individual. We use language “as the medium through which we come to understand
or know the world” (Edley, 2001, p.437) and we draw on the available discourses to
help us make sense of the experiences in storied forms. The “epistemic sense” of
social constructionism, as suggested by Edley, produces the assumption that we
cannot know the reality outside of discourse but it is instead a product of discourse.
However, this should not be taken to mean a rejection or denial of an event’s
occurrence as illustrated in the example offered by Laclau and Mouffe. Their example is useful as it provided a way to clarify the ontological and epistemological positions specific to this research. The research focus in this thesis is on the illness experience of living with HIV, a ‘real’ disease with tangible consequences. The deterioration of the material body that ends with corporeal death or anti-HIV treatments improving corporeal health are not constructions. However, just as the ‘earthquake’ example illustrated, how the experience of these events is made sense of is dependent on the available discourses. The understanding of social phenomena such as illness experiences demands the examination of the ‘real’ body processes and practices and the way these processes and practices are constructed in our talk. My interest here is on the way people ‘talk’ about and construct meanings in their experiences as a corollary of being infected with HIV. From this perspective, the research, on which this thesis is based, is drawing on the material-discursive approach, which is an approach “to material being which could be readily reconciled with discursive analysis [and] to incorporate an understanding that activity and context profoundly affect not only socio-linguistic meaning but also the material aspects of our existence” (Yardley, 1997, p.10).

In the next section, I want to discuss the pertinence of people’s stories with which to understand their lived experiences. Also in this section, I will also make clear the way the term ‘story’ is used by delineating its usage with reference to its connection with ‘narrative’. The purpose for doing so is to achieve conceptual clarity when subjective stories are used as the analysis materials.
3.4.2 Stories as Analysis Materials

“The stories people tell are important not only because they offer an unmatched window into subjective experience, but because they are part of the image people have of themselves…They shape how we conduct our lives, how we come to terms with pain, what we are able to appropriate of our own experience…” (Ochberg, 1988, p.173-174)

I want to begin this section by clarifying the use of the term ‘story’ as compared with the term ‘narrative’. I would argue this is necessary as these two terms are used interchangeably in scholarly literatures (e.g., Charmaz, 1999; Ezzy, 2000; Mello, 2002; Thomas-MacLean, 2004; Werner, Isaksen, & Malterud, 2004), and ‘narrative’ has also been used in the study of illness experiences (Bury, 2001; Ezzy, 1998, 2000; Nilmanat & Street, 2004). With respect to whether to use ‘narrative’ or ‘story’, Frank (2000a; 2000b; 2001) offered a way of examining this issue when he responded to a criticism levelled at him for using ‘story’ and ‘narrative’ interchangeably (Atkinson, 1997). In response, Frank (2000b) argued that in the act of providing an account of lived experiences, people tell ‘stories’, not ‘narratives’. Frank’s position is supported by Redwood (1999) who defined a ‘story’ is what an individual tells while a ‘narrative’ is the researcher’s account of the story in academic endeavours. From this perspective, it would appear that ‘story’ and ‘narrative’ refer to the same account but the different terms refer to the different positions from which the account is produced and engaged. In his examination of the illness experience, Frank (1995) also referred different types of narratives pertaining to the illness experience. A ‘narrative’, as he described, is “the most general storyline that can be recognized underlying the plot and tensions of particular stories” (p.75). In spite of Frank’s seemingly clear description of a ‘narrative’, Riessman (1993) suggested that there is considerable disagreement on the definition of a ‘narrative’ as some definitions include “just about
anything” (p.17) whilst others are more restrictive and precise. However, Riessman (2004a) made clear that “[n]arratives do not mirror the past, they refract it” (p.708). An interesting and important conceptualisation as it makes clear that narratives should not be treated as accurate or factual accounts of an objective ‘reality’ but are means through which an individual makes sense of the past and its connection with the present and the future.

From the descriptions presented, it would appear ‘narrative’ indicates the structure which underpins the story, and the analysis of narratives is to locate the structures on which storytellers rely to make their stories compelling. Frank (2000b) further argued that although the narrative structure is important, to privilege it over the ‘story’ itself in the research analysis may marginalise what is important to the storytellers, which in this instance, are the research participants. Stories are what participants offer to the research, and informed by the work of Mishler (1986) on research interviewing and the empowerment of respondents, my attention is on “respondents’ problems, specifically, their efforts to construct coherent and reasonable worlds of meaning and to make sense of their experiences” (p.118). Informed by the clarifications offered by Frank and Redwood, I will use ‘story’ when referring to accounts presented by participants and ‘narrative’ as the theoretical concept on which stories are constructed.

Stories are important, for they offer a way to understand “experiences that may otherwise be inaudible” (Thomas-MacLean, 2004). The defining characteristic of human beings is that we are story creators and tellers (King, 2001; M. Murray, 2003). Mattingly (1994) suggested that “[w]e make as well as tell stories of our
lives” (p.811), and the need to make sense, that is, to locate meaning and coherence in life events is pivotal to our understanding of our experiences (Frankl, 1984; King, 2001). These are useful ideas as they offer a way to examine the stories of individuals in their efforts to construct meanings to their lived experiences. They are linguistic resources with which individuals could make sense of their lived experiences by organising these experiences into coherent accounts. The stories people tell of themselves are not only to describe but efforts to persuade (Ochberg, 1996; Riessman, 1992). Stories are produced in the intersubjective space, and they are socio-culturally embedded. People share their stories in a particular way so their actions are constructed as reasonable and acceptable within the socio-cultural and historical contexts in which the stories are produced and located. Stories are valuable social resources as they serve to connect people as well as to enable individuals to understand, to articulate and to share subjective experiences.

The act of storytelling “moves us into the place where we trust what we know, even if it can’t be measured, packaged, or validated empirically” (Simmons, 2001, p.xvii). Storytelling also facilitates movement from a subjective, local view to a broader, global one by situating subjective experiences into another or a new perspective (Boykin & Schoenhofer, 1991); it is a way of finding new or different meanings in lived experiences (Simmons, 2001). There is a ‘need’ to tell stories, for stories broaden the context in which the storyteller lives as it is a way to make sense of subjective experiences by drawing on social resources that help to give contexts to these experiences. By telling stories, people could convince others of the way they made sense of their actions, as well as to enlighten and explain. However, they should not be construed as Machiavellian devices to persuade (Riessman, 1992) but
should be interpreted as creative ways through which people link disruptive events to mend the discontinuities caused by a trauma, such as an illness experience.

The story and the act of storytelling are important in the illness experience. In his book *The Wounded Storyteller*, a poignant and incisive title, Frank (1995) argued that people who are ill are wounded not only in body but also in voice, “[t]hey need to become storytellers in order to recover the voices that illness and its treatment often take away” (p.xii). The act of constructing and telling a story is a way the individual uses to negotiate the disruptions caused by the illness experience and to develop a sense of where she/he is in life and where she/he is going. Storytelling is, as Simmons (2001) argued, “a powerful tool for social, political and personal activism” (p.241).

Through stories about our everyday experiences, we are able to give meanings to a series of events that might have no apparent or profound connections. It is “by telling stories and writing history we provide ‘shape’ to what remains chaotic, obscure, and mute” (Ricœur, 1991, p.115). This idea of shaping chaotic or seemingly incoherent events through stories to express meanings is most useful in the experiencing of disruptive events such as a diagnosis of HIV. The disturbance experienced from disruptive events can be redressed and re-ordered by placing it within a narrative (M. Murray, 2002) through which the disruption is made comprehensible. Gergen and Gergen (1984) argued that comprehensibility is attained only by the historical context in which the stories are placed. ‘Time’ is critical in storytelling; the temporal structure which organises the events and the telling of these events provide coherence and meaning. A ‘narrative’ is situated in time and has a sequence in the
flow of events so to produce a ‘beginning’ and an ‘end’ (Hydén, 1997; Werner et al., 2004). This idea suggests that a narrative and a story are analogous and both are constructs that locate events in a time continuum so that the narrator or the storyteller has a means with which to link events that when put together produces an account that serves the intended purpose of conveying the story.

The situating of events temporally in the storytelling facilitates an understanding of an earlier event by the occurrence of a later one. From this perspective, it could be argued that one of the most important aspects of narrative is its potentiality to construct and to direct events that might otherwise have less significance if observed in isolation. The narrative structure conveys a goal or a valued endpoint to the story (K. J. Gergen, 1985, 2001; M. M. Gergen, 1988) which means we tell stories to construct meanings for ourselves and others. This is important as narratives are “stories we develop and discover in our own lives and in our interactions with others. Our narratives contain meaning – the meaning of our struggles, joys, lessons, loves, and illnesses, as well as themes about life, our hopes, our findings, our expectations, our fears – that which makes us real, vital, human beings. Narrative includes the context of our lives as well as fullness of the present moment, what is said and unsaid, gestures, expressions, tone, inflection, and posture” (K. Murray, 2004, p.77).

It is through stories that we make sense of the social world, and we use language to give interpretations of our experiences, which means we use language to do things, such as to express feelings, to solve problems or to engage in social interchange (Viney & Bousfield, 1991). People are able to render their personal experiences meaningful by the telling their stories (Ezzy, 1998, 2000; M. Murray, 2003) as evident in a counselling and psychotherapeutic context (Besley, 2001; White, 1995).
More significantly, in the context of my research, the focus is on the lived experiences of people with HIV, the expression of these experiences in the stories they tell and how these stories serve as resources with which they use to express, as ways to reconcile and to make sense of particularly sensitive or traumatic times and events in producing “success stories and moral tales” (Coffey & Atkinson, 1996, p.62); that is, stories that have a point which at times are imbued with morality and ethicality.

3.5 Summary

In this chapter, the intention was to be clear and unambiguous about the theoretical framework that informed the research on which this thesis is based. I argued for the utility of a qualitative research methodology in relation to the research aims, that is, to understand, to explore and to interpret subjective lived experiences with HIV. The research is informed by the relativist ontology of postmodernism and drew on poststructuralism as the epistemological stance by which a narrative analytic approach to participants’ stories is engaged. The research materials are the stories people tell and these stories, I would argue, are social constructions that are socio-culturally and historically situated. I argued that HIV is not a social construction but how people make sense of having an HIV-infected body is socially constructed and the stories they tell are mediated and constituted by language. Assuming a poststructuralist approach allows me to explore and to examine the constitutive power of language and the discourses that shaped stories of the HIV illness experience. This research does not privilege universality but individuality. What I
mean by this is that this research is not aiming to draw causality or to produce grand narratives that explain the lived experiences of all people with HIV.

In the next chapter, the second part of the methodology section, I will make clear the research protocol which guided this research, that is, the practical aspects of the research process.
Chapter 4: Methodology: Research Protocol

4.1 Introduction

In this chapter, the second chapter of the methodology section, I will discuss the design and protocol that guided this research. I will explain the recruitment process from the point when ethics approval was obtained to its completion. I will detail the participant selection criteria, and in doing so, I will provide the bases on which particular individuals were targeted and subsequently included into the participant group. I will provide profiles or pen portraits of the participants as means to offer the reader an awareness of some HIV-related biographical details that are pertinent to this research. I will also describe the research design, and the procedure deployed for collecting the analysis materials, the interview process and the manner in which the analysis materials were then organised for analysis. The analytic strategy will also be further discussed in greater detail.
4.2 Research Design

This is an in-depth qualitative research study involving eight participants who were interviewed twice about their subjective experiences with HIV and AIDS. Although participants were interviewed twice, the research is not positioned as a longitudinal study. The purpose for the second interview will be discussed in Section 4.4.5.

4.3 Participant Group Size

Patton (2002) suggested there are “no rules for sample size in qualitative inquiry” (p.244) but the number of participants required depends on factors such as the scope of the study, the quality of the materials obtained in interviews and the number of interviews conducted with each participant (Morse, 2000). It has been suggested that the number of participants in qualitative research is usually small (Mason, 2002; Miles & Huberman, 1994; J. A. Smith, 2003), for in-depth information from a small number of people is valuable particularly when the information is rich (Patton, 2002). In Chapter Three, I clarified the utility and advantages of qualitative research methodology when examining lived experiences particularly when the aim of the research is to understand subjectively constructed meanings ascribed to these lived experiences. In this context, a small number of participants makes it possible for me to perform intensive analysis of the research materials (Silverman, 2005). In determining the number of research participants, I drew on the grounded theory concept of ‘saturation’ (Willig, 2003), wherein data collection is completed when
additional interview materials no longer add richness to understanding about the research topic and issues (Mason, 2002; O'Leary, 2004).

4.4 Research Method

In this section of the chapter, I will detail the participant selection criteria, the recruitment process, strategy used to obtain the analysis materials, that is, the participants’ stories and the manner in which the interviews were conducted. I will discuss the interview questions and the development of an interview schedule. Lastly, I will discuss the purpose for having follow-up interviews as a part of the research design.

4.4.1 Participant Selection Criteria

The participant selection criteria were as follows:

1) the prospective participant has to have known of their HIV antibody positive status for at least two (2) years (that is, two years before 1999);
2) the prospective participant has to be able to converse in English;
3) the prospective participant has to be eighteen (18) or over in order for them to provide valid consent to participation in the research; and
4) the prospective participant has to have knowledge about HIV anti-retroviral treatments.
Criterion 1 aimed to include people with HIV who were able to tell stories about their lived experiences with HIV from a position where they could compare and contrast their lived experiences when effective treatments for the disease were absent or when the effectiveness of treatments was uncertain. Criteria 2 and 3 were for pragmatic reasons and I would expect these types of criteria were common in most academic research: firstly, English was chosen for this research because it is my preferred language when conducting research; secondly, to meet my legal and ethical responsibilities, it was prudent to only include people who were, within the legal framework, able to provide informed consent for participating in academic research. Criterion 4 aimed to include people who have had first-hand experiences with or knowledge of the routine of taking HIV treatments and the physical effects consequent to taking treatments, including both the beneficial effects as well as the adverse side effects.

4.4.2 Recruitment Process

Prior to commencing the recruitment process, approval from the University of Western Sydney’s Human Ethics Review Committee (HERC) was sought (reference number HE99/118). In the application for conducting the research, the University’s Ethics Protocol for Research Projects Involving Humans was adhered to.

The recruitment process was conducted in Sydney. A purposive sampling approach (Nichols, 1991; Silverman, 2005; J.A. Smith & Osborn, 2004) was utilised in this research because I wanted to target and recruit individuals with particular
experiences with HIV who were suitable in terms of the key questions this research aimed to answer. It has been argued that many qualitative researchers employ “purposive, and not random, sampling models. They seek out groups, settings and individuals where and for whom the processes being studied are most likely to occur” (Denzin & Lincoln, 2000, p.370). According to J.A. Smith and Osborn (2004), a purposive sampling approach enabled the research findings “to say: (1) a lot about the particular participants in the study, and (2) something about the broad group they represent” (p.232).

Within this sampling framework, some participants were recruited directly in that they were approached by me, while others were recruited through personal contacts or the ‘snow-balling’ strategy (see Miles & Huberman, 1994; Patton, 2002). The personal contacts were friends or professional colleagues of mine who worked in HIV organisations or services. They were provided with copies of the Information Sheet (Appendix 1) to give to appropriate and interested individuals. The Information sheet succinctly outlined the research project. My contact details were included on the Information Sheet so that interested individuals could contact me directly and in confidence.

The ‘snow-balling’ strategy was utilised for recruitment with individuals who agreed to participate in the research and those who declined to participate after learning more about the research. They were asked to inform other people they knew (e.g., friends, acquaintances, work colleagues) who fit the selection criteria, and likely to be interested in this research to contact me, or alternatively, for the contact details of

1 There were three men and one woman I contacted or made contact with me who declined to participate.
these people to be made available so I could contact them directly. They were asked to only provide general information about the research to others, specific details about the research were provided by me when contact was established with prospective participants. The initial communication with prospective participants who made contact or were contacted was by telephone. This initial communication was regarded as a consultation in which prospective participants were given detailed information about the research, its process and were able to ask any questions or raise any concerns they might have about their participation. Also during this consultation, the type of issues relating to their experiences of living with HIV that would be canvassed during the interviews was described. The main goal of this initial consultation was to ensure that prospective participants were clearly informed of the research process. When people agreed to participate, a mutually convenient time and venue for the interviews were arranged at the end of this consultation.

4.4.3 Data Collection

Face-to-face semi-structured in-depth interviews were conducted with participants. The advantages associated with this method of collecting analysis materials have been noted in literature (see Grix, 2004; Liamputtong & Ezzy, 2005; J. A. Smith, 1995; Wisker, 2001). The semi-structured interview approach was employed because it made available the ‘space’, and the opportunity needed, in order for participants’ unique stories about their experiences with HIV to be expressed and for particular points of interest to be pursued by the researcher. In this context, the semi-structured interview approach provided flexibility in the interview process that structured and unstructured interview approaches are unable to provide.
Each interview was between 60-90 minutes in duration; and each interview was terminated when there was a ‘natural’ end or that it was exceeding the agreed length of time. The interviews were audio-taped and the venues in which the interviews took place were determined by the participants, which included their homes, their workplaces and my workplace. The primary concerns for the interview setting was that they were conducted at a venue where the interviews could be clearly recorded and in which the participants felt relaxed and comfortable.

Prior to the commencement of each interview, the participants were given copies of the Information Sheet again and the Consent Form (Appendix 2) which detailed the interview protocol. They were asked to read the documents presented and to raise any concerns or queries they might have about the research. It was also made clear to the participants the manner and the circumstances under which the information they give about themselves would be used. Confidentiality issues were emphasised and they were informed that they would be given pseudonyms in the research as a way to ensure anonymity. To further instil confidence in the interview process for the participants, I explained that they could decline to answer questions during the interviews and it was possible to withdraw their participation from the research at any time, even after having participated in the interviews. It was explained to the participants that the interviews were not meant to provide counselling but that they would be given the opportunity to debrief after the interviews. My experience as a clinician made me aware that the issues raised and explored during the interviews could trigger emotional responses in the participants, as a precautionary measure,
contact details of appropriate counselling and support services were available to the participants should they require these services.

4.4.4 Interview Questions

The research questions and issues that guided the interviews attended to the ways in which people made sense of their lived experiences with HIV as well as the social and corporeal changes produced by the effective HIV treatments. Although I was clear about the questions I wanted to ask and issues I wanted to present to participants during the interviews, I was concerned about the way the questions were phrased so that they would produce narratives about their illness experiences. I considered the different ways questions could be constructed that would turn research participants into storytellers rather than as people politely giving responses to thoughtfully developed questions. In the end, I decided there were not ‘perfect’ questions but rather I needed to constantly remind myself of my research questions as a way to guide the questions asked during the interviews. I decided the opening question to the interviews needed to be broad and wide-ranging as I wanted participants to tell the particular stories that were important to them. I began the interview by asking the question “Can you tell me what it’s like living with HIV in recent years?” If necessary, questions relating to the availability of treatments were directly asked, for example, “Since anti-retroviral (anti-HIV) treatments became available, what did this mean to you?” or “How did you deal with the changes or issues or challenges that the treatments created?” Subsequent questions were asked with reference to the responses participants provided to the opening question. As a way to ensure that the interviews would draw out relevant stories, I designed an
interview schedule with prepared questions (Appendix 3) to be asked in the event of participants needing prompts or triggers to assist them in telling their stories. This was an useful exercise as the design of an interview schedule encouraged me to think explicitly about what I wanted to canvass during the interviews and helped with the wording of particular questions that might be sensitive or confronting (J.A. Smith & Osborn, 2004).

Not all questions on the schedule were asked when it became clear that the questions would disrupt the flow of pertinent stories participants wanted to tell. Depending on the responses from participants, follow up questions were asked so that they were given the opportunity to clarify or to elaborate their responses. Interviews are social activities and my interview questions are parts “of the process through which a narrative is collectively assembled” (Silverman, 2005, p.47). I regarded each interview as an ‘organic process’. That is, I listened to the stories participants wanted to tell and then to engage them in a discussion about particular aspects of those stories and the obvious trajectories that these stories would take us. I also aimed to draw out other stories which were important and relevant. From this perspective, the way that the interviews was conducted was like conversations (see Denzin & Lincoln, 2003; Kvale, 1996; Silverman, 2005) where the participants and I ‘talked’ about their lives, which included the specific events they experienced, the meanings they constructed to make sense of these experiences and other unexpected stories triggered by the telling of a story. Some of these unexpected stories were less directly related to my research but I decided that hearing them could facilitate a deeper understanding of the stories that were integral to my research. For this reason, I decided all stories participants wanted to tell were relevant and therefore I did not
interrupt or guide the conversations in the direction I thought was appropriate, but rather allowed for each story to be told before asking a question that was ‘more directly’ related to the research. Reading the work of Arthur Frank, particularly his book *The Wounded Storyteller* (1995) greatly influenced the way I thought about the research questions and the questions asked when in conversation with participants. Moreover, I preferred the term ‘conversation’ because it connoted the social interactivity of the time spent with participants. The approach to the interviews allowed a flow in the dialogue that was casual and highlighted that the interviews were occasions of sharing and that the materials were jointly constructed by the participants and me. This idea was supported by Grbich (1999), who argued that “the interview is a form of discourse shaped by asking and answering questions…the interview becomes a speech event, the discourse of which is jointly constructed by interviewer and interviewee” (p.86). The interviews were a “co-operative inquiry” where participants were not “treated as passive objects of observation” (Reason & Heron, 1995, p.122). Furthermore, by referring to the interviews as conversations, it underscored my involvement in the research process whereby my subjectivity was a significant aspect of this research.

4.4.5 Follow-Up Interviews

At the end of the first interviews with participants, they were asked to participate in a second or follow-up interview in approximately twelve months. All participants agreed to this request. Also at the end of the first interview, an offer of providing them with copies of their transcribed interviews was made to the participants, although not all participants accepted this offer. Of the eight participants, four
accepted the offer and copies of their interviews were made available to them soon after they were transcribed. On separate occasions or at the time of their second interviews but before the commencement of the interviews, I shared with them my thoughts and ideas about the stories they told and invited them to comment. The significance of this issue will be discussed later in the Coding section.

By the end of the process, two interviews were conducted with each participant\(^2\). The rationale for the second interview component in the research design was to afford me the opportunity to conduct preliminary analysis of the materials from the interviews and to ask follow-up questions concerning responses given during the first interviews. Moreover, operating on the assumption that life circumstances could change for the participants from one year to the next, I was interested to have another opportunity to speak with them to further explore their experiences with HIV. In this context, the second interviews were opportunities to note how the stories articulated and shared in the first interviews might have changed (or not) by the contexts in which the participants found themselves over twelve months after the initial contact. I considered the second interviews as a continuation of the first interviews in that new issues were not introduced by me except those which emerged from the first interviews.

On a theoretical level, the inclusion of follow-up interviews in the research design was to acknowledge that stories people tell are situated within a temporal and socio-culturally context. Riessman (1993) argued that stories are influenced by social discourses and power relations and since they are unstable over time, there is no

\(^{2}\) Participant 2 – Lisa contacted the researcher independently requesting that she would welcome a third interview in order for her to further expand her thoughts about the research topic and issues.
reason to assume that an individual’s story would be consistent from one setting to another. From this perspective, the second interview component was to (re)engage with participants at another time in their lives with the intention of affording them the opportunity to (re)tell their stories with HIV in possibly different circumstances. Gergen (1973) argued that “…social psychology is primarily an historical inquiry…it deals with facts that are largely unrepeatable and which fluctuate markedly over time. Principles of human interaction cannot readily be developed over time because the facts on which they are based do not generally remain stable. Knowledge cannot accumulate in the usual scientific sense because such knowledge does not generally transcend its historical boundaries” (p.310). Informed by Gergen’s work, Burr (2003) argued that all knowledge, including psychological knowledge, is historically and culturally specific and therefore urged that psychological inquiries need to extend beyond the individual and into social, political and economic realms for the understanding of social life.

The notion that knowledge is historically specific underscored the premise that the stories constructed in the first interviews were shaped by the social, political and economic contexts in which the participants were situated at that particular time, it was therefore of interest for me to explore the sameness or changes in the stories when issues were revisited at a different time and possibly in a different social context.
4.5  The Research Participants

The participant group consists of five men and three women. Of the eight participants, seven participants identified as gay or lesbian and one as heterosexual. The age of the participants at the time of their first interviews ranged from 33 to 51. The first and second interviews were conducted between 1999 and 2003. Four of the eight participants had received an AIDS diagnosis. Three participants were not using HIV treatments at the time when they were first interviewed. Four of the eight participants were born overseas but regarded their first language as English. Of the eight participants, four were in regular paid employment (either full-time or part-time) and four were receiving financial support from Centrelink.

4.5.1 Participant Profiles – Pen Portraits

I want to introduce the participants in greater details because it is vital in the framework of this research that the participants are known and that their HIV-related biographical details that are pertinent to this research are available. I will introduce the participants in the order they joined the research. Obviously for reasons of privacy and confidentiality as explained to the participants, not only pseudonyms are used, but any identifying details are also either omitted or altered. In providing background descriptions of the participants, some details are replaced by a similar or a broader description so not to reveal the specifics that could breach their anonymity. This issue is especially pertinent for the women participants as the number of women

3 Centrelink is an agency of the Department of Human Services, a department of the Australian government.
with HIV in Australia is comparatively fewer than that of men (K. McDonald, Bartos, & Rosenthal, 2001) and therefore any specific details about them, particularly those who made themselves visible by being candid about their HIV status, are more likely to be identified. The months and years in brackets following the names of the participants refer to when the first and the follow-up interviews were conducted.

Participant 1 – **Eric** (1\(^{st}\) December 1999; 2\(^{nd}\) March 2001): Eric was born in 1956 and in the Middle East to English parents. He lived mostly in England since childhood before migrating to Australia. Eric learned of his HIV status in 1986 but had not received an AIDS diagnosis. At the time of the first interview he was using treatments for HIV and has been doing so since 1996. Eric identified as gay and lived in Sydney with his partner whom he believed to be HIV antibody negative. Eric’s previous partner died from AIDS in the mid 1990s. Eric worked in an AIDS related community organisation but his professional training was in a non health-related field.

Participant 2 – **Lisa** (1\(^{st}\) January 2000; 2\(^{nd}\) February 2001; 3\(^{rd}\) 2002): Lisa was born in 1958 and was diagnosed with HIV in 1985; she believed she was one of the first women in Australia to have been diagnosed with HIV. She disclosed she contracted the virus by sharing injecting equipment. She was diagnosed with AIDS in 1994 and said she had prepared for imminent death from AIDS on several occasions. Lisa had used medications for HIV since 1993 and had used AZT as monotherapy. As well as using HIV treatments, she said she was also using medications for a mental illness.

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4 In Australia, HIV continues to be transmitted through sexual contact between men (A. McDonald, 2002; National Centre in HIV Epidemiology and Clinical Research, 2002; 2005), and women comprise of approximately 6% of all people with HIV (FPA Health, 2002).
Lisa was born in Australia, and was the youngest child in her family. She lived alone and did not have a regular partner. Due to her physical health, she was not in regular employment and this was the situation for several years. She had worked in the area of public relations. Although not in regular employment, Lisa continued to be involved in volunteer work when feeling well. Lisa self-identified as a lesbian. The third interview was instigated by Lisa because she believed she had more to say about the research topic. Lisa died in 2003 from a possible AIDS-related condition.

Participant 3 – **Ben** (1\(^{st}\) July 2000; 2\(^{nd}\) August 2001): Ben was born in Sydney in 1953 and was again living permanently in Sydney when the interviews took place. Ben had lived overseas for about fifteen years before returning to Australia in the mid 1990s. He lived alone and did not have a regular partner. He self-identified as gay. Ben was diagnosed with HIV in 1987 and was diagnosed as having AIDS in 1991. He started using HIV treatments at the end of 1996. He was not in regular paid employment at the time of the interviews but was very active in volunteer work within the HIV sector as well as contract work when opportunities arise. Ben’s professional training was in the entertainment field in which he said he was relatively successful.

Participant 4 – **Helen** (1\(^{st}\) April 2001; 2\(^{nd}\) May 2002): Helen was born in 1955 outside of Australia but in an English-speaking country. She had lived in Australia for a long time and considered it to be her permanent home. Helen had three children with a male partner who subsequently died from AIDS in the 1980s. She was diagnosed with HIV in 1985 but had not had an AIDS diagnosis. Like Lisa, she believed she was one of the first women in Australia diagnosed with HIV. Helen was
a worker in HIV health education and was very active politically in developing
necessary services for women with HIV in Sydney. At the time of the first interview,
she had moved out of HIV work and was not in regular employment. Also at the first
interview, Helen said she had ceased treatment use after two years. At the time of the
interviews, Helen was living with a female partner and their children.

Participant 5 – **James** (1st April 2001; 2nd June 2002): James was born in the same
country as Helen in 1960. He received his HIV diagnosis in 1992 but had not had an
AIDS diagnosis at the time of the interviews. At the time of the first interview, James
was not taking HIV treatments but had taken them for the six years previously. James
had worked in a variety of jobs but at the time of the first interview he was working
part-time in the HIV sector and had done so for the previous four years. In his spare
time, James was pursuing an interest that he hoped to turn into a commercial
enterprise. He reported that he has a mental illness and consults with a mental health
worker regularly. James self-identified as gay and was in a relationship with a
partner who was also known to be HIV antibody positive, they lived separately.
James lived alone in an inner city suburb of Sydney.

Participant 6 – **Athena** (1st January 2002; 2nd June 2003): Athena is the youngest
participant of the group. She was born in an English-speaking country in Africa to
English parents in 1969. She has lived in Australia since childhood. She learned of
her HIV status in 1997 when she went for a routine checkup. At the time of the first
interview, Athena had not used HIV treatments and the possibility of using
treatments was a prominent concern for her. Prior to her diagnosis she had wanted to
be health care worker but had not pursued her studies in that area since. She had
worked for an AIDS community-based organisation but at the time of the interview she was not in regular employment. She and her male partner, whom she believed to be HIV antibody negative, were planning to move to a rural area in the near future. The second interview was conducted in Athena’s home outside of the Sydney metropolitan area. She was studying full-time in a tertiary institution. During the period between the first and second interviews, Athena had started but had also ceased HIV treatments.

Participant 7 – Dan (1st July 2002; 2nd September 2003): Dan was born in Australia in 1960 and was living in Sydney with his regular partner of over ten years; his partner was believed to be HIV antibody negative. Dan self-identified as gay and said he had been active in both gay and HIV politics. He received his HIV diagnosis in 1985 and an AIDS diagnosis in 1994. He started to use HIV medications in 1993 and had not taken any break from them. Dan had worked in the entertainment industry and had travelled extensively for his work. After decided to retired from that field, he began work in the HIV sector with a government department. In 2003, Dan had separated from his partner and was living in another capital city in Australia. The second interview was conducted in that capital city. He was in shared accommodation and was not in paid employment. In 2004, Dan made contact to inform that he and his partner had reconciled their difficulties and were again living together. They had moved permanently away from Sydney.

Participant 8 – Steve (1st July 2002; 2nd October 2003): Steve is the oldest participant in the group. He was born in 1951 and in Australia. Steve was diagnosed with HIV in 1986 but had not had an AIDS diagnosis. He started to use HIV treatments when
they became available in 1996. He self-identified as gay and lived alone at the time of the first interview. He had two partners who died of AIDS whom he cared and nursed until they die. He also cared for friends who died from AIDS. Steve described his work career as mainly administrative and was working in this capacity with an HIV organisation when he was first interviewed. In 2003, Steve had moved into shared accommodation and had changed jobs. He was living in a part of Sydney in which he had not lived before which he thought was a significant change for him.

4.6  The Analysis of the Materials – the Stories

The procedure for ‘doing’ qualitative research analysis is not always sequential. This became apparent when I was transcribing and coding the materials. I was struck by the experience that when transcribing and coding the research materials, I was already analysing the materials by the way I was making sense of them, even on a logistical basis. In this section, I will describe the transcription protocol, the coding practice and the implications that the logistics involved in the organisation of the materials had on the analysis. I will describe the analysis strategy employed, which included the use of case studies and a narrative analytic approach to the materials.

4.6.1 Transcription

I considered it was an important part of the research process for me to transcribe the interviews. There were two reasons for this decision. Firstly, as I was the interviewer and a participant of the conversations, I could recall the contexts in which particular
questions and responses were asked and given, it was more likely that I could identify some words that were unclear due to reasons such as the lowering of voice volume, unexpected intrusive noises or the use of particular jargons specific to issues pertaining to HIV. However, these were not the only imperatives for me to transcribe the interviews, for if the interviews were transcribed by someone else, it would be expected that I read the completed transcripts and listen to the taped interviews in order that mistakes or omissions in the transcripts could be rectified. Secondly, the benefit of transcribing the interviews myself, the rehearing of the interviews and the need to immerse in the interviews as would be required when transcribing, afforded me the opportunity to start thinking about the stories presented by the participants soon after the interviews were completed. In this context, the act of transcribing initiated the analysis process. This point is supported by Riessman (1993) who suggested that “[a]nalysis cannot be easily distinguished from transcription” (p.60). Furthermore, when listening to the stories as I was transcribing, I was starting preliminary coding of the interviews as means to organise the vast amount of materials that were available in a single interview.

Another benefit to transcribing the interviews personally was that it enabled me to identify important non-lexical or non-verbal utterances from the participants that were important in the context of the stories they were telling. Transcription of what is spoken and to turn it into written text entails not only the spoken words but of the non-lexical qualities in speech such as the emphasis or intonation we placed on particular words or indeed the silences (Malson & Ussher, 1997). There are different transcription conventions or systems (see Malson, 1995; O'Connell & Kowal, 1995; Potter & Wetherell, 1987; Riessman, 1993) and common errors in the transcription
process have been noted (Easton, McComish, & Greenberg, 2000) which led some researchers to further develop conventions that could redress errors and unreliability (MacWhinney & Snow, 1990). However, the purpose for transcription needs to direct the way the interviews are transcribed. The transcription convention used in this research privileged readability of content rather than detailed reproduction of speech features such as the timing of length of pauses. I endeavoured to re-present the participants’ stories and conversations we had with as little editing as possible. This, as Ariss (1997) argued, allowed individual subjectivities to emerge through idiolect. Additionally, I was informed by ideas offered by O’Connell and Kowal (1995) whose recommendations for transcribers seem to suggest that the process is to produce transcripts that are useful to the particular research enterprise, and to avert from conventions that exacerbate confusion or ambiguity\(^5\) when speech is turned into text which undermines the utility of the transcripts. Their recommendations served as a useful guide for my transcribing practice.

I am aware that “transcripts have been asked to bear a heavier burden of scientific intelligibility than is reasonable” (O’Connell & Kowal, 1995, p.105), for they serve as important records of what was said during interviews. However, there are limits to what transcripts can provide such as that they cannot illuminate the abstract or subtle and the non-verbal components that permeate human interactions. Bearing this in mind, I did not strictly adhere to one particular transcription convention or system but aimed to ensure what was said by both participants and myself were accurately transcribed, to produce transcripts that are readable and to serve the form of analysis I aim to undertake for this research. I transcribed all that was said during the

\(^5\) For example, O’Connell and Kowal (1995) referred to the use of supernumerary symbols which interrupt the internal integrity of words (e.g., ‘floo\(t\)’, ‘v(e(h)ry’) as a way to indicate how the word was pronounced or possible emotions attached to the word used.
interviews except for identifying details that I deemed could compromise the anonymity of the participants. Names of people and places participants mentioned were noted by initials or by the type of relationship participants has with the person (e.g., partner) so to further ensure anonymity. I did not remove repeated words, unfinished words or the non-lexical utterances such as ‘um’, ‘oh’ and ‘ah’ for I consider they are parts of the linguistic process in producing a phrase or sentence which formed the stories or as parts of an interaction between people in conversations. Words in square brackets are words not used during the interviews but are added by me during transcription to provide clarity (e.g., it [HIV]). The use of particular punctuations such as exclamation marks (!) and question marks (?) were used to denote the tone of the utterance. Words in italic were to show that the speaker had infused emphasis and intensity in these words. Other non-lexical communications such as a laugh (laughs) or a sigh (sigh) were noted for they could provide a sense of the occasion or to present the ‘spirit’ in which an utterance was made. I did not time the pauses in between utterance as is the practice of some conventions but I did note pauses by the use of an ellipsis (...)⁶; and when pauses were much longer, this was noted by simply writing (long pause). Interjections by the listener were noted differently depending on the circumstances. When appropriate, the interjections were incorporated into the transcriptions of what the speaker was saying (e.g., A: This is taking too long (B: Not true.) to write.); or if the speaker stopped talking due to an interjection, this was denoted by the ‘equal’ sign (=).

⁶ In the analysis chapters where sections of the transcripts were used, some parts of what was said were omitted as they were unrelated or extraneous; these omissions were denoted by an ellipsis in curve brackets, that is, (...).
4.6.2 Coding

At the completion of transcription and having listened to the interviews a couple of times to ensure that there were no typographic errors or mishearing of words, the next step was to identify the sections of the transcripts which appear to take the form of a story that are significant to this research. This was done by repeated reading of each transcript to firstly develop an appreciation of the interview as one story, that is, how the participants and I started our conversations, what issues were raised, the directions the conversations took and the ‘mapping of the territories’ explored in the course of the interview. I would also argue here that the repeated reading of the interviews is necessary and crucial in order to appreciate the contexts in which different stories are located in the interviews. Having gained this appreciation for each interview, informed by the work of Ussher (2003a; 2004) the transcripts were then coded line-by-line for specific themes or stories; these themes or stories are then collated to check for patterns of variability and consistency across all transcripts as well as to identify the significance or meanings of the different stories told. The themes or stories were identified at the “manifest level”, that is, able to be read in the transcribed texts, and at the “latent level”, that is, themes or stories which underlie the phenomenon (Boyatzis, 1998). The identification of themes or stories involved reflexive practices which required me to constantly reflect on my own position in the reading of the materials.

At this stage of the coding process, it started to merge with the analytic process as the identification of themes or stories in the texts also began to emerge as the focus of analysis. Following Cosgrove and Riddle (2003), who employed thematic
decomposition in their work, these themes from participants’ stories were then grouped and examined in terms of their function and effects. Interestingly but not unexpectedly, as I immersed myself in the reading of the transcripts and began to identify the stories told, I noticed my ideas and the focus of my analysis also changed. This experience was noted by Riessman (1993) who suggested that as the researcher engages deeply with the materials, analytic ideas change. Moreover, when transcripts are rigorously studied, “features of the discourse often “jump out,” stimulated by prior theoretical interests and “fore-structures” of interpretation (Riessman, 1993, p.57).

My approach to the coding and reading of the transcripts could be described as being informed by ideas embedded in grounded theory methods, such as, developing analytic codes and categories from the research materials and not to engage the materials with preconceived hypotheses (Charmaz, 1995). The coding process was also influenced by knowledge I gained from the review of available literatures, my personal and professional experiences with HIV, the field notes I took at the end of interviews as well as, and perhaps most influentially, the comments participants made about the content of the interviews and my ideas when I conversed with them after they had the opportunities to read through their respective transcripts. The incorporation of participants’ thoughts and views in the coding process and analysis is important within the context of the theoretical framework of this research.
4.6.3 Analytic Strategy

The presentation of participants’ stories in the analysis was done so by drawing on elements of case study methodology. Stories of particular participants were presented as case examples to illustrate particular phenomena or experiences. I found elements of case study methodology useful “when “how” and “why” questions are being posed…and when the focus is on a contemporary phenomenon within some real-life context” (Yin, 2003, p.1). More specifically, I also drew on elements of a multiple-case study approach in that the analysis materials (the participants’ stories) are treated cumulatively (Kompier, Cooper, & Geurts, 2000), for this approach offers the researcher the opportunity to develop new theories (Willig, 2003). In this context, I am also treating the stories as “explanatory case studies” (Willig, 2003, p.74) in that the aim is not only to provide detailed descriptions but to also generate explanations by exploring, through the use of pertinent theories, the significance of the constructed meanings embedded in the stories as means to make sense of subjective experiences.

The analysis is informed by a narrative analytic approach within a poststructuralist framework. A narrative analytic approach takes the story as the object of investigation (Bury, 2001; Riessman, 1993), attends to the context in which the story was generated and told (Bury, 2001), and “embraces more fully the meaning-dependent and ambiguous nature of human action” (Liampittong & Ezzy, 2005, p.128). I am interested in the stories and how participants make sense of their experiences and position themselves within the social reality of living with HIV and AIDS in the temporal frame of the post-treatment era. The analysis is interested in
the participants’ constructed stories about their lived experiences which are shaped by available discourses. The stories people tell or participants’ “narratives do not simply report events but rather give a teller’s perspective on their meaning, relevance and importance” (Cortazzi, 2001, p.384). In the presentation of the stories, informed by the work of Riessman (1990), I will identify “longer stretches of talk that take the form of narrative – a discourse organized around time and consequential events in a ‘world’ recreated by the narrator” (p.1195). Thus, long extracts from interviews were used in the analysis as a way to maintain the integrity of the participants’ stories and to illustrate how the stories were constructed. The narrative analytic approach I employed examines the ways in which the participants’ stories are used to construct meanings, to construct subjectivity and how their constructed stories are shaped by available socio-cultural discourses. I will explore the manner in which discourses (e.g., HIV and medical) constituted and regulated the diseased body and lived experiences of people with HIV in the post-treatment era. As such, the analytic focus will also examine subject positions and the language used by participants who positioned themselves or are positioned by others as people living with a chronic illness. My approach is informed by the poststructuralist concept of ‘subject position’, which implies “position within a particular discourse which may be occupied or taken up by a person, providing a basis for their identity and experience” (Burr, 2003, p.204).

In analysing participants’ stories, I also drew on ‘thematic decomposition’ (Marshall, Stenner, & Lee, 1999; Stenner, 1993) as part of the analytic strategy. This analytic framework requires a close reading of the analysis materials that separate a given text into coherent themes or stories, as well as to trace these themes or stories running
through the text (Marshall et al., 1999). It assumes, common to most discursive and narrative analysis, stories do not mirror a putative reality but are “constructed, creatively authored, rhetorical, replete with assumptions and interpretations” (Ussher, 2003b, p.134). Furthermore, the constructed-ness of stories suggests that the way participants made sense of their stories is by adapting stories that are already available, such as, stories about being ill, living with and recovery from an illness. As such, these “‘socially sedimented’ stories can be well thought of as trans-individual, historically localized, culturally specific formations of language-in-use” (Stenner, 1993, p.114). In this context, narratives are also “genres” (Daiute & Lightfoot, 2004) in that they are “culturally developed ways of organizing experience and knowledge” (p.x). A narrative approach to participants’ stories about their lived experiences with HIV is that their stories are constructed in and through historically and socio-culturally available discourses and practices as well as through shared patterns of meanings. “Narratives are laced with social discourses” ( Riessman, 1993, p.65) and are also “specific discourse forms, occurring as embodiments of cultural values and personal subjectivities” (Daiute & Lightfoot, 2004, p.x). From this perspective, I am using a narrative approach to examine discursive resources participants employ to make sense of their experiences through their stories. A narrative approach to the research materials (the stories), emphasises and brings into prominence the language used and the social functions of discourses in shaping the manner by which participants make sense of their illness experiences. The notion of language as having a ‘function’ is based on the assumption that people use language to ‘do’ things, to interact with their social worlds (Potter & Wetherell, 1987; Wetherell & Potter, 1988). According to Cortazzi (2001), narratives could be analysed based on their functions, that is, the purposes of participants’ stories. In this
context, the analysis aimed to address the four key thesis questions by examining what the participants aimed to ‘do’ in their stories, that is, the functions of their stories in illustrating the ways they make sense of their illness experiences with HIV, the significance of the treatments, their negotiations with medical discourses and practices, and their subjectively constructed notions of a meaningful life.

4.7 Trustworthiness of Research Analysis

The next section of the thesis (Chapters Five to Eight) presents and analyses the constructed stories people tell of their lived experiences with HIV. Prior doing so, I want to discuss the trustworthiness of research analysis.

Questions of veracity, that is, truthfulness in the analysis and findings, depend on epistemological and ontological stance. As noted in Chapter Three, a postmodern approach to research regards objective knowledge and truth to be contestable, and that reality is socially mediated and interpreted (Power, 2004). In this context, what is produced, that is the knowledge the analysis chapters contain, are my interpretations; these interpretations are not ‘fixed’ but are informed and constructed by my subjectivity and the social, political and historical contexts in which this research and myself are situated. Parker (2002) suggested that there is plurality in interpretative research work as there is a surplus of meanings, which means that additional interpretations, other than those presented by the researcher, are always available. It is argued that the researcher’s subjectivity, his/her attributes and perspectives are central to the research endeavour in producing a rigorous piece of
work that has integrity (Johnson, 1999; Ward-Schofield, 1993). Tindall (2002) argued “[a] reflexive account that reveals the researcher’s story allows the reader to identify the level of understanding at which the researcher worked, their tendencies, preferred models, biases, preoccupations and blind spots. This then enables others to reinterpret the findings to ‘read’ the analysis differently” (p.157). I have endeavoured to be reflexive in the research process by making explicit my subjectivity and the perspective from which I engaged with the research. However, reflexivity is not in and of itself an instrument to establish or to demonstrate validity in research, for the purpose of reflexivity in qualitative research is not to produce an objective or value-free account of the phenomenon. More pertinently, the notion of validity in qualitative research “is not to produce a standardized set of results that any other careful researcher in the same situation or studying the same issues would have produced. Rather it is to produce a coherent and illuminating description of and perspective on a situation that is based on and consistent with detailed study of the situation” (Ward-Schofield, 1993, p.202).

The above discussion should not be interpreted as a negation of the relevance of validity in judging the quality of qualitative research; a point emphasised by Morse (1999) who suggested that although the notion of validity in research is “operationalized very rigidly in quantiative texts, and these instructions are not pertinent to qualitative inquiry” (p.717), this does not mean that it should not be considered nor be constructed in a way that suits the conditions and circumstances of qualitative research. The validity issue in qualitative research has been a contentious debate (Morse, 1999; Riessman, 1993; Silverman, 2005; Sparkes, 2001), and there are different ways in which the quality of qualitative research are assessed (e.g.,
Hammersley, 1998; Parker, 2002; 2004; Willig, 2003; Yardley, 2000). In examining the validity issue in the context of qualitative research, I am informed by the ideas posited by Riessman (1993; 2002) who argued that validity in a narrative approach to analysis is about the trustworthiness of our interpretations. In achieving trustworthiness in my analysis, I detailed my theoretical framework that informed the research process and analysis, positioned my analysis as possible interpretations, and drew on notions of persuasiveness/plausibility, correspondence and coherence in my analysis (Riessman, 1993, 2002). I aimed to be persuasive or plausible by using participants’ stories as bases for my theoretical claims. I shared with participants my ideas after the first interviews to get their feedback about the directions I was taking in the analysis, for “their responses can often be a source of theoretical insight” (Riessman, 1993, p.66). I attended to coherence, which highlighted the context in the participants’ subjective experiences. Participants were asked to tell stories about their lived experiences with HIV. Identifying embedded narratives in these stories means identifying units in which context and action are connected, with inherent integrity. Trustworthiness in my interpretations was achieved by maintaining the integrity of participants’ stories so that narratives were “preserved, not fractured, by investigators, who must respect respondents’ ways of constructing meaning and analyse how it is accomplished” (Riessman, 2002, p.220).

Riessman (1993; 2002) also addressed the “pragmatic use” of a particular research, that is, its usefulness as a way to assess its validity. In this context, the question that needs to be asked when evaluating the value of a piece of qualitative research is whether or not it provides useful knowledge (Kvale, 1996), knowledge that is useful.

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7 Riessman (1993) argued trustworthiness is not truth. Truth “assumes an objective reality, whereas the former (trustworthiness) moves the process into the social world” (p.65).
to the wider community. The notion of transferability of research findings has been suggested as a useful indicator in assessing the value of the research (O'Leary, 2004; Willig, 2003). Although the analysis was based on stories from eight people with HIV, the analysis of the participants’ stories could provide an understanding of the experiences of people with HIV in the post-treatment era. Rather than make claims about populations, transferability highlights the knowledge produced and lesson learned from the analysis could ‘illuminate’ relevant issues that are pertinent to people with HIV who are not participants of this research.

There is also the issue of internal coherence as a criterion of validity (J. A. Smith, 1996; Willig, 2003), which J.A. Smith (1996) argued as an appropriate way of assessing qualitative research. Internal coherence refers to “the extent to which the analysis ‘hangs together’ and does not contain major contradictions” (Willig, 2003, p.146). However, this should not be interpreted as an absence of contradictions or ambiguities in the analysis, but it is the manner in which these contradictions or ambiguities are coherently addressed that would provide a sound analysis of the participants’ stories. In this thesis, there are contradictions or ambiguities embedded in participants’ stories. By making these contradictions and ambiguities visible, I explored the lived experiences of people with HIV in the post-treatment era and developed a coherent argument about the pertinence of these experiences in their lives.
Chapter 5: Living with HIV in the Post-Treatment Era: Now That I’m Not to Die, How am I to Live?

5.1 Introduction

The act of living with HIV and AIDS in the post-treatment era could be argued as being profoundly different to that of the ‘Free Fall’, the ‘Slow Progress’, or even the ‘High Hope’ periods (Sepkowitz, 2001, p.315) as described in Chapter Two. In the post-treatment era, HIV is constructed as a manageable chronic disease, and mortality from HIV infection is less of a probability due to the availability of effective treatments. The significance of this change in HIV treatment and management is that people with HIV could be positioned as having had experienced two contradictory life orientations: the preparation for a shortened life due to being infected with a fatal disease; and the expectation to re-engage with life and new possibilities whilst living with a chronic disease.

In this first chapter of the analysis section, I want to address the thesis question of ‘how do people make sense of their lives and their illness experiences with HIV in an

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1 Written by “S”, a homeless person with HIV (Howard, 1999)
era when effective treatments for HIV are available?’ Given the different social and medical contexts in which people have lived with HIV – as both a fatal and chronic disease, I want explore the ways participants negotiate their experiences with HIV in terms of how they are living with this disease in the present and the future. I will do so by attending to their stories about past experiences of living with HIV when it was constructed as a fatal infection, their stories of negotiating the contradictory life orientations, and their stories of normalising their experiences with HIV since the ‘protease moment’. In this context, it could be argued that people with HIV now have the opportunity to reflect on their past experiences with HIV and in the process, it enables them to construct a productive present and future. As noted in Chapter One, the remarkable change in health of people following treatment use has led to the examination of issues pertaining to the activity of “restructuring” or “rebuilding” lives (Sowell, Phillips, & Grier, 1998; Trainor & Ezer, 2000). These terms are significant, for they not only position people with HIV as having prolonged lives, but also a productive future. Therefore, the ways participants make sense of their lived experiences could provide an understanding of how this disease is negotiated in the post-treatment era.

5.2 Drawing on the Past to Make Sense of the Present and the Future

“Time is a fundamental part of human existence. In our creation of meaning and the construction of our ‘life’ our actions are situated, and we situate ourselves, within an interweaving of past, present and future” (Roberts, 2004, p.175)

In Llobera’s (1998) work on the historical method, which examines the past in order to understand the present, he argued that “the past is in the present” and that “history
helps us to explain the origins and development of specific social phenomena, which otherwise would appear as universal and atemporal, and hence necessary” (p.73). Polkinghorne (1988) detailed the interconnectivity of the past-present-future time frames by suggesting that “past, present, and future are aspects of our existence. I am that existence which includes what I have done, what I am doing, and what I will do, and each moment is part of the whole that I am.” (p.130-1). Gergen and Gergen (1993) argued the view of oneself, and I would also include one’s situation, in a given moment is fundamentally nonsensical unless it could be meaningfully related to the past and is placed in the context of preceding and subsequent events. The temporality of events is constructive as it produces a plot through which the events are connected meaningfully. The narrating of a story allows individuals to construct and to give coherence to otherwise random events. It is in this context that I want to explore and examine the significance of past experiences with HIV in shaping the way people live with the disease in the present, and the way in which they make sense of their future.

In the following sections, I want to examine the stories of people whose lives have been disrupted as a result of HIV infection. As discussed in Chapter Two, the prospect of surviving HIV before the availability of effective treatments was remote and thus many people infected with the disease had prepared for a shortened life. In the post-treatment era when surviving HIV is probable, the changes people made in their lives in adjusting to the disruption produced by HIV prior to the availability of effective treatments have to be negotiated and made sense of. In this context, they now have the opportunity to review, reconsider and restructure their lives in order to construct meanings and understanding to the interruptions that HIV has caused.
5.2.1 Reconstructing a “Life Interrupted”

People with HIV have undergone a disruption that is profound and its consequences are arguably indelible. It could be argued an activity of living with HIV in the post-treatment era is to embody the disruptions, and to make sense of these disruptions in a productive manner. I want to attend to the disruptions caused by HIV as constructed in the stories of Dan and Athena. Dan provided the title for this section when he told the story of HIV as having interrupted his life and diverted him from the life course he had constructed for himself. He is a gay man in his early 40s who received his HIV diagnosis in the mid 1980s. He was prescribed treatments when they were available and was taking them at the time when he was interviewed for this research in 2002 and 2003. Although Dan experienced adverse treatment side-effects, he acknowledged that the treatments have been effective in prolonging his survival and diminishing the prospect of an AIDS-related death.

When Dan was first interviewed in 2002, he related a medical encounter he had in the mid 1980s in which he was positioned by a doctor as a person with a shortened life due to his HIV infection.

D: Oh look, let me tell you one of the things that I’ll never forget was going into (clinic) for a check-up and (…) it was that first year of (training institution). And it was a female doctor and she turned around to me and she said, “so what are doing with yourself?” and all that and I said “oh I just got into (training institution) and I’m really enjoying it”. “Oh” she said, “that’s very optimistic of you.” (…) And I thought that’s a great bedside manner, love (laughs), really good, you know. Didn’t say anything to her but I thought that’s not exactly the right
thing I’d, it’s not something I would be saying to an HIV patient, you know. A three-year course, that’s really optimistic of you. So I would never forget that little comment. I walked away and just laughed. I thought that was just ridiculous. I thought no lady, you’re wrong. But again that goes back to that attitude of no, I’m sorry, this is not going to kill me (Q: Hm.). You know, it’ll affect my life, yes, but it’s not going to kill me. (…).

Q: So I presumed you continued with (training institution)?

D: Oh yeah, graduated and everything and all that, yes. Stayed [working] for about 10 years and then got sick of being poor like most (profession) do and (laughs) actually that’s when I got ill (Q: Right.) (…) So that’s why I gave it (profession) up in the end. Both health and just that it was getting to be too much. (2002 – first interview)

In accordance with the medical construction of HIV at a time when effective treatments were unavailable, as discussed in Chapters One and Two, the predicted outcome from HIV infection was death (e.g. Selwyn & Arnold, 1998). The disruptiveness of HIV was made visible in Dan’s story by way of being positioned as an individual with a limited lifespan that was evident in the medical encounter in which his doctor suggested that he was “optimistic” in pursuing a three-year training course. Despite his success in not only completing the course but to have also worked in his trained profession for ten years, his life was disrupted again when he had to resigned from his profession due to reasons that included health deterioration. Notwithstanding the potential of a prolonged survival due to the effective treatments, the disruptive experience produced by HIV was revisited by Dan when he was interviewed again in 2003.
D: Well it’s because of that physical, well that knowledge that hey you know there is a good possibility here that I’m going to live to 60, thanks to the new drugs and thanks to my health being maintained. But that’s caused a whole new series of problems. I mean there is this wonderful film which I’ve never seen but I love the title called what is it “Girl Interrupted”, I often interpret my life as being “life interrupted” because you know I was an (profession) (Q: Hm.) and I gave all that up for varying reasons but health was part of it, and I had a career and it was, it was not a bad one. Um and I could go back to that if I wanted to but to re-establish that now would be so hard. So then I switched careers and just became this admin person you know and then ending up doing desktop publishing and internet web design. Everything I’ve done has failed. Now whether that’s because of my um own problems, fine, I’m ready to accept that but I don’t think it is that. My life has been interrupted because you know when I was 25 and diagnosed, I didn’t expect to have a huge future because that’s what I kept getting told. Now there is a future there, but what the hell do I do with it?! And there are so many PLWHAs [people living with HIV and AIDS] in my position. I know there are because I’ve spoken to them you know and a lot of us are wondering what to do. I remember P (friend) saying this too. “You know we have a future, what do we do with it?” And the irony is that he’s not here to have a future now and so you know you wonder, like with super funds you know, the fact that you could be putting all this money away supposedly into a bank account when you’re retire, I’m not going to be here to retire, why do I have to put that money away (Q: Hm.)?

(2003 – second interview)

In analysing Dan’s story, I want to draw on Bury’s (1982) conceptualisation of chronic illness as a “biographical disruption”, for it has utility in exploring and providing an understanding of Dan’s story of “life interrupted” – a construction which could be positioned as a signifier of the life orientation of preparing for a
shortened life due to HIV infection. ‘Biographical disruption’ has been often cited and used as a conceptual tool in research on health and illness (e.g., Bell, 2002; Corbin, 2003; Kangas, 2001; e.g., Werner, Isaksen, & Malterud, 2004) and specifically in the illness experience of people with HIV (Carricaburu & Pierret, 1995; Nilmanat & Street, 2004). The concept signifies the changes in the lives of individuals brought about by the presence of chronic illnesses; the effects of the chronic illnesses are not limited to the corporeal but also, and especially, in the lived experiences. Bury proposed that chronic illness, as an experience, is a disruptive event in the life course of the individual who not only has to contend with the materiality of the illness (Carricaburu & Pierret, 1995) but the experience which disrupts “the structures of the everyday life and the forms of knowledge which underpin them” (p.169). In Dan’s everyday life before the effective treatments, he cast doubt on whether or not a future was available to him, for he “didn’t expect to have a huge future because that’s what (he) kept getting told” after receiving his HIV diagnosis. He recounted his experience of having had to forgo a career in a desired profession due to his health, and provided an account of the series of unsatisfying jobs he has since engaged. For him, HIV was constructed as a disruption, a discontinuance of an ongoing life. The “shattered assumptions” concept (Davies, 1997; Janoff-Bulman, 1992) is useful here in understanding and analysing Dan’s story, for it signifies the profound impact that a traumatic event, such as an HIV diagnosis, has on an individual’s fundamental assumptions about the world (Janoff-Bulman, 1992). From this perspective, it could be interpreted that Dan’s everyday life experiences and the plans he had were hindered, altered and shattered by the presence of HIV. The presence of the disease affected his assumptions about his life in a way that produced uncertainty, and disrupted the taken-for-granted-ness he held
about his future – a disruption to his temporal orientation (Davies, 1997). Bury (1982; 1991) argued that one aspect of the biographical disruption is in the ‘taken-for-granted’ assumptions held by the individual with which life is engaged. Life no longer is inevitable in the manner that was previously shaped. Nothing is guaranteed. From this perspective, it could be argued that Dan’s “life interrupted” story is also a story of ‘loss’ (Crossley, 1999b), a story that served to construct his lived experiences with HIV in a way that highlighted the disruption that the disease has produced, and which he has to negotiate. Although Dan pursued his desired career even after the HIV diagnosis, his life plan was affected and future planning was predicated on his continuing corporeal health; for him, living with HIV was a struggle for meaning to compensate for the “shattered meaning” (Barroso & Powell-Cope, 2000; Schwartzberg, 1993) and to make sense of his disrupted life.

In his development of the ‘biographical disruption’ concept, Bury (1991) argued the pertinence of ‘context’ in the understanding of the illness experience, for he suggested that meaning and context in chronic illness are difficult to separate. Context provides the meaning and significance of the illness experience in the lives of those affected. The importance of considering the context in which individuals are situated is that it provides clarity to the everyday experiences of these individuals. The experience of facing HIV in the context of it being incurable and fatal as compared with when the same disease is constructed as manageable has to have different meanings. For Dan, since HIV and AIDS are now constructed and contextualised as manageable and chronic, the probability of a longer life has produced a paradox as indicated by his rhetorical question: “Now there is a future there, but what the hell do I do with it”. It is apparent from his story that his
subjective experience is not unique for “there are so many PLWHAs [people living with HIV and AIDS] in my position. I know there are because I’ve spoken to them you know and a lot of us are wondering what to do”. The intersubjective experiences with his HIV seropositive peers served to reinforce his notion that the discursive construction of HIV as a condition with which an individual could live has produced a “whole new series of problems”. Wheeler and Shernoff (1999) argued that treatments have complicated the lived experiences with HIV by producing new problems and dilemmas. These new problems could be argued as a corollary of being positioned as having a future, for Dan has to now reconcile with his decision to abandon his valued career (“and I gave all that up for varying reasons but health was part of it”), his failed endeavours in establishing different career paths (“Everything I’ve done has failed.”), and his lack of clarity about what to do with his prolonged life. This lack of clarity could be argued as a result of his paradoxical uncertainty pertaining to his longevity as illustrated in his story. Although Dan began his story by postulating that “there is a good possibility here that (he’s) going to live to 60” as a result of the treatments, this was made uncertain by the death of his friend (P) who also positioned himself as having a future. In this context, these “new series of problems” are concerns embedded in his ongoing illness experience with HIV, for which resolutions are not readily available. Dan, like other people with HIV as noted in his story, is confronted by a situation where their life orientations are shifted from facing imminent death to engaging with life and new possibilities. The problems that they now face in their ongoing illness experiences could be made understandable in ways that are productive and subjectively meaningful.
What I want to do now is to examine one possible strategy people employ to negotiate and to construct meanings in their illness experiences. Williams (1984) argued that ‘narrative’ is used to make sense of incidents and events of daily life so they are given a plausible order, and introduced the concept of ‘narrative reconstruction’ as a strategy individuals with chronic illness employ to make sense of their illness experience. This concept has been employed in research on health and illness (Hydén, 1995, 1997; Murray, 2000), and has been argued as being crucial in the reconstruction of an individual’s life story by producing meaning to events that have disrupted and changed the course of his/her life. In this context, ‘narrative reconstruction’ could be argued as a discursive device people use to make sense of their illness that contribute to the reconstruction of experiences as expressed in their narratives. This concept enables people to construct a meaningful account of living with a yet to be completed illness experience. Just as Dan presented a story of his difficulty in reconciling the prospect of surviving HIV, with a health condition he thought would shorten his lifespan, Athena negotiated the disruption caused by HIV by constructing it as an “adventure”. Although she was diagnosed with HIV at the time when the protease inhibitors and combination therapies began to emerge as resources for treating HIV, their effectiveness was equivocal, which meant she had grave concerns about her health and survival. She did not expect an HIV diagnosis when she undertook the test, and when she was interviewed, she told stories of struggles and fears experienced as well as the shattered assumptions she had for her life, such as relinquishing career aspirations. After years of adjusting to her diagnosis, this is the story she told of her negotiation with HIV and the way she made sense of the disruption it caused.
A: I think I’m just starting to form a new relationship maybe with it [HIV]. Um…about accepting that I have it and what it might bring at times. And having to just, I think it’s so much more courageous to try and, without believing or making, oh, it’s going to be this terrible thing, it may or may not whatever but just trying to be a bit surrendered to it without being surrendered to the virus killing you (laughs), like there is still a balance, I don’t want to just totally think oh, that’s it you know. But, I don’t know, it’s about accepting it, that it’s a part of my life and in so doing…it will, it won’t be such a big part. (...) And I thought I had accepted it, but on some deeper levels, I hadn’t I think. Yeah, I was determined that it was, I was going to make it what I want it and blah, blah, blah and so having to just, it’s more about accepting life as well and what’s, where I’m at and, yeah and I didn’t expect this [HIV] to happen to me and you know I’m supposed to be famous by now and (laughs) you know, it’s sort of like it’s becoming a bit more real with what is and looking at it as a, as an adventure too. (2002 – first interview)

Athena’s assertion that she has constructed “a new relationship” could be argued as a way of narratively reconstructing her experiences with HIV that enabled her to engage with her life with the disease productively. By constructing this “new relationship” with HIV, it was a way through which she came to accept it and its consequences. Schwartzberg (1993) argued that some individuals construct a “high meaning” in their attempts to negotiate the disruption brought about by HIV in their lives; this “high meaning” refers to the construction of the HIV illness experience as a challenge rather than as despair, as an opportunity for growth rather than as distress. It is a way of constructing HIV as “not only something to be accepted, but inherently, and paradoxically, a thing of value – an agent that conferred specialness or unlocked some inner potential, strength, or wisdom that had previously been dormant” (Schwartzberg, 1993, p.487). From this perspective, Athena’s negotiation
with the disruption that HIV has produced was narratively reconstructed as a “courageous” act. It is an act that drew on her “inner potential, strength, or wisdom” that enabled her to interpret her act of being “surrendered” to her predicament as a productive act which facilitated her acceptance of HIV. This act of surrendering is not positioned as a passive act of giving up, for it is not being “surrendered to the virus killing (her)”. It is however an act of embodiment through which it made possible for her to live with HIV productively and “that it’s a part of (her) life and in so doing…it will, it won’t be such a big part”. HIV is constructed as disruption, an interruption in her life, for she “didn’t expect this (HIV) to happen to (her)”. Her assertion that “I’m supposed to be famous by now”, although expressed with a jovial tone as indicated by her laugh, it could be interpreted as a reflection of her shattered assumptions or loss of what might have been. More significantly, the disruption is made sense of as an imperative to be “more real with what is”. Her construction of living with HIV “as an adventure”, as I interpret it, is to position herself as someone who is constructing a productive life, and to engage with new possibilities in spite of the embedded difficulties.

When Athena was interviewed in 2003, she was asked again about her acceptance of HIV and the disruptions it had caused.

Q: So how is the June 2003 sense of acceptance different to the January 2002 sense of acceptance about HIV?

A: Um…maybe it’s more of an acceptance of myself, or acceptance of mortality (Q: Um.), an acceptance of…humanity I suppose. Not trying to be so perfect and looking at reasons why I might have had those, such strong critical side um…hard to answer! How’s the acceptance
that is different…well…Well when I read back over the interview I could see that there was um, there were parts that I was verbalising but hadn’t really felt as well or experienced (Q: Uh-uh.). I was looking at it as a um, can’t think of exactly what…er, um…as a way of accepting it (Q: Um.) um. I feel much more, just much yeah, some of the ideas that I was talking about then, like being able to get on with my life once I accepted it, I feel that’s actually happened in reality now (Q: Ah.) (laughs). (…) There were lots of ideas then that I was saying then as well which I thought well that’s similar to what I have now and yet everything’s changed (Q: Um.) as well. (2003 – second interview)

The point of interest in this part of Athena’s story is that ideas presented in the first interview are positioned as having “actually happened in reality now”, for these ideas were “verbalised (previously) but hadn’t really felt as well or experienced”. From this perspective, it could be interpreted that the “high meaning” (Schwartzberg, 1993) she constructed in making sense of her HIV experience by describing it as a “courageous” act or as an “adventure” is embodied in her everyday life, which might not have been the situation when she was interviewed in 2002. Athena’s comment that “it's more of an acceptance of myself, or acceptance of mortality, an acceptance of…humanity” is a discursive construction to illustrate her reconciliation with the disruptions caused by HIV. It is a means with which to locate meaning in the way she wants to live and as a way of reconciling with the shattered assumptions she had to confront when she first learned of her infection. The two extracts presented above, in combination, not only provide an understanding of the way Athena made sense of her HIV illness experience with respect to the changes that HIV has caused, but they indicate a way of living with HIV that is subjectively meaningful and which enabled her to construct a life orientation that makes it possible for her to live productively and contentedly.
In examining the life orientation of people re-engaging with life and new possibilities, I want to present the stories of Steve and Helen who learned of their HIV status in the mid 1980s when an HIV diagnosis was tantamount to a ‘death sentence’ \(^2\) (Schiltz & Sandfort, 2000). Their stories also illustrate the utility of drawing on the past in order to make sense of, and to give coherence to the experiences in the present. Their stories insightfully describe the varied and complex ways individuals made sense of issues and concerns that are important to them in their efforts to produce meanings in their lives.

5.2.2 The “Live Now, Live Today” Story

Steve’s story is about his initial reaction to his HIV diagnosis and the way he came to make sense of life in the post-treatment era. He was diagnosed with HIV in the 1980s and has been using the effective treatments since they became available in the mid 1990s. When he was asked to describe his experiences of living with HIV in his first interview, he began his story by recounting the time when he was first diagnosed and the strategy he employed to make sense of his HIV diagnosis. Although the following is a long extract, I want to present it in this form as it illustrates the specific way he constructed his story. I also included my presence in the extract to illustrate that his story is a co-construction with respect to the discursive resources he utilised to make sense of his HIV infection.

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\(^2\) Some researchers have continued to argued that since a cure for AIDS and a vaccine to prevent HIV infection are unavailable, “an AIDS diagnosis remains associated with a death sentence” (Metadilogkul, Jirathitikal, & Bourinbaiar, 2005, p.469).
S: Well yeah, what, I think what happened was, it was you know, in the 1980s when you were diagnosed HIV+ and you were then, in that, it was indicated fairly strongly that you were probably be sick and die within a number of years um so you had to get your head around that aspect of being alive, all of a sudden. Um, and what happened with me was that, I would had been around 34, 35 at the time (Q: Hm.), and I realised that I had a self-fulfilling prophecy that I had always lived with. When I was very young, I decided that um I would probably die when I was about 38. So, and I had lived with that from a child, because 38 was really old, like beyond that was just too silly for words, you know (laughs).

Q: 38 sounds like a good number.

S: Yeah, exactly and it was, for me it was 38. So because I was 34, 35 and then I got this news, I went ooh, maybe my self-fulfilling prophecy is coming true. Now you know, this can sound a little bit airy-fairy but it’s exactly what I thought (Q: Hm.). And so I went well maybe if there is such a thing of that, I don’t totally believe in it, I wasn’t thinking about it all the time, but it came into my mind at that time. And I thought well maybe if there is such a thing, as a self-fulfilling prophecy along those lines, maybe you can, if you’re given enough opportunity, reverse it (laughs). So that’s what I did. I started to just think beyond that (Q: Oh, ok.) and think around reversing that self-fulfilling prophecy and, but then I had a whole lot of friends who, I mean I’ve had three lovers who have died of HIV/AIDS. And a half a dozen people in my life who are fairly close who died from 1988 to 1996 (Q: Hm.). So um there was a lot of evidence around to suggest that you might go because you were living with it on a daily basis the whole time, life had changed…and then in 1996 after my last lover had died, in early 1996, I was sort of ready to sort of give in like “I can’t, you know, it’s all too hard” and that, that t-cells are going down every time I go and er the percentages are coming down. And so then my doctor said to me um, he said “oh, Steve don’t give
up just yet because there’s some medications coming out and I’ll them on, I’ll have you on them as soon as they arrive. So don’t give up yet”. You know, that was, this was a conversation we had in probably June of [19]96. And then so that’s, I went “oh, ok”. And then I read about it and I thought “oh yeah you know all these sort of on the horizon, we’ll see how it goes”. And I, I do believe that um…had that not happened at that time with me, I probably would have gone you know, taken a down hill turn. And um, had maybe died within a couple of years of that (Q: Hm.)…

Q: Yeah, what’s that like?

S: Um, well it’s interesting because it’s er um, it takes you to an edge that um, you know, you’re on, you’re on an edge and you get to learn a lot. And you get to um…really what the, the classic thing that I had to do was um get to live in the moment. Live now, live today, not be doing, you know, what I think psychotherapy is all about, dwelling on the past or thinking too much about the future but being in the moment and having your life now, this day, this moment. So um, but I had to go to lessons to do all that as well. I mean I’ve, I’ve um been in various forms of psychotherapy for 20 years anyway. Even before HIV came along, I started when I was about 30 (Q: Hm.) and had done various forms of psychotherapy (Q: Hm.). Like one-on-one, group stuff um, you know other new-age group activities weekends away of screaming and bashing pillows and all that you know. So um (laughs) I really had, I really had begun to explore a whole lot of things anyway (Q: Right.) about just being alive and about trying to get more out of it (Q: Hm.). Um, so, that was yeah and that was one of the lessons that I had to really learn (Q: Hm.) um, was about being in the now and really savouring the moments you know, really having it really bright and clear and delightful, no matter what. Yeah. (2002 – first interview)
Steve’s story was one of overcoming adversities and could be interpreted by drawing on the ‘quest’ narrative (Frank, 1995), which describes the efforts of individuals to “meet suffering head on; they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest” (p.115, italic original), and that the illness experience is constructed as being useful and transformative (Thomas-MacLean, 2004). From this perspective, Steve’s story is about the ‘quest’ he undertook through which his HIV diagnosis was negotiated, accepted and made sense of in a way that was subjectively meaningful. HIV medical discourses, at the time when he was diagnosed, positioned him as an individual facing imminent mortality, for he would “probably be sick and die within a number of years”. In spite of this ominous prediction pertaining to an early death, the benefits he experienced from the effective treatments, and the understanding and awareness he gained from psychotherapeutic work have enabled Steve to position himself as having learned to enjoy life, and to be “in the now and really savouring the moments...having it really bright and clear and delightful, no matter what”. There is a progression in his story of learning to live in the moment and to make sense of his life after having had lived with HIV for over 15 years. The ‘progressive narrative’ (K. J. Gergen & Gergen, 1983; M. M. Gergen & Gergen, 1984) is useful here to describe the temporal structure of Steve’s story, for it has been employed to explore subjective accounts of experiences with chronic illness (Kelly & Dickinson, 1997). The Progressive narrative connects “events in such a way that...increments...characterize movement along the evaluative dimension over time” (M. M. Gergen & Gergen, 1984, p.175-6). In this context, Steve organised the events he experienced in such a way that made sense of his “live in the moment” position and to emphasise the significant changes in his life as a result of having effective treatments at his disposal. Drawing on the idea that a story
is an effort to persuade (Ochberg, 1996; Riessman, 1992) and as a product to describe, it could be argued that Steve wanted to produce a convincing story that illustrated his undertakings to accept as well as to change his situation by overcoming, against the odds, the adversity he faced. The narrative in Steve’s story is also found in the experiences of people living with other forms of chronic illness who made sense of their experiences by constructing ways of having contented lives and a hopeful future (Exley & Letherby, 2001; Little & Sayers, 2004).

In exploring Steve’s initial response to his HIV diagnosis, it appears he constructed the “self-fulfilling prophecy” as a way to account for an event that was unexpected, and unpredictable despite the prevalence of the disease in the Australian gay male population, particularly at the time when he was infected. The lack of information about the disease at the time of Steve’s diagnosis, and the conflating of a medico-scientific concern with moral imperatives, as discussed in Chapter Two, positioned HIV as a signifier of perverted lifestyles, which served to justify and legitimise the marginalisation and discrimination enacted on particular social groups, such as gay men. From this perspective, it is possible, given the medico-scientific and socio-historical contexts in which Steve received his diagnosis, Steve’s “self-fulfilling prophecy” is a construction, which could be interpreted as a resource that enabled him to not only account for his infection but as a device through which moral accusations embedded in the situation were neutralised, and thus made it possible for him to reject the tyranny of moral condemnations.

3 I referred to HIV infection as an unpredictable event in the sense that despite the identified high risks to transmission, namely, unprotected penetrative sex and sharing of injecting equipments, not everyone became infected even when engaged in these activities. This is not to undermine the importance of the public health messages pertaining to safer sex and injecting practices but to highlight that infection is not absolutely predictable. MacQueen (1994) in analysing HIV transmission issues noted that “there is no way to predict whether a particular individual will become infected after a single exposure or remain uninfected after several thousand exposures, regardless of efficiency.” (p.514)
Steve’s experiences of living with a stigmatised disease that was constructed as fatal, and the opportune arrival of treatments that prevented the “down hill turn” were positioned as experiences that took him “to an edge that … you get to learn a lot”. In analysing the way Steve made sense of the ‘extreme’ experiences he had as a result of being infected with HIV, I want to draw on the ‘conversion / growth’ discourse (Crossley, 1999a, 1999b), which positions the individual as having accepted his/her HIV diagnosis and as a result, he/she “focus(es) on the ‘inner’ or psychological dimension of experience and a commitment to achieving greater self-understanding, awareness and progression” (Crossley, 1999a, p.117). In the latter part of his story in which the “on an edge” descriptor was used, it could be interpreted that the way Steve made sense of his life in the post-treatment era was to achieve “self-understanding, awareness and progression” in order to construct a productive and meaningful present. Informed by his experiences of participating in “various forms of psychotherapy”, as well as his opportunity to have treatments available when he most needed, “to live in the moment” was positioned as the goal towards which he aimed to live his life. It could be argued that the construction of this goal was shaped by the profound events he experienced in the past (e.g., the deaths of friends and lovers, his own imminent death due to failing health, and the despondency he experienced – “it’s all too hard”), which produced an imperative for him to construct a productive and positive way of making sense of his present situation – “Live now, live today”. The acceptance of his HIV infection was a ‘conversion/growth’ enabled him to progress productively into the future despite the ever present possibility of failing health and mortality. From this perspective, his “self-fulfilling prophecy” construction could be positioned as an ‘enabling’ device, which made it possible for
him to assume an ‘active’ position in constructing a desirable future as illustrated by his argument – “if there is such a thing, as a self-fulfilling prophecy along those lines, maybe you can, if you’re given enough opportunity, reverse it (laughs)”. In this context, the treatments could be argued as the “opportunity” that enabled him to position himself as having the capacity to “reverse” the situation and to construct a productive future. In doing so, he resisted the notion of inescapable death or the sense of defeat as experienced by people when diagnosed with HIV (Anderson & Spencer, 2002).

By drawing on the past, Steve produced an understanding of his present experiences through which the “Live now, live today” story emerged. For Steve, living with HIV in the post-treatment era could be interpreted as “being in the now”, which, consistent with research findings into other forms of illness experiences, is positioned as a strategy with which people employ to negotiate the uncertainty embedded in their illness experiences (Crossley, 2003; King, Carroll, Newton, & Dornan, 2002). Steve’s description of psychotherapy further emphasised the subjectively constructed significance in his “live now, live today” story. Steve’s interpretation of psychotherapy as “dwelling on the past or thinking too much about the future” was a way of emphasising the importance of living “in the moment and having your life now, this day, this moment”. It could be interpreted that since his diagnosis, the events he experienced, the understanding he gained from living with HIV for sixteen years (at the time of his first interview), and having a prolonged life due to the effective treatments have provoked him to act on “one of the lessons” he learned, which was that living in the post-treatment era is “about just being alive and about trying to get more of it”. In this context, for Steve, his life orientation has
shifted from preparing for a shortened life, to re-engaging with life and new possibilities.

The shift in life orientation of preparing for early death to re-engaging with life and new possibilities is also illustrated in Helen’s story. In contrast to Athena who was diagnosed with HIV at a time when the needs of women with HIV were acknowledged in that social support and community services specifically for women have been established; and despite the construction of HIV as a ‘non-women’ disease, the needs of women with HIV have ceased to be on the margin. Helen’s experiences, in terms of when she was diagnosed and the issues she confronted, were significantly different to those of Athena.

5.2.3 The “Completely Different Life” Story

I want to present Helen’s story because she was infected with HIV at a time when it was constructed as a disease of gay men, injecting drug users, and prostitutes (Lupton, 1994; Sendziuk, 2003); she did not fit into any of these social groups. The social construction of HIV and AIDS as a ‘non-women’ disease, except when referring to female prostitutes, had meant that the needs of women with HIV were initially ignored (Sherr, 2000; Wright, Blackburn, & Taylor-Brown, 1999). Women were thus placed in a vulnerable position where they lack the information to prevent or to treat the disease (Corea, 1992), or to engage with social support networks through which the fear engendered by the isolating experience of living with a stigmatised disease was lessened. Notwithstanding the failure to meet the needs of women infected with HIV, for there were very few prevention campaigns
specifically for women who were not injecting drug users or sexual partners of injecting drug users (Hughes, 1999), women with HIV were also maligned for being irresponsible. The acknowledgement of women’s vulnerability to HIV infection has produced greater attention on the particular needs of women with HIV (Carney, 2003; Clark, Maupin, & Hammer, 2004; Wyatt, Myers, & Loeb, 2004). In the last decade or so, specific issues for women with HIV have been examined (Crossley, 1998b; Karus, Siegel, & Raveis, 1999; Sherr, 2005), such as treatment use issues specific to women (McDonald, Bartos, & Rosenthal, 2001), the inclusion of women in clinical trials (Sherr, 2000) and reproductive health care needs of women with HIV (Bergenstrom & Sherr, 1999; Sherr, Bergenstrom, Bell, McCann, & Hudson, 2001). In this context, Helen’s story is different to Steve’s in that her needs were initially marginalised because of being a woman.

At the time when Helen learned of her HIV diagnosis in 1985, she was caring for her male partner from whom she contracted HIV, and was pregnant with their second child. When she learned of her diagnosis, like other women with HIV in her situation, she was concerned about infecting her unborn child (Sherr, 1995; VanDevanter, Thacker, Bass, & Arnold, 1999), caring for her family (Carney, 2003; Karus, Siegel, & Raveis, 1999) and thus was less focussed on her own health. In explaining and exploring her way of making sense of living with HIV in the post-treatment era, she reflected on her life with HIV in the 16 years since she learned of her HIV status. She began her story by situating her early experience with HIV within the social context of the time. It was a time when her HIV status had to be hidden, which produced isolation and thus made her ‘invisible’ as a person with HIV.
H: What it’s like living with HIV? Um, um, it’s no big deal really. Um, I
don’t feel that you know it’s a major part of my life. I guess in terms of compare, comparatively, I mean I’ve been positive now for um, nearly 16 years. And in the early, you know, the first say 5 years when nobody knew, I hadn’t told anyone you know I was living in isolation, and um shame. Um, it’s just, I started a support group and I remember the first national women’s conference and there was a woman there who was quite active and had set up a peer support group in her state. And she was saying HIV is, I think she said “HIV is 80% or 90% of my life” and I thought, “oh, it must be about 30% of my life” because nobody knew and stuff. And then as time went on I think it became like about 90% of my life. But now I’d say, I would say it’s probably, you know, in terms of my consciousness and, you know, 10%. (2001 – first interview)

When she was asked recount her experience of living with HIV in recent years, her response summarised the time by circumscribing the significance of HIV in her present life with respect to its significance in the past. In spite of her opening declaration that HIV is no longer a “big deal really” and doesn’t “feel that you know it’s a major part of (her) life”, this position was countered by her description of “living in isolation, and um shame” in the early years of her diagnosis. In this context, Helen’s opening response provides a narrative arc of her experience of living with HIV. The narrative structure of the response is important, for it illustrates the change in how she constructs the significance of HIV in the present. Her experiences with HIV were made subjectively understandable and meaningful when she had the opportunity to compare her experiences with others (e.g., the woman at the first national women’s conference), which in turn enabled her to identify the isolation in which she was living. This initial response to her HIV infection is a key to an understanding of the way she negotiated the difficulties of living with a
stigmatised disease. The apprehension associated with disclosing HIV infection to others and fear of stigma associated with HIV have been noted as underlying issues relating to the experience of isolation for people with HIV (Carr & Gramling, 2004; VanDevanter, Thacker, Bass, & Arnold, 1999). Helen’s experiences of “living in isolation, and um shame…because nobody knew” were made visible to herself when she was able to draw on the experiences of other people, particularly other women. Her experiences with other women could be interpreted as an incentive for her to take on a political activist position, which facilitated the shift from “isolation” to visibility. In the following response, Helen described the period of her illness experience when she made herself visible as a woman with HIV through the work she did with other women.

H: Um, I wanted to know everything about it. I wanted to know everything that was happening on the scene. Um, I wanted to be at the epicentre of information and…I was fighting for visibility and awareness and support for women who were infected who were living in isolation and fear and fear of being discriminated against…I think at the time that I was politically active, feeling that I was doing what I could do, thinking that I was helping to make change, helped me keep it [HIV] in perspective. (2001 – first interview)

In the context of HIV and AIDS, political activism is argued to be crucial for survival (Callen, 1990). Taking up a position of a visible woman with HIV could be interpreted as a political act for Helen, and this act could thus be positioned as being crucial for Helen in accepting her HIV status. By making her HIV status visible, it could be argued that it was strategy she employed to negotiate her initial experiences associated with her diagnosis. For Helen, “fighting for visibility and awareness and
support for women who were infected who were living in isolation and fear (…) (and) thinking that I was helping to make change” was positioned as activities through which she could make sense of her own experiences, for these activities enabled her to “keep it [HIV] in perspective”. The participation in support groups for people with HIV is to achieve a “community belonging” (Schwartzberg, 1993, p.485), and as a strategy with which to negotiate the “alienated, alone and isolated” experience (VanDevanter, Thacker, Bass, & Arnold, 1999, p.189). Ariss (1997), by drawing on the theoretical framework on stigma, introduced the notion of “collectivization among the HIV infected” (P.65) as a way to explore and to argue the import of group membership as means to minimise the isolating consequences of being HIV seropositive. He argued that by having the opportunity to relate with others in similar circumstances, this enabled the individual to construct and to ascribe different, and more importantly, helpful meanings to the predicament of being infected with a stigmatised and fatal disease. “Collectivization” through support groups could thus “provide the environment necessary for a long term reconstruction of self necessary for the successful management of spoiled identity” (Ariss, 1997, p.66). The availability of an inter-subjective space in which subjective stories of experiences with HIV are constructed, told and heard, could mean that Helen was in a position to negotiate the embedded difficulties associated with HIV, such as the noted “spoiled identity” produced by negative images and representations of HIV (Chapman, 2002, p.174). The availability of this space could also mean that Helen was in a position to face subjective and collective histories with HIV directly, which could facilitate a productive integration of the HIV experience through which a ‘healthier’ subjectivity could be constituted.
The examination of HIV as a stigmatised disease is useful here, in order to explore the strategy Helen used to make sense of her infection, particularly in the early years of diagnosis. Stigma associated with HIV infection is well researched (Barroso & Powell-Cope, 2000; Brown, Macintyre, & Trujillo, 2003; Cree, 2004; Duffy, 2005; Parker & Aggleton, 2003; Siegel & Lekas, 2002) and specifically on women (Carr & Gramling, 2004). Despite an acceptance that there is stigma associated with all forms of illness, HIV stigma is unique and sets it apart from other chronic and life-threatening conditions (Cree, 2004). In exploring HIV stigma, I want to draw on the work of Goffman (1968) who delineated three types of stigma: “abominations of the body”, which locates stigma in the corporeal in the outward appearance of physical deformities; “blemishes of individual character”, which makes reference to the individual’s subjectivity and are inferred from personal history such as (homo)sexuality and stability of mental health; and “tribal stigma”, which can be passed on through lineages and association with a particular social group. Ariss (1997) attributed the signifying power of AIDS as being derived from the conglomeration of Goffman’s three types of stigma. HIV infection and subsequent manifestation into AIDS produce physical changes, and to use Goffman’s word “deformities”. Opportunistic infections, such as Kaposi’s sarcoma⁴, produce physical signs of unwellness that mark the individual with HIV overtly and publicly, which has the propensity to cause social isolation (Kermode, 1992). The individual is positioned as being flawed, for it is the blemish of his or her character that allowed infection to occur. Furthermore, because it was believed that HIV infection was due to ‘who you are’, the individual is stigmatised for being a member of or associating

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⁴ Kaposi’s sarcoma is a malignant abnormal growth of endothelial cells. Its appearance is typically dark red or purple painless spots on the skin or oral cavity (Foltyn, 1994).
with the identified risk groups. The combined effect of stigma is the production of the ‘other’ and the ‘normal’ (Goffman, 1968).

For Helen, the “shame” she experienced signified the marginalisation resulting from being infected with a stigmatised disease, which positioned her as the ‘other’, the non-normal. Therefore, to be an active member of a group of HIV seropositive women means that for Helen, her subjectivity was altered from that of the ‘other’ to that of ‘normal’. However, the centrality of HIV in her everyday life took its toll on her for she said,

H: Well, I’ve worked at the coal face you know, HIV for ten years and I just feel like I need a rest. I need to like nurture myself and um, learn…new things. Learn something else…But I don’t, I don’t sort of think now well, I did what I could, you know, I’ve paid my dues and I’m alright now. I don’t, I mean I don’t really think that. I just think that I’ve got other things that are more important you know, my family um, myself um, um, renewal I suppose, um, things that are more important to me than [HIV]. (2001 – first interview)

She then went on and expanded on this idea by stating that she is in

H: a place now of having made a connection with a whole group of women, um, who have young children (Q: Hm.) so there’s new life all around me, they don’t know I’m positive, don’t talk about HIV. Um, I’m furthering my education at a place where no one knows, I’m back, I’m back in the closet (laughs) and it’s like well I mean I could tell them that I’m not hiding it and if they found out, then you know, that’s or if I mentioned it, it’s like just doesn’t seem to be something that I need to speak about. Um, yes, so everyone knew I was positive,
now it’s hardly like anyone knows I am. I don’t really talk about it um, don’t really think about it. Um, haven’t been to a funeral for a year (Q: Hm.). Um, I still you know go to a doctor on a three monthly basis for my blood test. Um, but I’m more often more likely to go to discuss some other things that’s wrong with me that’s nothing related to HIV. I don’t read, I used to sit up till three o’clock in the night reading stuff on HIV, I don’t read about it anymore. You know I have a, yeah completely different life. (2001 – first interview)

This part of Helen’s story is about her experience of living with HIV in the present, and the emphasis here is on having a “completely different life”. After having had worked “at the coal face … for ten years”, she has accepted HIV but equally, she does not want it to be the focus, for there are “other things that are more important”. Helen’s emphasis on her family as “more important to (her) than [HIV]”, and her “connection with a whole group of women, um, who have young children” could be interpreted as her (re)positioning herself as a ‘carer’, a position she inhabited when she was first diagnosed. It is also interesting to note that she is ‘silencing’ herself as person with HIV but not due to fear or shame, as was described in the early part of her story, for she now reasoned that:

H:  (…) when I never told anyone before it was because I was afraid and scared and terrified of being you know, my children being you know stoned on the playground you know. Whereas now I don’t tell anyone because I just don’t, like it’s not worth mentioning you know (laughs). (2001 – first interview)

Helen’s story thus far has made it possible to understand the relevance of the percentages she used earlier to describe the significance of HIV in her life. The percentages were used as a discursive device to describe her subject position as a
woman with HIV, and to articulate an abstract experience in a tangible way. The percentages also served to produce a story that aimed to persuade the listener that her journey, and experiences, with HIV have changed substantially. The use of social markers such as attending funerals, non-HIV related medical consultations, and furthering her education, are structured into her story to produce a convincing narrative of considerable disparity between living with HIV in the past as compared with the present and likely into the future. This is similar to the ‘quest’ narrative and the ‘progressive narrative’ as identified in Steve’s story. The differentiation of living with HIV in the past as compared with the present is important for Helen, for the centrality of HIV is shifted discursively. Her project in the post-treatment era is to reconstitute her subjectivity from that of a woman with HIV to a mother, a partner, and a carer who also happens to be infected with HIV. This is the manner in which Helen positioned herself and made sense of her life in the post-treatment era. The diminished need or imperative to disclose her HIV status could be interpreted as a (re)positioning of HIV as a ‘lesser’ issue. Helen declared that she has a “new life” because of the different relationships she has fostered, in contrast to those she had when HIV was centrally positioned. HIV is positioned as no longer demanding the attention in her subjectively constituted world as it does not fit with the life she is constructing for herself. The “back in the closet” metaphor is a device that indicates the position Helen has assumed for herself with respect to the current circumstances surrounding her health and social considerations. Similar to the more common usage of the “closet” metaphor associated with (homo)sexual identity construction, in this instance, the metaphor connotes Helen’s resistance to HIV being dominantly positioned in relations to her subjectivity and in her everyday life. Helen’s act of committing herself to the needs of women with HIV through her work and her act of
withdrawing from HIV commitments could be understood through Roth and Nelson’s “process of membership in the community” (1997). They argued that the process of becoming a member is to relinquish the “involvement in and commitment to a former life” (p.171), which is informed by the theorising of the individual’s reconstruction of his/her worldview and subjectivity. From this perspective, it could be interpreted that Helen has relinquished her membership to the ‘HIV community’ and resumed her membership as a member of ‘wider/general community’. In this context, it could be argued that Helen has a different life orientation in the post-treatment era as compared with when she was initially diagnosed.

For both Helen and Steve, the act of living with HIV in the post-treatment era is positioned as being about looking beyond the disease that was once central in their everyday lives. Their stories could be interpreted as stories about progression and transformation. The way they made sense of their experiences, in the context of HIV being constructed as a chronic disease, is by positioning themselves as people who could survive HIV. The ‘sense⁵’ of their narratives (Polkinghorne, 1988) is concerned with changes and the reconstruction of their subjectivities. The descriptions and accounts of events are not only chronicles but are devices Steve and Helen draw on to make sense of how their lives have changed from people without HIV, to people with HIV facing mortality, and to people with HIV anticipating a productive future.

⁵ Polkinghorne examined the significance of plot in narrative and distinguished that a plot can be about the reference and content of a story or be viewed as the sense of narrative. He drew on the work of the German philosopher and mathematician Gottlob Frege who made a distinction between the reference of a word, which is the object designated, and the sense of the word, which is the additional meaning.
The stories of participants that I have presented thus far would suggest that the activity of ‘drawing on the past’ has utility in their endeavours to make sense of their lives in the post-treatment era. However, I want to also make clear here that by ‘drawing on the past’, I don’t mean being ‘backward looking’. There is a critical difference between these two ideas, and the difference is that being backward-looking, an individual seeks comfort in the familiar as a way to avoid the present which is in contrast to drawing on the past that signifies the individual’s act of using what is known to enhance the present. From this perspective, I would argue in the participants’ endeavours to understand their experiences with HIV, they are drawing on the past, rather than being backward-looking, in order to make sense of the present.

Furthermore, by drawing on their past experiences, they made sense of their lives with HIV in the post-treatment era by highlighting the profound difference in their life orientations, for it could be argued that instead of preparing for death, they have re-engaged with life and the opportunity to construct a productive future. From this perspective, it could be argued that their stories are about constructing a ‘normal’ life context, particularly when it has been suggested that “lives would return to “normal”’ due to the availability of effective treatments (Maticka-Tyndale, Adam, & Cohen, 2002, p.1353). I am aware that the word ‘normal’ should be used cautiously, for it raises a range of socio-political and culture concerns. The way I am using ‘normal’ here is the subjective pursuit of constructing a life that meets the socially and culturally defined expectations, and as a way to make sense of their lived experiences. People with HIV are social subjects bounded by socially and culturally defined expectations. This, I argue, is an important point because contemporary HIV
discourses shape the view that long-term survival for people with HIV is probable and therefore they need to (re)engage with life in a manner that is socially constructed as productive and constructive.

What I want to do now is to explore the stories that participants told of their endeavours to construct a ‘normal’ life context, or to ‘normalise’ their experiences in terms of corporeal changes and social expectations.

5.3 Constructing a ‘Normal’ Life Context

In spite of HIV being constructed as a chronic disease, people are confronted by the uncertainty of living a disease that is manageable but nevertheless incurable (Brashers et al., 2003; Brashers et al., 1999; Siegel & Lekas, 2002). It could be argued that the endeavour to negotiate the uncertainty embedded in living with HIV, albeit with effective treatments, is for individuals to make sense of their lives by constructing their lived experiences with HIV within the context of a ‘normal’ process, such as that of the aging process. A process through which individuals could make sense of their physical changes in a manner that is not HIV focussed, and to situate the changes within a ‘normal’ process that their non-HIV infected peers would also experience.

Dan, whom I introduced earlier, provided a story in which he explored his prolonged survival, the consequences of living with a disease for which he required to take treatments and the effects of these treatments have had on his body.
D: (...) Because I was born in 1960, so consequently turned 40 in 2000. And the two were sort of related, you know, will I see 2000? Will I see 40? At the age of about 35 I thought, “yeah, I’ll see 40 easily”. Now I’m questioning will I see 60? You know, and that’s, that’s now my next thing. Will I see 60? Huh, I don’t know. Wouldn’t surprise me if I didn’t because the pills that I’m on aren’t exactly great for the system and things like that and all that sort of thing, but I’m happy to have reached this far. (...) I have a disease; will it kill me before I’m 60, who knows? I’m not saying it will, I’m not saying it won’t. But it wouldn’t surprise me if, you know, if it did. Your body just, does, after 40s starts to go down, I mean I know (laughs) I now need glasses, I have back problems, all these things I never had when I was a kid, so you know. (...) I mean and it’s just physiology (Q: Hm.), your body does start to wind down after, you know, 40 or 50, it does naturally do that. And again I don’t think it’s being pessimistic saying this, it’s being realistic. (2002 – first interview)

Siegel and Lekas (2002) argued that in the era of effective treatments for HIV, people are afforded the prospect of not only good health but are able to normalise and to compartmentalise their health condition. Normalising and compartmentalising are discursive strategies which act to minimise the significance of their situations so to produce a ‘taken-for-granted-ness’, and in doing so, allow individuals to maintain a continuity with their lives before their HIV diagnoses. In analysing Dan’s story, I want to draw on Crossley’s “normalising story” (1999b), which she argued is a dominant cultural story employed by individuals in narrating their illness experiences. One aspect of the normalising story is the minimising of negative effects and uncertainty associated with the illness experience in the everyday life. In Dan’s story, notwithstanding the benefits treatments have produced, for which Dan was “happy to have reached this far”, he conceded that “the pills that (he’s) on aren’t
exactly great for the system”, which suggests that he was concerned about the long-term consequences of treatments use on his overall health. Uncertainty relating to the long-term use of treatments is an important issue for people with HIV (Trainor & Ezer, 2000), particularly when it has been argued that the adverse side effects could be a significant impediment to continued successful clinical outcomes” (Emery & Cooper, 2002, p.21). In this context, in spite of the potential of treatments to prolong life, the situation of living with an incurable disease and the reliance on treatments that could affect his health has produced an uncertainty which he has to negotiate. It appears that Dan is not living with the constant threat of mortality, as illustrated by his acknowledgement that although “I have a disease, will it kill me before I’m 60, who knows? I’m not saying it will, I’m not saying it won’t”. The equivocal outlook posited by Dan could be interpreted as his effort of positioning himself as an individual whose mortality is unknown and therefore enabled him to normalise the uncertainty embedded in his illness experience. Furthermore, as noted in Chapter Two, given that treatments have the capacity to disrupt the clinical disease progression, it could be argued that people with HIV do not “differ from the rest of the population, insofar as “nobody knows how long they’ve got” ” (Davies, 1997, p.565), and that the number of people with HIV who will age into their 50s and beyond will grow (Goodkin et al., 2003). In this context, Dan’s reference to his age and the change in his body is relevant here, for it has been argued that treatment efficacy has constructed the management of the disease as longitudinal, a long-term proposition (Baer & Roberts, 2002), which suggests that the ‘normal’ aging process that was considered to have been denied to him because of premature death from HIV infection, is now a likely process he will now experience. From this perspective, Dan constructed a story in which he situated, and minimised, his physical
experiences, including those that are HIV and treatment related, within a normalising story, “it’s just physiology, your body does start to wind down after, you know, 40 or 50, it does naturally do that”. Similarly, in his second interview, Steve told the story of his negotiation with treatment side-effects, that is, the discomfort and fear they cause while conceding that without them he would have died, he normalised the discomfort experienced as part of the “aging process”.

S: …I mean I really feel that if I didn’t take these drugs, I probably wouldn’t be around now, if they didn’t exist, I really honestly feel that, so if I honestly feel it, there must, even though there’s, my truth is in there. So therefore if I’ve taken them and I’m alive and I can do the things that I’m doing, the way I do them, well, that’s you know, it has. But um, that’s the way I look at it. And then avoid anything [HIV drugs] that’s going to “zombify” you too much, you know that’s what I’m also wary of. So…I think you actually, you either, you get used to it. I think it’s, you can forget what it was like once upon a time, and then you can also throw in, as I’m doing a hell of a lot, the aging process. Well maybe this is all part of aging as well you know, so um…you know, I’ll, I throw that one in as well now and I, I’m aging on it (laughs). Oh you know you can find lots of things to blame (laughs) if you want to you know or um, you know come up all sort of little scenarios if you want to, if you think about it. (2003 – second interview)

Steve, like Dan, constructed his survival with HIV as a consequence of the treatments. Steve minimised the discomfort associated with treatments by (re)constructing his expectation of how he could feel. In spite of him disliking side-effects, such as the “zombify” effect that he wants to avoid, he negotiated these undesired experiences by normalising them as aspects of his life with HIV in the
post-treatment era. He positioned side-effects as experiences he has to accept by abandoning the expectation of “what it was like once upon a time”.

Siegel, Schrimshaw and Dean (1999) examined the experiences of care among late middle-aged and older adults with HIV, and found that participants in their study normalised symptoms of illness as signs of aging. Drawing on their ideas, it could be interpreted that the “aging process” is used by Steve as a discursive device to assist his endeavour to make sense of his lived experiences with HIV in the post-treatment era. Positioning treatment side-effects within an aging discourse enabled him to normalise and to use it as a strategy to negotiate undesired and unwanted experiences, for he argued that “maybe this is all part of aging as well you know, so um…I’ll, I throw that one in as well now”.

The experiences of older adults with HIV are under researched as it was previously unimagined that people with HIV will grow old (Shippy & Karpiak, 2005). Thus, people with HIV such as Dan and Steve, are negotiating novel, and unexpected, issues embedded in the post-treatment era. Not only are they continuing to negotiate the complexities of living with a disease, chronic or otherwise, they are also confronting the aging process; a process, which could be argued, is a privileged experience, for it signifies survival. In this context, they are normalising the difficulties embedded in their illness experiences, and positioning themselves as having the same opportunities as well as having to negotiate the same life-cycle issues confronting people who are not infected with HIV.
The use of the aging process and the strategy of comparing subjective experiences with peers who are non-HIV infected were also employed by Eric in his endeavours to construct a ‘normal’ life context. He provided a story about the experiences of negotiating the life issues for any individual in their forties, such as, future financial security. Eric positioned himself as surviving the same disease that has caused the death of many of his friends, including a previous life partner. However, he is aware his survival is uncertain, for the disease is incurable. The manner in which he constructed the story was to illustrate the challenges of planning as if there is a future, as is the experience of any person in their “mid-life”, but constantly being reminded that he lives with a disease that could undermine, if not obliterate, any plan he might make. From this perspective, as he commented in his story, he lives in a “contradiction”. The following extract is long but I want to present it in this form as it maintains the integrity of Eric’s story.

E: Yeah, it sort of like having that um “a red rag to a bull” almost. It’s like when it’s [HIV] not there, it’s um, it doesn’t impact and I’m not thinking about it and I can make plans for the future and I can think “ah, wouldn’t it be great you know 30 years time, we’ll have the mortgage paid off (laughs)”, and um you know thinking, thinking stuff about…um like buying the house as well, it’s making me sort of think about putting my financial affairs in better shape because again thinking “well I’ve got this house is a repre-, is a symbol of a future”. It’s like, for me that’s how I was sort of seeing it. And thinking this is really great you know I’ve never visualised myself own-, and again I know that it’s slightly contradicting what I was saying before about not getting excited about buying the house because I wasn’t but at the same time I was, and I guess feels this constant sort of, this is about taking away again. This is where HIV can take away because my lived experience before was, before I bought a house and HIV took it
away. Now, now I was thinking “oh, I buy this house and something would, and something, maybe HIV, probably HIV would take it away because I’ll, I won’t be here and it’ll be (partner’s)” Um but at the same time I was also thinking well, now I’ve got something to plan for, I’ve got, you know I should try to make better use of my um…my time, my future so that I’ve got you know, I’ve money around for when I retire and you know stuff like that, which it’s never been a main, a, a primary motivator. And again I suppose that’s part of you know, when you get to your mid-life, you start thinking about oh, it’s not just about changing jobs anymore (laughs), it’s maybe about well maybe I won’t be working in 15 years time or whatever. Um…so yeah, so I was, I was thinking along those lines when we bought the house as well, it was like it was a symbol of a future and, and um…getting a better future, and the future being better yeah. (2001 – second interview)

When Eric was asked to elaborate his experience of living with HIV in the post-treatment era in the context of his future planning, he said:

E: (...) that’s the, the inevitable contradiction of, of what HIV now represents. Because it isn’t now a death sentence, um it isn’t that you’re HIV positive and you, you know you might as well start getting your world trip planned and you know =

Q: Start spending up big on your credit cards (Laughs).

E: Yeah (laughs). And, and yeah so that there’s that, that inevitable contradiction that yeah, you’ve got, you’ve got something that could take your life away, so has everyone (laughs) and er and at the same time you know you’ve got, you’ve got the rest of your life stretching ahead, ahead of you. Which you didn’t either plan for or expect or even dare to hope in, in, in the worst moments when I was thinking
sort of 7 or 8 years ago when you know when people were, there’s always someone that you knew who’s either sick or dying or whatever. (…) it’s, there’s a sort of sense of security in that like oh, this is a given, ok, right, now we know what to do with this (laughs). But now it’s like all the um, all that security and predictability has been taken away. (…) And so it’s, I think, I think it reinforces a lot of those things that people will go through normally in their 40s maybe into their 50s um. Um, and again I suppose how it’s played out for me a little bit is feeling that, again looking back to where, up to where I think I was before feeling like now, I’m down in a bit of a valley, and what’s ahead is all a bit kind of misty and mysterious, um and not necessarily anything to look forward to (laughs). (2001 – second interview)

Employment and financial concerns are important issues for people with HIV (Ezzy, De Visser, Grubb, & McConachy, 1998; Grierson, Thorpe, Saunders, & Pitts, 2004), and in the post-treatment era, people with HIV are positioned as being able to resume a productive work life and to be financially independent (Nixon & Renwick, 2003). The use of financial indicators, such as “have the mortgage paid off”, “buying the house”, “putting my financial affairs in better shape” and to have “money around for when I retire”, illustrate the everyday expectations Eric is now confronting. The indicators were positioned as ‘normal’ tasks to which he has to attend as expected “when you get to your mid-life”. These indicators are particularly pertinent in Eric’s situation as they signify a future towards which he, with his partner, is aiming. They are constructed as goals to make “better use of (…) my time, my future”. For him, to be in position where he could purchase a house, is a “symbol of a future”. Eric’s story is significant, for he, like Dan and Steve, has to situate his life situation and lived experiences within the frame of ‘normality’ as shaped by discourses on living with HIV in the post-treatment era (Maticka-Tyndale, Adam, & Cohen, 2002).
indicators serve as devices through which he could establish normality in his present life. He has to now consider his situation in terms of the socio-culturally constructed expectations on a person in his or her “mid-life”. He did not consider these expectations would be necessary or available when surviving HIV and AIDS was improbable, for these expectations were not “either plan for or expect or even dare to hope”. From this perspective, it could be interpreted from his story that the activities of buying a house and ensuring a financially secure future are means with which to orient him to the present and future. A future he neither expected nor planned for.

Eric is “excited” by the prospective of purchasing and owning a house, a prospect that he “never visualised” as he did not consider he would be in this position again. However, just as buying a house is a “symbol of a future”, it would seem that it is also a ‘symbol of loss’ in the context of past experiences. “I bought a house and HIV took it away” was an experience he had when he was with his previous partner. Eric’s experience of his house being ‘taken away’ by HIV could be interpreted as one of a number of “shattered assumptions” (Davies, 1997) experienced by people with HIV when the consequences of HIV infection disrupt their life plans, and the “biographies they had constructed” (Carricaburu & Pierret, 1995, p.77). Just as the act of purchasing another house was positioned as a signifier of resuming a ‘normal’ life, it is also a signifier of uncertainty that he has to make sense of given the loss and disruption he experienced as a result of HIV. For Eric, this uncertainty has produced a sense of angst (Davies, 1997), which is defined as “the absence of anything holding one in place and anchoring one’s action” (p.565). In this context, the prospect of owning a house has produced angst because Eric has no certainty, or an ‘anchor’ to
which he could depend in order to ensure that his experience of owning this house would not again be taken away by HIV.

Despite the uncertainty embedded in living with HIV, the strategy Eric used to negotiate the unpredictability and uncertainty embedded in his situation is to position his subjective experiences as experiences “that people will go through normally in their 40s maybe into their 50s”. In this context, it could be interpreted that there is utility for Eric to position himself within the general population, for it enabled him to make sense of his “lack of security” and the uncertainty associated with having an incurable disease. Eric’s construction of HIV as “something that could take your life away” but diminishing its significance by arguing “so has everyone” enabled him to engage with his future productively and to continue with his life course. Bauer and Bonanno (2001) explored the manner in which people construct a sense of personal continuity after major life changes by claiming that “people transform discontinuity into continuity by understanding the personal meanings of activities before the loss and how these meanings can foster a sense of unity and purpose for various activities after the loss” (p.124). From this perspective, despite the uncertainty and angst he experienced, it could be argued that Eric’s activity of purchasing a house with his current partner is positioned as a resumption of his life plan prior to HIV by redressing the “discontinuity” produced by HIV. Hydén (1995) argued that in constructing a narrative account of disruptive events, there is a “platform”, which defines “the point from which a connection with one’s previous life can be established” (p.67). From the perspective of Eric’s narrative, owning a house is a platform that serves as a starting point from which it is possible for him to create
order, to interpret and to understand disruptive events connected with his past and continuing experiences with HIV.

5.4 Summary

In this chapter, the stories presented and the interpretations I offered provided an understanding of the experiences of people living with HIV in the post-treatment era. More importantly, I examined the manner in which participants made sense of their lived experiences with the disease in the context of it being medically constructed as chronic, treatable and manageable. By utilising the strategies of drawing on the past and constructing a ‘normal’ life context, participants were able to make sense of their experiences in a way that enabled them to not only negotiate the difficulties and interruptions that HIV has produced, but also to position themselves as being in the process of “restructuring” or “rebuilding” their lives. Living with HIV is no longer an experience that connotes premature death, for it is a disease that people can now live with, not metaphorically but in actuality. Although uncertainty continues to be a part of living with an incurable disease, the subjectively constructed meanings ascribed to the lived experiences in the everyday life enabled people with HIV to negotiate this uncertainty and to make sense of their present and future productively. In this context, the implication of living with HIV as a chronic disease in the post-treatment era for people is that their life orientations have shifted from preparing for a shortened life to engaging with life and future possibilities.

What I want to do in the next chapter is to continue to examine how people make sense of their lives but specifically in the context of the constructed meanings
ascribed to the treatments in their ongoing negotiation with HIV. The celebrated benefits and the adverse side effects have produced different meanings for people with HIV. The exploration of these meanings could further provide an understanding of their experiences with HIV as in the post-treatment era.
Chapter 6: The Use of Metaphors in Making Sense of the Anti-HIV Treatments

“…[R]ecognizing drugs are concrete material objects does not prevent their simultaneous analysis as complex social phenomena, embedded in the web of individual and collective meanings and interactions”

6.1 Introduction

As outlined in Chapter Two, the reduction of HIV-related morbidity and mortality has been attributed to the effective anti-HIV treatments that emerged in the mid 1990s (Holtgrave, 2005; Préau et al., 2004; Sowell, Phillips, & Grier, 1998). These treatments have produced an improved health outlook and long-term prognosis for many people living with HIV (Vanable, Ostrow, & McKirnan, 2003) by increasing their CD4 cells, decreasing their viral loads and reducing the prevalence of opportunistic infections (Au, Chan, Chung, Po, & Yu, 2004). The attention on medical technologies and practices in the post-treatment era is therefore important. However, this attention given to medical technologies and practices has also produced a social reality in which people with HIV are constantly required to weigh up issues pertaining to treatments and their use. Some of these issues are challenging, for treatments have produced new problems and dilemmas in the lives of people with HIV (Wheeler & Shernoff, 1999). From this perspective, the tasks of negotiating and determining the utility of treatments in terms of advantages and disadvantages, benefits and costs, and how they could improve or diminish the quality of subjective
lived experiences, are embedded in living with HIV and AIDS in the post-treatment era. It is here that the idea offered by Cohen et al. (2001) noted above resonates. People need to make sense of the treatments, for they need to engage with treatments by positioning them in ways that are subjectively meaningful. Therefore, the embodiment of treatments in living with HIV is not only about the physical act of consuming the material drugs, but it is also about the psychic engagement with the discursive constructions of the treatments.

Subjectively constructed meanings for treatments are important, for it has been argued that it is these meanings ascribed to the treatments which shape the way people make sense of their lives in relation to necessary treatments for a disease, such as HIV (Conrad, 1985). The use of metaphors in the context of illness is documented (Lupton, 2003; Sontag, 1978, 1989), and it is argued to be “an epistemological device, serving to conceptualize the world, define notions of reality and construct subjectivity (Lupton, 2003, p.59). Montagne (1988; 1996) explored the use of metaphors as discursive devices to give meanings to medical treatments and their usage. He suggested that “[m]etaphors are, poetically, bits of language which imply a relationship of similarity between two things and so changes our apprehension of either or both” (Montagne, 1988, p.417). He argued that it is through the use of metaphors that individuals are enabled to structure and to gain an understanding of their subjective experiences of taking treatments. The metaphors embedded in the stories participants offered in making sense of their treatment experiences illustrate the multiple and varied ways in which meanings are constructed and ascribed to the treatments. Treatments signify both the promise of improved corporeal health, and the compromising of wellbeing, as reflected by
having to endure possible adverse treatment side-effects that are paradoxically constituted as precursors to poor corporeal health. This apparent contradiction to treatment use is profound and confusing for people for whom treatments have been deemed necessary. In this chapter, using participants’ stories about their experiences with treatments, I want to address the thesis question of ‘how do people make sense of these treatments in their lived experiences with HIV?’ I will do so by examining the constructed meanings participants ascribed to treatments, which enabled them to make sense of their experiences with treatments in the post-treatment era.

6.2 Treatments as ‘Life Savers/Restorers’

The following story from Steve is about the fortuity of having an extended life made available by the treatments. Steve constructed his story, and made sense of his own experiences by referring to a medical consultation he had with his doctor.

S: [I]n 96 after my last lover had died in early 96, I was sort of ready to sort of give in like “I can’t, you know, it’s all too hard” and that, that t-cells are going down every time I go and er the percentages are coming down. And so then my doctor said to me um, he said “oh, Steve don’t give up just yet because there’s some medications coming out and I’ll them on, I’ll have you on them as soon as they arrive. So don’t give up yet”. (...) I do believe that um...had that not happened at that time with me, I probably would have gone you know, taken a down hill turn, and um, had maybe died within a couple of years of that. (2002 – first interview)
To further emphasise the point, Steve then referred to a conversation he had with a friend with whom he shared similar issues.

S: I sort of strongly believe it, I had a, had a conversation with another good friend of mine who um is HIV+ for many years and he was the same. He just said to me one time, you know, like a few years ago “what do you think would had been the outcome of our lives had this not, had HAART not come along?” And I said, “well, you would have died in a particular year” because he was actually quite sick. I said “you would have died, you would have well and truly gone and I would have been dead for two years now.” And he said, “yeah, I believe that too, that’s what I think” (laughs). So you know, it’s um…but we didn’t and here we are (laughs), and we’re alive to talk about it. Yeah. (2002 – first interview)

Drawing on his consultation with his doctor and his friend’s experience, Steve constructed a story that emphasised the timeliness of the treatments in his life. This was made significant when death was positioned as his fated outcome in the years before the treatments’ arrival as illustrated by the reference of his lover’s death in early 1996 and that he “was sort of ready to sort of give in”. The manner in which he constructed his story enabled him to make sense of his survival, for he acknowledged that without treatments, he “would have been dead for two years now”, as would have been the case for his friend. From this perspective, it could be interpreted that Steve positioned the treatments as ‘life savers/restorers’, for if “this not, had HAART not come along”, he would have followed the fate of his friends and lovers who died when effective treatments were unavailable. Steve’s position is supported by the suggestion that a remarkable aspect of the treatments is that they have ‘rescued’ people from near death (Persson, 2004) and produced the expectation that living with
HIV is “to plan for living” (Sowell et al., 1998, p.36). The use of the conversation by Steve in his story could be interpreted as a device with which to emphasise the meanings he constructed in making sense of his survival. Ariss’ (1997) notion of “collectivization among the HIV infected” noted in the previous chapter also resonates here. It could be argued that by comparing, and sharing his experiences with others, his positioning of treatments as savers or restores was made convincing and credible. In the second interview which took place approximately fourteen months after the first interview, Steve revisited the meanings he held for the treatments.

S: Well all of the drugs yeah um…look I think it’s given me a um, an extension of existence, that’s the way I look at it. Um, and I can still walk, I can still talk and I can still go to work and I can still do things I want to do generally. (2003 – second interview)

In the period since the first interview, there were many significant changes in Steve’s life. He changed jobs and moved out of the suburb in which he had resided for close to two decades. In the context of these changes, it could be interpreted that not only the treatments have extended his life but they were also positioned as resources on which he could rely to achieve the outcome of doing “things I want to do generally” and perhaps the confidence with which to instigate changes in his life. The treatments presented him with the opportunity to engage with living with HIV in a way that was different to when it was constructed as a fatal disease. The positioning of treatments as resources on which individuals could depend on, as expressed by Steve’s notion of “an extension of existence”, is affirmed by James.
James was in his early 40s, and learned of his HIV status in 1992 or 1993. He was diagnosed at a time he described as being “reasonably late in the epidemic” but it was also a time when he was told that treatments for HIV were starting to appear promising. He was prescribed a demanding treatment regime when they became available. At the time of first interview in 2001, James had ceased taking the treatments because his blood tests consistently showed that his t-cell count was healthy, his viral load was ‘undetectable’ but more significantly, he was experiencing adverse treatment side effects. When he was asked to explore the significance and meaning he held for the treatments, he put it in the following way.

J: Um, the first thing I was told when it, when I sero-converted was that you know, it looks good in terms of treatments…the um treatment thing, situation has, has meant that I, actually been able to sort of you know survive this long whereas I don’t think I would have otherwise… I mean I still accept that it was probably a good thing in terms of longevity to take that amount of drugs because I think it actually um bombarded you know the virus for such a length of time and so heavily that um, it’s take you know like it means I’ve got the sort of hiatus period now um that I, that I wouldn’t have had… I think if we want to go back to sort of treatments, um, that’s what’s that’s done is it actually managed to put off, like prolonged the period between you know be hit with the news and actually dying to a point where well, I’m not quite sure when that’s going to happen. (2001 – first interview)

Just as Steve positioned his survival as a corollary of treatment availability, James also positioned the treatments as the resources which extended his life, for they enabled him to “survive this long whereas I don’t think I would have otherwise”. Although the demanding treatment regime required James to “take that amount of
drugs\textsuperscript{1}, it has provided him with the opportunity to “put off, like prolonged the period between you know be hit with the news and actually dying”. His undertaking in following a demanding treatment regime provided him with a “hiatus period” in which he was in a position of not needing to use treatments. This issue was highlighted by James in the second interview in which he explored the significance of treatments in his life.

J: Um… I suppose when I look at, look at my, my um situation which is not treating and having not, not being on treatment for two years, there is a very good chance that I’m going have to go back on it soon. And the reason why I came off it was because I couldn’t, you know I was getting too many side effects from the regime I was on, so whereas at the moment without treatment, I’m fine, um dubious about how I would be if I go back on it. (…) I actually am in a better situation for not being on it, having, having been on it for sort of five or six years and then coming off, so um consequently my reticence and confusion about what to do. (2002 – second interview)

It could be interpreted from James’ story that he positioned treatments not only as ‘life savers’, but that they are resources he utilise only when they are necessary, not permanent fixtures in his everyday life as treatment side effects were negatively affecting the quality of his lived experiences. Given he was not using treatments at the time when he was interviewed in 2001 and 2002, treatments were positioned as resources at his disposal and he would make use of them in a way that is appropriate to his needs, not bound to them as shaped by medical discourses (Cooper et al., 2002; Gold, Hinchy, & Batrouney, 2000; Gold & Ridge, 2001). In terms of treatments

\textsuperscript{1} James’ comment referred to the number of pills he had to take. When effective treatments were initially introduced, and combination therapies became a common practice, an individual could be required to take close to thirty pills per day (Sendziuk, 2003).
having the capacity to ‘save’ lives and to ‘restore’ health, Dan offered a different perspective on how treatments are positioned in his life. Dan stated that “I’m much more relaxed about it [HIV] nowadays because of the treatments that are there” but went to say:

D: …the whole time on it, I had terrible side effects. You know diarrhoea constantly and 3 o’clock every afternoon I would find myself having to sit down for half an hour because I’d just “lose it”. Um, but the thing was it [treatments] was keeping everything in control, so I stayed on it. (2002 – first interview)

In spite of the adverse side effects he experienced from treatment use, treatments were positioned as crucial in his prolonged survival.

D: You know, I mean yes, these pills are toxic, you know, I’m the first to recognise that, or can be toxic. But um, the other alternative is death. And that was my attitude when I was on ritonavir for two years. Yes, this is a painful thing to be on and it causes some terrible side effects, but what’s the alternative, dying. No thanks! I’d rather be on the pills and that has been the attitude there. (2002 – first interview)

Notwithstanding the adverse treatment side-effects Dan experienced, he positioned the treatments as a beneficial resource, for they have enabled him to be “much more relaxed” about HIV. The treatments were positioned as resources on which he could rely as they were “keeping everything in control” and he would “rather be on the pills” than confront probable mortality. Sowell et al. (1998) argued that the treatments, particularly the protease inhibitors, have offered “a hope for the future”
(p.36). This is an interpretation which could be made about the constructed meanings Steve, James and Dan ascribed to the treatments. Hope is embedded in their everyday living, for treatments have, to draw on Dan’s idea, kept HIV in control which enabled them to position themselves as having a productive present and possibly positive future. This position was made most visible by Steve’s ideas about his capacity to do what he wanted to do, and James’ present situation of not using treatments. The treatments are resources James could access whenever they are needed, which means vulnerability to corporeal threats is minimised. For these participants, the act of taking treatments (or not) is a subjective strategy for negotiating the illness experience. However, as Nichter and Vuckovic (1994) argued, taking treatments involves more than the “in-body-ment” (p.1509) of treatment consumption, it also involves the embodying of ideas about self, illness causality and responsibility, meaning of sickness, and perceptions of entitlement. They further suggested that taking treatments connotes assumptions about what is normal and desirable, which link the physical body to the social body and the body politics. From this perspective, it could be argued that socio-political ideologies are not only important considerations but are also firmly embedded in the act of treatment use.

6.3 Treatment as a ‘Political/Moral Obligation’

J: There was this whole thing about there are treatments out there that you can’t get because you know it’s the whole drug regulation system and it’s too slow here and that was, you know dealt with, dealt with quite well. And they became available so the natural um step was to take them, to take as many of them as you could, as soon as you could because you’ve been waiting for them for so long and finally um (2001 – first interview)
The issues highlighted by James pertain to the history of HIV treatments in terms of making them available to people who are in need. This history is fraught and complex, for it was complicated by the inadequacies of bureaucratic systems as noted by James’ observation that “there are treatments out there that you can’t get because…it’s the whole drug regulation system”, which in turn led to political activities and lobbying by individuals in making them available. So when treatments became available, as James’ argued, the “natural step” was to use them as soon as possible and arguably, without question for “you’ve been waiting for them for so long”. It could be interpreted here that treatment use is an imperative due to the struggles and difficulties encountered. From this perspective, treatment use is an obligation; a moral and political obligation.

Social, medical and political pressures are embedded in the act of treatment use (Gold & Ridge, 2001). When effective treatments emerged in the mid 1990s, a journalist with the Sydney Star Observer, a Sydney gay and lesbian newspaper, claimed that “for the record, I do regard someone with a fatal disease who refuses to accept proven treatment as being stupid” (Goddard, 1997). This comment is informing, for it positions people with HIV as being obligated to use treatments even when they are not inclined to do so or even when there are serious side effects. From this perspective, it could be argued that the use of treatments is constructed as a social responsibility and a moral obligation (Wheeler & Shernoff, 1999). In exploring the function of medicine in the social, Zola (1972) interrogated the notion of personal responsibility for fulfilling explicit and implicit moral obligations which individuals owe to themselves and to others in ensuring good health. Specifically
with respect to treatment use, he argued that although individuals are not condemned for being sick, they are condemned if their actions do not follow sanctioned remedies in treating their disease or health condition. Drawing on Zola’s idea, my argument is that for individuals who resist treatments for HIV when they are available and medico-scientifically endorsed, the act would be regarded as a reflection of their “personal flaws” (Zola, 1972, p.490) and their integrity and morality could be questioned.

It is important to appreciate that the notions of individual responsibility and moral obligation, as social constructs, have a distinct history in HIV discourses (Adam, 2006). When health promotional campaigns and educational resources were produced as strategies to prevent HIV infection, they identified ‘risk behaviours’ by linking these behaviours to health and to locate the potential risk of infection in all individuals. In her examination of the socially constructed threats associated with AIDS, Lupton (1994) explored the concept of ‘risk’ and the moral implications on the individual for placing him or herself in danger of contracting the virus. She contested that the manner in which ‘risk’ was embedded in HIV discourses not only implied danger but a moral transgression, it was constructed as a sin. The interrogation of risky behaviours was informed by moral codes and imperatives. Lupton further argued that the concept of ‘risk’ interrogated within the frame of health promotion and disease prevention has a ‘forensic’ property for “it works backwards in explaining ill-fortune, as well as forwards in predicting future retribution” (p.136). The behaviours and the risk taken by individuals that led to HIV infection could be analysed within the frame of personal responsibility. Constructing ‘risk’ forensically was to produce a surveillance mechanism through which
behaviours were monitored, assessed and controlled. The ‘risk’ activities of individuals were publicised, for health discourses constructed these activities as issues demanding intervention. The individuals needed to be monitored for the ‘greater good’ and failure to exercise personal responsibility was a punishable contravention which legitimised the intrusion of public institutions – for example, health authorities, into the private. The ideas presented by Lupton are pertinent here because the use of treatments is a behaviour by which an individual is judged as to whether or not he or she is continuing to place him or herself at risk of corporeal damage caused by HIV. The act of resisting or rejecting treatment use is interpreted as a transgression, and individuals who resist or reject treatments are positioned as failing to fulfil their moral obligations and responsibilities.

In her first interview, Helen spoke of the obligation to take treatments even though she opposed the use of allopathic western medicine as means to manage HIV. She had not used any form of HIV medications for over ten years since her diagnosis but had to consider this option when the clinical indicators were showing that that her health was deteriorating. Apart from the perceived corporeal imperative to consider treatments, Helen also discussed the political and moral pressure to use them. The following is a series of conversational exchanges between Helen and me that constructed a story about the social and political forces that shaped her subjective view of treatment use. Moreover, the forces she had to contend positioned her as a social subject who owed a moral obligation to the social group to which she belonged, that being people with HIV.
Q: Hum, so was there pressure for you to go on treatments other than what you have said?

H: I think, I think there was yeah. I mean I feel that there was. I mean I, I don’t feel like anyone like personally pressured me but at the time um that I made the decision, there was a NAPWA [National Association of People Living with HIV/AIDS] conference on, I’d been in Vancouver, so I heard all the you know, the hype. Um, and then there was a conference, PLWHA [People Living with HIV/AIDS] conference on here, um, and it was just at the beginning of this um, the whole thing around, you know, starting them early and taking you know, a million things, a million combinations and lots of people were doing it um, and lots of people were having success. So in that way um I felt there was pressure yeah.

Q: The pressure of seeing success?

H: Yeah. And also it’s almost like the pressure of being irresponsible if I didn’t take them because you know my immune system was being damaged by the virus and I was sitting by, idly by sort of thing.

Q: Interesting word that you used, “irresponsible”. (H: Hm.) I just found that interesting because it would show you know, irresponsible would imply that you’d be doing something inappropriate or not the “right thing to do” (H: Hm.). Is that how you felt as well?

H: At the time yeah, at that time I think that’s, there was a lot of excitement you know around the combinations, and the results from the combination therapies (Q: Hm.) um and also having come back from Vancouver where there were lots of um, it was just the beginning then of the big, you know, the realisation of the inequity of other countries (Q: Hm.), you know, that if you’re from an eastern bloc country, you’re lucky to get an aspro! I mean I talked to women that were in that situation (Q: Hm.) um, you know, I mean we all know the big fight in Africa at the moment with the drug companies and governments trying to you know get affordable treatments and
you know, so speaking to these people *knowing*, you know, that we’re in a country that they were available and affordable and you know, not *taking* up the offer, and um, and also you know that, you know, seeing this, seeing people that honestly had withdrawn to die and were back on the scene again and stuff, so, yeah. (2001 – first interview)

Although Helen didn’t “feel like anyone like personally pressured” her but “the hype” generated by the knowledge presented at the conferences produced a pressure that she could not ignore. Affected by her observations that others had noticeably improved by the use of the treatments, she was unable to negotiate the pressure and to maintain her oppositional position to HIV treatments. She was discursively positioned as an unhealthy subject because of her failing health as shaped by HIV medical discourses which therefore made treatments necessary. From this perspective, she didn’t have a choice. Furthermore, “the pressure of being irresponsible” positioned Helen as needing to be responsible and to be self-reflexive. She located herself on a global context by acknowledging her privileged position of living in a country where treatments availability is not a concern as compared with women with HIV in Africa, or a person from an eastern bloc country where “you’re lucky to get an aspro”. The global inequity of treatment availability politicised her decision. As Jonsen (1988) argued, the activity of prescribing medications and taking them needs to be understood in moral terms. Helen has had to consider her action within a political and moral framework; that is, what is subjectively ‘right’ is situated within a broader social context. The treatment decision was, for Helen, situated on the world stage where to refuse treatments, as it could be argued, was to negate the responsibility of being a person with HIV, and to disregard the privilege of having treatments of which others are denied. She no longer could sit “idly by”, not only
because of the harm caused by HIV on her material body, but also because she wanted to resist the position of “being stupid” (Goddard, 1997). It could be argued that there is an imperative for her to position herself as a rational and responsible subject. Living with HIV in the post-treatment era and making sense of her lived experiences is a constant negotiation of moral imperatives.

Further exploring Helen’s story of acceding to treatment use, I want to refer to the work of Cohen et al. (2001) on prescribed medications as social phenomena. They introduced and critiqued the “rational use of drugs” discourse as a framework with which to interrogate the activities of prescribing and using medication. They defined it “as the judicious prescription by well-informed professionals of well-studied drugs to well-informed patients for well-defined conditions” (p.444). The “rational use of drugs” constructs a social reality of appropriate medication use without necessarily considering the socio-cultural, historical and political contexts in which it is used. In this way, the use of drugs implies a straight-forward and unproblematic use of medication, which marginalises important considerations, such as, the psychical process in medication use, the meanings ascribed to the medication, the social context in which individuals are asked to consider its use, and perhaps more significantly, the adjustments and changes for people who are on long-term drug treatments as is the case for HIV. The privileging of medical science and the “rational use of drugs” positions the diseased individual as passive and submissive. This in turn allows for the discursive construction of ‘(non)compliance’ as a device with which to position individuals as accountable and responsible for their activities that contravene with accepted practices (this issue will be further discussed in Chapter Seven). That is, how meanings and values have been assigned to the use (or
non-use) of treatments through the invocation of medical discourses. In this context, it could be interpreted that if an individual rejects or resists the endorsed or sanctioned treatments, he or she is positioned as an ‘irrational’ subject (Cohen et al., 2001; Vuckovic & Nichter, 1997). It could be argued also that the positioning of individuals as irrational subjects is informed by discourses of modernity, which construct “human beings as progressively gaining control over nature define adverse circumstances as a problem to be solved and as an opportunity to deploy the human qualities of rational thought and forward planning” (Willig, 1999, p.44). From this perspective, the rejecting of accepted medical practices is discursively constructed as non-compliance and as an abnegation of individual responsibility for “rational thought and forward planning”, but in doing so, it marginalised subjective fears, doubts and concerns associated with the recommended treatments.

The history of AZT and the political struggles that made it available as detailed by Ariss (1997) and Sendziuk (2003) provide an understanding of the imperative to take treatments and the incrimination cast on individuals, such as Helen, who resisted the use of treatments. In Chapter Two, I provided an account of AZT and the political activities that led to its availability to people with HIV. This account was clearly not a comprehensive history of AZT in Australia but what I aimed to achieve was to present two pertinent points to the issue of treatment use. Firstly, treatment for HIV was not a taken-for-granted situation as the right for treatment access was hard fought. The socially constructed meanings ascribed to AZT positioned it as a social and political symbol that reflected the struggles that people with HIV endured in attracting the due attentions to their plight. Therefore, when treatments became available, as noted by James above, people were positioned as being obligated to use
them. Secondly, AZT not only produced socio-political controversies but it was also clinically controversial. The toxicity and side effects undermined the confidence embedded in its effectiveness and was later positioned as a detriment to corporeality. This is significant for it provides an understanding to the misgivings associated with treatment use. Despite the promising results associated with the currently available treatments, they have been also constructed as possible causes of discomfort. It is in this context that I want to further my exploration into the constructed meanings of the treatments as ‘feared objects’.

6.4 Treatments as ‘Feared Objects’

I want to begin this section by revisiting the provocative binary statement – “be alive or be happy”, noted in Chapter One. The oppositional positioning of “alive” and “happy” resonated with me and made me think about the participants’ stories of treatment experiences in a way that disrupts the notion of treatment use as a precursor to better health.

None of the participants made a charged forced choice statement such as the one above. However, when treatments were explored in terms of the effects that they had on their lives, the adverse side effects were often positioned as issues demanding consideration and negotiation, either by changing particular drugs in their regimes, or by taking drugs to counteract the side effects or by pondering on the option of temporarily (or permanently) ceasing treatments. The pertinence of AZT history with reference to how newer generation of treatments and combination therapies were received comes to the fore here. Similar to AZT, the protease inhibitors and
combination therapies were greeted with excitement, and like AZT, they were thought to be cures. However, when jubilation gave way to acceptance that they were not to be the categorical successes, the AZT experience was positioned as a reference point with which the protease inhibitors and combination therapies were compared. More significantly, when the protease inhibitors and the combination therapies were recognised also as objects of harm due to noted adverse side effects, this served to entrench the view that they are pernicious and to be feared, despite the benefits they could produce.

Ben, who was in his mid 40s, received his HIV diagnosis in 1987 and has been taking treatments since 1997, narrated the story of how he was initially vehemently resistant to the use of HIV medications in his first interview because of what he observed in his friends’ experiences, but advice from a trusted friend encouraged him to reconsider his strongly held position.

B: (...) one period there I think in ’94, like this time June ’94 to about middle of August or the end whatever, for about a six week period, I had about 17 friends died of HIV/AIDS. In such a small time and a lot of it was due to a lot of the drugs and the toxicity, I guess.

Q: Was that combination therapy?

B: No, not then, it was mostly AZT and different other things. It was weird. That’s what made me promised never to take any drugs. This doctor I had or health provider rather, told you know, tried to put me on AZT from 1991 in [name of country] but I wouldn’t take them ’cause I just didn’t want to take AZT. Cause I don’t think there was still much known about it up until 5 years ago or whatever. (2000 – first interview)
The construction of treatments as feared objects was echoed by Steve who after having used different types of drugs summarised his view about treatments in this way in the second interview.

S: Um well I had an experience with um…indinavir [a protease inhibitor] where I was on it for 6 months and hated it and I knew that it was the indinavir because it was the last one that I went on (Q: Hm.) and it really made me feel “zombified” for 6 months…So anything that I, I say now, anything that ends in ‘vir’, fear (laughs)! Um just don’t do it. So I don’t want to take anything that ends in “vir”, so I probably won’t. (2003 – second interview)

The effectiveness of the treatments and the practice of combination therapies are matched by the acknowledged and well researched complications associated with their use. Just as treatments are constructed as ‘life savers/restorers’, they could also be constructed as ‘feared objects’ for the difficulties they have produced in the forms of adverse side effects and the toxicity individuals have had to endure. The positioning of drug toxicity by Ben as the cause of his friends’ deaths produced doubts and concerns about treatments. It could be interpreted that the concerns were profound, for he “promised never to take any drugs”. It was a bold declaration given HIV was constructed as fatal disease at the time when he was asked to consider the use of treatments. Steve positioned his concerns pertaining to treatments by his humorous comment, “anything that ends in ‘vir’, fear (laughs)”. The drug ‘indinavir’ is a protease inhibitor. His comment is significant when viewed from the perspective that the protease inhibitors were positioned as drugs that revolutionised HIV treatment and management but now are drugs he is rejecting. Steve’s resistance could
be interpreted as an evaluation of the benefits against the costs to treatment use, and that his subjective feeling is privileged over the benefits of what the drug could achieve.

The paradox of medications as both a remedy to and a cause of dis-ease can be analysed by the Greek word ‘pharmakon’ as a conceptual tool (Jonsen, 1988; Montagne, 1996; Persson, 2004). Jonsen (1988) proposed that the ideas which ‘pharmakon’ signifies are useful for they enable us to interrogate the complexities of medication use and its effects. The word pharmakon means drugs but there are crucial implications embedded in its meaning, for the word not only means ‘remedy’ but also it means ‘poison’ and ‘magic charm’. The subtlety and the inherent ambiguity in the word are lost in modernity when in the treatment of disease or illness, drugs are constructed solely in the ‘cure’ or ‘remedy’ framework but not as ‘poisons’ except when referring to illicit substances, or as ‘magic charms’. The construction of drugs as being ‘magical’ are dismissed by medico-scientific discourses, yet in everyday vernacular, the term “magic bullets” are used to represent many drugs (Montagne, 1996). AZT was referred to as the “miracle drug” (Sendziuk, 2003), currently available treatments were deemed as “miraculous” (Siegel & Lekas, 2002), and all drugs from prescription drugs to vitamins could be constructed as modern day talismans or amulets (Cohen et al., 2001). The implications of diminishing the import of other meanings associated with drugs are that the subjective experiences of adverse side effects from treatment use are marginalised and the construction of drugs as cures is centrally positioned in medical discourses. This produced a tension individuals have to confront when deliberating the use of treatments, or when negotiating directives embedded in HIV treatment discourses.
History of HIV treatments has shown that they are contradictions in that they are toxic and poisonous, and yet they are remedial in treating a disease with material consequences. This is why living with HIV in the post-treatment era could be argued as an experience that individuals are continuously deliberating and incessantly negotiating issues pertaining to the use of treatments.

The way people make sense of their experiences with treatments is to construct treatments in a subjectively advantageous and meaningful way. It would appear that they do so by employing discursive strategies to help them make sense of the need to tolerate the adverse side effects which they concede are an integral part of their lived experiences with HIV and treatments. Also in his second interview, Steve described the way he made sense of his experience with treatment side effects in this part of his story on treatments.

S: Um…I think probably what it does is, you just get used to the fact that you just feel a little bit off kilter. You know you just little bit left of where you want to be or a little bit right of where you want to be but you just get used to that. It becomes your life you know, which is interesting. (Q: It is.) Yeah, and that’s what I’ve done. (2003 –second interview)

Steve’s story is about having to “get used to the fact” that the quality of his lived experiences is diminished as a result of treatment use, for Steve has accepted that the quality will be “just little bit left of (…) or a little bit right of” his subjectively constructed ideal. It could be interpreted here that Steve has resigned himself to the likely possibility that he would not feel the way he would like by evocatively suggesting that the diminished quality is an experience he has to “just get used to”.
Not only has Steve to accept the ‘less-than-ideal’ quality of his lived experiences, but this quality “becomes your life”. In this context, Steve made sense of his experiences with treatment side effects by positioning his experiences as being the way he would feel henceforth, “and that’s what (he’s) done”. In doing so, Steve discursively (re)constructed the difficulties and discomfort associated with treatment use in a subjectively beneficial way. By accepting that treatment use will produce different lived experiences in terms of how he might feel, he was able to reconcile, or to make sense of, the “fear” he noted previously, which enabled him to continue with treatment use.

In spite of Ben’s initial resistance to treatment use as described by him in his first interview, he narrated a story of making sense of his continual use of objects he feared in his second interview.

B: …I don’t particularly like taking the amount the medications I do which is about 28 pills a day, something like that but um that’s what I have to do. As I think I might have said it before, I’m from the old world, when you get sick, you take drugs so I will (laughs)…I don’t want to stop the medication cause what’s gonna happen if I stop it, no one knows. Am I gonna get sick? I might still, stay perfectly well but I don’t want to take that chance (Q: Um.). Ok I’m putting a lot of toxins in my body and stuff, but um, hey I seem to be fine by all the tests I have. (2001 – second interview)

When Ben eventually decided to use treatments, there was reluctance for he did not “particularly like taking the amount the medications I do”. However, it could be interpreted that he made sense of his situation by positioning himself as a person “from the old world” which enabled him to engage with treatments in a productive
way, for he argued “when you get sick, you take drugs so I will (laughs)”. Despite his concern that he was “putting a lot of toxins in my body”, treatments were positioned as a ‘remedy’ for he “seem[ed] to be fine by all the tests” that he had. Positioning himself as being “from the old world” and the positioning of treatments as ‘remedy’ could be argued as discursive strategies that enabled him to re-negotiate his position of not wanting to take treatments. The discursive shift in the way treatments were positioned could be interpreted by the use of one of the three meanings of pharmakon, that being ‘magic charm’. Jonsen (1988) argued that “the act of being given and ingesting medicine has strong psychologic and emotional repercussions” (p.199). In this context, in spite of the “toxins” he was ingesting and his fear of toxicity, the material consequences of improved health as indicated by the clinical markers from the tests that he had, produced an acceptance of these objects that he previously had avoided. Conrad (1985) noted that while individuals dislike the prescribed medications necessary for treating their disease or illness, they continued to be disciplined in taking them. He reconciled this seeming contradiction by arguing that the desire to be well or ‘normal’ takes precedence over the emotional resistance, or, as I would argue, takes precedence over the positioning of treatments as ‘feared objects’. The following section will attend to the notion that in spite of the difficulties produced by side effects, and the construction of treatments as feared objects, living with HIV in the post-treatment era is to live with these ‘necessary evils’.
6.5 Treatments as ‘Necessary Evils’

The “Second Life Agenda” (Rabkin & Ferrando, 1997), which underscored the profound changes witnessed in the experiences of people with HIV and AIDS, was instituted by the advances in HIV medical sciences. Stories of people with HIV “returning from death’s door” resulting from treatment use (Maticka-Tyndale, Adam, & Cohen, 2002, p.1353) emphasised the indelible place that treatments, their use and effects are embedded in HIV discourses. The sanguinity produced by treatments is juxtaposed with the dreaded, and even feared, treatment side-effects that are also embedded in contemporary HIV discourses which also shaped HIV as a manageable and chronic disease. From this perspective, just as treatments are constituents of everyday living with HIV in the post-treatment era, it could be argued that there is a tacit, if not an explicit acceptance that treatment side effects are also constituents of living with HIV.

The proposition is that in exchange for a “Second Life Agenda”, as Steve declared, “you just get used to the fact that you just feel a little bit off kilter”. Lupton (1997), in exploring medicalisation and the hegemonic medical discourses and power relations embedded in medical knowledge and practice, contended that despite “the medicalisation critique”\(^2\), medico-science and its practices are able to produce outcomes desired by individuals afflicted by disease and illness. Drawing on her ideas, it could be argued that in spite of the treatment associated adverse side effects

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\(^2\) The medicalisation critique premised on the paradox that “medicine, as practised in Western societies, despite its alleged lack of effectiveness in treating a wide range of conditions and its iatrogenic side-effects, has increasingly amassed power and influence” (Lupton, 1997, p.95). Social life and social problems are constructed and problematised within a medical framework, and medico-scientific discourses have social regulatory power and are forms of social control. I will undertake a more detailed examination of medicalisation in the next chapter.
and drug toxicity, the treatments are useful resources for they “may contribute to
good health, the relief of pain and the recovery from illness” (Lupton, 1997, p.98). It
is this contradiction which makes medical practices, such as the use of treatments,
robust (Filc, 2004). Therefore, in spite of the unwanted consequences from treatment
use, treatments could also be positioned as ‘necessary evils’, for they signify the
potentiality of achieving wellness.

Eric agreed to start HIV treatments after twelve or thirteen years of not having to use
pharmaceutical treatments. His clinical markers were showing that his health was
deteriorating and treatments were needed to manage the virus in order to prevent
further harm. Soon after commencing treatments, he experienced serious bouts of
unwellness which he argued made him feel worse than before he began treatments.
Despite the lack of clarity from his doctor as to the cause of his unwellness, he
positioned his experience of unwellness as a result of treatments. He was previously
wary about treatments and his experience confirmed his cautiousness. Subsequent to
feeling unwell, he decided to stop taking treatments for he was doubtful about the
benefits they proffer if his lived experiences were to be severely and negatively
compromised. When treatment side effects and the meanings he ascribed to
treatments were further explored, I was surprised when Eric informed me that he had
resumed treatments. The story he presented in accounting for this occurrence is as
followed.

E: No, I’m back on them. Um because I tried, when I started, I tried to
be really positive about them and to…look at them as not in terms of
causing this huge battle field within my body. Like you know, the
drugs are going in and cause damage but they were actually there
kind of killing off the virus you know, there is this whole kind of (laughs) internal thing happening. Um and that…that really the bottom line for me with them was that they were just going to be there, they were just going to block the virus serenely and silently (laughs). That’ll be their role and I can, I would endorse them in that role and that was fine. Um and that there will be no negative effect or um, yeah, no struggle, however, when my body started to sort of react by throwing up hepatitis in response to the treatments, hum I got really angry and I thought um, you know, bugger this because they suppose to be making me feel better and improve my quality of life and bloody hell, they’re not! … I’ve sort of fought that battle and I thought no, I don’t want to be that cynical of them. Because I know, from, again from people that I know that, the drugs have turned their lives around or some drugs have turned their lives around. And that from being close to death, people are now back at work, and looking great and you know all trace of being sick or whatever has been removed outwardly. And from having talked to them, internally as well, they’re feeling better than ever and able to take on the world. So I have this sort of range of people in front of me from, you know on the one hand where they obviously haven’t, treatments aren’t working and people have decided not to continue with them to other people who are doing really well on them. So, no, I’m trying to still keep an open mind…(and) trust that somewhere along the line that they’re, there is something around the corner that will be maybe a wonder drug. And I think to put myself in a position of saying “no” is, they can’t help and just you know, chasing my tail here with treatment that, no, there’s a chance and I don’t want to rule that out. (1999 –first interview)

Eric’s story conveys the tension, as subjectively experienced, that is embedded in HIV treatment discourses. Treatments could be positioned diametrically as resources with which to address concerns associated with HIV infection and as causes of
discomfort. The anticipation Eric had for the treatments to “block the virus serenely and silently” was dashed when he experienced the adverse side effects; instead of “making (him) feel better and improve (his) quality of life”, they diminished it. However, his inter-subjective encounters positioned treatments differently, for he observed the benefits derived from their use. His observations enabled him to restrain his cynicism and to “keep an open mind” so to maintain his belief that a “wonder drug” would materialise. He wanted to be in a position where he had the opportunity to take the “wonder drug” by not positioning himself as a critic or an antagonist towards treatment use. In spite of his reported negative experience with treatments, Eric maintained his “trust” in medical science, which could be interpreted as his acceptance that the treatments are necessary, and continued to look towards them as being the solution to HIV, despite the negative consequences he experienced. In this context, it could be argued that the manner in which Eric positioned treatments as necessary is produced by pervasive medical discourses on the use of pharmaceutical materials to remedy illnesses and diseases.

In their critical examination of the practices of drug companies, Moynihan and Cassels (2005) argued that medications are constructed as resources to placate the fear or to redress the ambiguity produced by the presence of a disease. They argued that fear is used as a currency to necessitate the utilisation of pharmaceutical materials as means to counter the destructive, if not fatal, consequences of diseases or any identified medical conditions. This is a useful way to think about the strategy Eric employed to make sense of his ongoing commitment to treatments in spite of his reservations. Informed by the destructive consequences of HIV and AIDS and the fear the disease signified, the way to ensure that death remains a distant possibility
from HIV infection is to use treatments regardless of the adverse consequences.
Moreover, it is of interest to note the use of military metaphors (“battle field”,
“fought that battle”) by Eric in his negotiation with HIV infection. Military
metaphors are frequently used in modern medical and public health discourses that
deal with conditions such as cancer and AIDS (Lupton, 2003). In her book AIDS and
Its Metaphors, Sontag (1989) invoked two metaphors for HIV and AIDS – as a
invader³ and as a punishment for immoral acts. I want to focus on the first metaphor
of AIDS as an invader and the military connotations it evokes. Although in her
conclusion of her book she advocated for the “retirement” of the military metaphor, I
see the metaphor as pertinent to my analysis here. I respect Sontag’s argument for
wanting to retire this metaphor⁴. However, I would argue, for Eric, the availability of
treatments as a resource is a ‘weapon’ to ‘fight’ against the disease. The locating of
that fight in his body by Eric could be interpreted as an important strategy with
which to position himself as being potent and as an active agent in controlling a
disease that up until the mid 1990s was constructed as fatal. The military terms are
used intentionally here to signify that HIV was and continues to be a threat to the
material body; and although discursive constructions of the disease do not remove or
eliminate the corporeal threat, they are strategies through which the disease is
productively constituted in the everyday life. By the use of Sontag’s “invader”
metaphor, it could be interpreted that Eric made sense of his doubts pertaining to
treatments by constructing his HIV infection as a battle between his body and the

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³ A metaphor she used previously in her work on cancer in Illness As Metaphor (Sontag, 1978).
⁴ Sontag argued that the military metaphor oppresses individuals who are diseased by providing a
persuasive justification for authoritarian rule, and an implicit suggestion for the necessity of state
sanctioned repression and violence against the intruders or invaders to the body. The subjectivities of
individuals are conflated with the disease and the military metaphor has the effect of “[i]t
overmobilizes, it overdescribes, and it powerfully contributes to the excommunicating and
stigmatizing of the ill” (Sontag, 1989).
invader – HIV. In this way, treatments were positioned as his allies against the invader. He needed treatments despite his bout of “hepatitis in response to treatments” and they were ‘necessary evils’ in order to stay alive. This is a useful construction of his experience with treatments, for it provided him with a way to negotiate the sense of impotence as previously experienced when treatments were inadequate and inefficient. Drawing again on the construction of treatment use as a binary of either “be alive or be happy” noted earlier, it could be interpreted that, for Eric, living with HIV in the post-treatment era is a proposition of either be alive (accepting treatments as ‘necessary evils’) or be happy (resisting treatments but accepting that deteriorating health and mortality are possible outcomes). While it seems the binary positions should not be mutually exclusive, the situation for Eric is that he has to make sense of treatments in a way that they are constructed as assets and not as liabilities to his health. From this perspective, it could be argued that by positioning treatments as ‘necessary evils’, he retained treatments as an option, but simultaneously, enabled himself to resist their use until the appropriate time. In this way, treatment benefits are not denied, but the use of treatments will be at a time when he is prepared to negotiate and to accommodate the associated adverse side effects.

6.6 Treatments as a ‘Safety Net’ and the ‘Last Resort’

The positioning of treatments as ‘necessary evils’ could be interpreted as illustrative of the centrality of treatments in the construction of HIV as a chronic disease. Treatments that are currently available have hitherto been shown to be effective in controlling HIV, and for some people with HIV, treatments are positioned as a
‘safety net’ on which they could rely if required. In this context, I would argue that the positioning of treatments as a ‘safety net’ is a device people employed to negotiate the hegemonic HIV medical discourses on the essentialness of treatment use. Davis (1996) argued tension in the use of pharmaceutical materials is inevitable because of their moral and symbolic character, for they have the power to heal as well as the potential to harm. Treatment effectiveness is established but their documented side effects are equally well known; these dichotomous positions in which treatments are situated produced a resistance to treatments as the first option for treating HIV. The ‘Hit Early – Hit Hard’ principle which exemplified the initial reception to the protease inhibitors and combination therapies in the mid 1990s (Ho, 1995) was later proved to be an excessive approach to treatment use (Harrington & Carpenter, 2000; Simmons, 1999). However, when to start treatments continues to be an issue (Thorner & Rosenberg, 2003) and a major constituent of contemporary HIV treatment discourses. Treatment use is grounded in the cost-benefit deliberation and when to use treatment is relational to the subjective positioning of being ‘healthy’ or ‘unhealthy’. From this perspective, treatments are not regarded as the first option, but for some participants, they are the “last resort”.

Athena was not using combination therapies when first interviewed in 2002, for she regarded them with antipathy due to her subjective beliefs and values. However, in her story, which explored changes in her subjective assessment of treatments, she moderated her position about treatments and conveyed her receptiveness to initiating them as part of her project of change. She acknowledged that the constructed

3 The principle denotes the treatment strategy of treating HIV with a strong combination of different class of drugs as early as possible with the aim of controlling the amount of virus in the body. It is premised on the theoretical position of preventing the virus from causing harm or damage before it has the opportunity to do so.
meanings she had ascribed to treatments were no longer of benefit to her. Her health was deteriorating and the way she made sense of treatments was to position them as a ‘safety net’ and therefore enabled her to engage with them in a way that is consistent with her subjective values.

A: I remember the doctor saying to me you couldn’t have been diagnosed at a better time! He said “it’s ok, they got treatments, they’ve got,” so there was this hope there but I had grown up for all those years when AIDS had come to people’s awareness with the whole grim reaper thing (Q: Hm.). So I had the whole idea about, I felt very strongly about all that AIDS, I was aware of that whole collected feeling around it, all the fear of it and death and, I still had that inside myself (Q: Hm.). Even though doctors are saying um, the treatments are really working and they have some good breakthroughs (Q: Hm.). I guess I felt that was ok but I never felt that it was an option or it was a very last resort, treatments. (2002 – first interview)

When the issue of treatments as ‘last resort’ was explored, Athena provided the following story.

A: Just because I’d heard about side effects. And um the idea that they are very strong drugs, yeah, just very powerful drugs. And my um, not total trust in western medicine, being as it’s fairly new compare to some of the older um, systems … to me it felt like a sense of giving in or losing control (to use treatments), which I kind of, turned around a lot lately. Er but as I got to know people who’re positive and who had, and I saw many success stories around it and I saw the relief that they felt. I felt it was a safety net, yeah, definitely. I thought that was a safety net, that’s the last resort you know. But I was also afraid of the impact on your body and um, I felt, I liken it to chemotherapy in a way except that you take it all the time. How can a person deal with
that but um, I changed a lot of my thinking about it and it’s a real relief in lots of ways. (2002 – first interview)

The manner in which Athena made sense of the change she made in her engagement with treatments was to discursively (re)construct the meanings she ascribed to them. She initially positioned herself as a person who did not have “trust in western medicine” and thus constructed treatments as the “very last resort” because of the side effects. It was also interesting to note that the use of treatments was constructed as an affront to her subjectivity for she construed the act of taking treatments as a “sense of giving in or losing control”. Athena’s story could be interpreted as her resistance to being positioned as passive and lacking agency. Cohen et al. (2001) argued that the patient-physician relationship functions within a medical model, and it is a paternalistic model in which the medical gaze of the physician is privileged over the subjective experiences of the individual. They further argued that individuals’ subjectivities need to be considered and be situated in a social context so to make possible to understand their positions of resisting or accepting treatment use. For Athena, her resistance to treatments was based on her positioning of western medicine as inadequate for it is “fairly new compare with some of the older systems” and it signifies her disempowerment. Notwithstanding the intersubjective construction of treatment benefits through the embodiment of others’ stories, Athena positioned treatments as a “safety net”, the “last resort”, that is at her disposal by which she could be positioned as an active agent in the management of her health care. This is important for it could be interpreted by the idea that treatment use is “based on personal, as well as societal and epistemological, systems of knowledge and social realities” (Montagne, 1988, p.419). The positioning of treatments as a “safety net” was a discursive device that enabled Athena to interpret the treatment
use experience positively and preserved her constructed subjectivity as an active agent by rejecting the act of treatment use as her “giving in or losing control”.

Just as Athena’s intersubjective experiences informed her of the benefits from treatment use, Helen offered a contrary story. Helen had used treatments, as noted in the ‘Treatment as a Political/Moral Obligation’ section, but had stopped using them at the time of the second interview in 2002 because she found the side effects were too costly in terms of her well-being, particularly when she recounted that “every time I have a blood test and they say “no, everything’s alright, you know, you don’t have to worry it” (laughs)”. The clinical markers positioned her as ‘healthy’ and she was unable to locate benefits for continuing or resuming treatment use. From her perspective, the benefits did not offset the costs especially when her health was sound. More significantly, at this time, the treatments were positioned as causing more harm than produced relief. Her observation of and encounter with others whom she knew were using treatments were contrary to Athena’s experiences, which led to the story she told about her resistance to using treatments unless its use proved to be necessary.

H: … But it’s, it’s about the side effects you know, and I’m thinking “well, is it gonna work?” and you know at what costs physically to me is this, you know. So that’s really my major concern. I mean if there weren’t side effects, I’d, and if it, you know, depress my viral, you know, load, I’d be taking them now, you know. But it’s just that sort of, that long-term stuff around what, you know, what I’ve seen it do to people. And, you know, people still taking them. They look like, you know, “death warmed up” and they’ve got diarrhoea and they can’t eat and they, you know, it’s just ruining their lives and, you
Helen’s intersubjective experiences informed her view about treatments. In addition to her subjective concerns about “side effects”, treatment efficacy (“is it gonna work?”) and the negative consequences on her corporeality (“at what costs physically to me is this”), remaining treatment free was also informed by her social reality in which she observed the unwellness of others resulting from treatment use. She asked the rhetorical question of “why stay alive” in the context of her observation that people looked like “death warmed up”. The idea of Montagne (1988) noted above also resonates here, for the manner in which she positioned treatment was informed by her personal knowledge and the social realities she observed. Despite her antipathy and resistance towards treatments, she, like Eric, did not dismiss treatments as a future option. When I relayed the construction by others of treatments as a ‘safety net’, Helen refuted this construction for she constructed treatment use as an “eventuality”, a consideration she would need to confront not so much ‘if’ but ‘when’.

H: Um, I guess that I would use um the combination therapy or whatever, the new thing on the market um…when I need to. But I’d rather put it off as long as I can because I, you know, know that the side effects can be pretty unpredictable and fairly, you know, awful. And um, that there’s a certain shelf life with them and, you know, I’d rather use it later rather than sooner … I hadn’t thought of it as a safety net. I’ve thought of it as a…an eventuality I suppose. Something that, you know, possibly eventuate and that I’m gonna have to consider at one stage or another, and just hope it’s later you know. (2002 – second interview)
Positioning treatments as an “eventuality” is consistent with Helen’s positioning of treatments as a “last resort” that she noted in the first interview, which took place in 2001. Helen acknowledged that the positioning of treatments as “last resort” needed to be shifted in order to overcome her resistance to what could be useful resources and perhaps, to be a politically principled subject as previously discussed. She suggested that she needed to construct them as “prophylaxis”, which I would interpret as a ‘safety net’, for, as “prophylaxis”, they were to prevent damage and to promote health.

H: (…) well I suppose having, seeing um…seeing other people having such success with them … I had sort of thought, well, there’s a time that I’m going to need to start using them but I like to, you know, do alternative treatments first and have, you know. I always seen, I’d always seen um allopathic, you know, protease inhibitors and antivirals as a, like it’s the last resort. And I felt that um, that I couldn’t, that I had to stop seeing them as the last resort. That I had to change my attitude um in terms of, that they were more of a prophylaxis that I should used them as more of a prophylaxis. (2001 – first interview)

The discursive construction of her intersubjective experiences which informed her resistance to treatments at the time of the second interview was the same discursive device she employed to make sense of her construction of treatments as a benefit in the first interview. This is noteworthy because Helen’s discursive shift signified not only the importance of the temporal frame when exploring lived experiences, but it also emphasised that the act of making sense of these experiences were
In this context, Helen’s discursive construction of treatments is both intra and intersubjectively informed. The positions she took with respect to treatment use, agreeable in the first interview and oppositional in the second interview, were informed by her subjective understanding of her health and the need to be personally responsible for her health maintenance. Moreover, the intersubjective encounters in which she observed others as “having such success” with treatments formed a social reality that not only constructed treatments as necessary but undermined her resistance to their use. Treatments were taken as resources to assure good health, the ‘safety net’ that she could depend on if “alternative treatments” proved to be insufficient. Despite positioning herself as oppositional to the use of “allopathic…protease inhibitors and anti-virals”, it could be interpreted that Helen was reassured that treatments were there for her as the ‘last resort’, a ‘safety net’.

The construction of treatments as ‘necessary evils’ and as a ‘safety net’ produces a relation between individuals and treatments that position the individuals as ‘in control’ of the circumstances in which treatments are received. To take ‘control’ or to take the ‘active’ position in treatment decision, be it consistent with or contrary to medical advice, is congruent with the value of autonomy and personal responsibility

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6 The notion ‘intersubjectively constructed’ is informed by the concept of subjectivity, which is a term used in social constructionism to refer to the state of personhood or selfhood (Burr, 2003). Intersubjectivity denotes the complex relational field in which the subject and specific subjectivities are produced and shaped (Flaskas, 2002). In this context, intersubjectively constructed positions an individual’s experience of the world as being produced with and through others by the use of available cultural and linguistic resources.

7 It is common for people with HIV to use alternative or complementary therapies/treatments (e.g., herbal remedies, acupuncture and nutritional supplements) as part of their broad health maintenance strategy (Agnoletto, Chiaffarino, Nasta, Rossi, & Parazzini, 2003; Colebunders, Dreezen, Florence, Pelgrom, & Schrooten, 2003; Foote-Ardah, 2004; Pawluch, Cain, & Gillett, 2000). Reasons for using alternative or complementary treatments include dissatisfaction with western medicine (Foote-Ardah, 2004; Pawluch et al., 2000) and a sense of control through active self care (Anastasi & McMahon, 2003).
(Bishop & Yardley, 2004). That is, they are ‘in control’ of the treatments which means treatments are *for them to use* in order to meet subjective needs. From this perspective, the participants are positioning themselves as resistant to the docile subject position as shaped by medical discourses in which they are subservient to medical imperatives.

Being ‘in control’ represents a philosophical shift in the way they relate to their disease and its management (Thorne, Paterson, & Russell, 2003). The metaphors used for treatments are important, for they enabled individuals to make sense of how treatments are constituted in their everyday lives with HIV. For people like Eric, Athena and Helen who positioned themselves as being dubious about the treatments due to subjective experiences of adverse side effects or being suspicious of western pharmaceutical medicine, the metaphors allow them to make sense of treatments in a way that is consistent with their subjective ideals of how life is to be lived and, particularly for Eric and Helen, to not dismiss the treatment option despite their adverse experiences. This conflict in treatment use is echoed by Demmer (2000) who suggested that the lack of enthusiasm in starting treatments could be due to scepticism about their long-term effects and preference to non-western treatment options. With respect to this conflict, it could be interpreted that for the participants, the metaphors are discursive devices to make sense of a situation in which they are not reassured by the possible benefits in light of the identified costs. The acknowledged adverse side effects from treatment use produced indifference in people with HIV and the complexities embedded in the treatment decision. The meaning ascribed to treatments is multiple and variable, and the subjective meanings can and do affect the manner in which treatments are engaged (Conrad, 1985). To
make sense of the treatments as ‘life savers or restorers’, a ‘political or moral obligation, ‘feared objects’, ‘necessary evils’ or a ‘safety net’ enables participants to engage with treatments meaningfully. In spite of treatments having undesirable effects or their use being politically driven, the construction of them as materials which could restore health and as resources that people could rely on means that they are important constituents of living with HIV in the post-treatment era. However, what is significant about treatments in the post-treatment era is that they are not positioned as a panacea and not necessarily the means through which wellness is achieved.

6.7 Summary

In this chapter I have examined the constructed meanings ascribed to treatments that emerged from the interviews. I argued that the discursive construction of treatments as ‘life savers / restorers’, a ‘political / moral obligation’, ‘feared objects’, ‘necessary evils’ and a ‘safety net’, and their material effects are important in the way that they enabled people to make sense of their lives in the post-treatment era. The material consequences of treatment use, both desirable (controlling HIV) and undesirable (adverse side-effects), produced a tension embedded in HIV treatment discourse that has complicated not only the use of treatment as the first option for treating HIV but also the subject position of people with HIV living in an era when HIV discourses continue to privilege and be shaped by medico-scientific advances. This is not unreasonable for medical science has made possible the discursive construction of HIV and AIDS as chronic and manageable. In this context, living with HIV in the post-treatment era cannot be divorced from treatments and from living with the
disease as a medicalised experience. The advances in medical sciences have produced strategies of engaging with the disease that have disembodied the notions of ‘healthiness’ and ‘wellbeing’ from the subjective lived experience. However, this has great implication, for people with HIV are positioned as medicalised subjects as it is medicine and medico-scientific advances that would ensure their survival. In the next chapter I want to examine the medicalisation of people with HIV, the implications this has on their subjectivities and their continuing endeavour to make sense of their lives.
Chapter 7: Medicalisation of the Experience of Living with HIV: The Medicalising of Wellbeing

“How do you feel?”
“I feel good, but I’m sick.”
“What do you mean?”
“My T-cells are down. I’m taking AZT. I must be sick.”
“Why are you taking AZT?”
“My doctor told me to.”
“Did you ask him why?”
“Because I’m sick.”
“But you’re not sick. You said you feel well.”
“I do, but that doesn’t mean I’m not sick.”

7.1 Introduction

When I recall the era when HIV and AIDS were immediate mortal threats as reflected by the late 1980s ‘Grim Reaper’ campaign, which equated AIDS with death, and the “death-saturated culture” (Rofes, 1996, p.29) in which we lived, especially gay men, the changes effected by the treatments have been momentous. In our need for shelter from the fatal consequences of HIV infection, we privileged medical scientific knowledge and positioned this knowledge as means through which we could be protected from the disease. In doing so, HIV medical discourses not only positioned social acts, such as, sexual activities and the use or non-use of

1 A conversation between Navarre and a man with HIV (Navarre, 1988, p.143-144).
2 An Australian-sponsored health education initiative aimed at the general public to reinforce that AIDS was a concern for everyone and as a strategy to counter the belief that AIDS was somebody else’s problem (Lupton, 1994). The central message of the campaign was that prevention from infection was the only cure available; notwithstanding the criticisms the campaign received for the exaggeration of risks posed by AIDS to heterosexual Australians and that it was the intention of the “gay lobby” to lessen the association between gay men and the disease, the imagery remains vividly intact for many people who saw it when it was first appeared nationally on 5 April 1987 (Sendziuk, 2003).
treatments to control HIV, as either ‘risky’ or ‘safe’ within the frame of health and wellbeing, but they also constituted these social acts as surveillance sites, which could be medicalised for their potential adverse consequences on the corporeal.

Many issues pertaining to HIV in the post-treatment era (e.g., treatments, clinical indicators, infectivity, and undetectable viral load) are, by their materiality, medically defined. However, in positioning ourselves as adherents of medico-scientific practices, these practices have become taken-for-granted and are firmly embedded in our everyday lives. In the era when HIV was poorly managed due to limited knowledge, an HIV seropositive status was an experience of the entire body (Rosengarten, 2005). The medico-scientific advances in HIV management, both in monitoring technologies and treatments, fragmented the body, and specific parts of the body are isolated for investigation. For example, the isolation of the amount of virus in the blood as compared with the amount in semen or in vaginal fluid. Advances in monitoring technologies have altered HIV medicine materially and socially (Rosengarten, Imrie, Flowers, Davis, & Hart, 2004), for they have influenced the way individuals are engaged in the evaluation of the illness experience and the effects that treatments have had on their lived experiences. I am not disputing the benefits of treatments on the material body and the utility of monitoring technologies, this was examined in Chapter Two, but it is important that the intersection of the medico-scientific construction and the lived experiences of HIV be interrogated, for it is at this intersection where the lives of people with HIV are situated.
In this chapter, I want to address the thesis question of ‘how do people negotiate the medicalisation of their lived experiences with HIV?’; and the way they negotiate the tension between doing what is best them as medically constructed and what is best in terms of how life is subjectively constructed and meaningfully lived. I will initially explore ‘medicalisation’ as a social process by which medical discourses shape the way the notions of health and wellbeing are constituted. After doing so, I will examine the HIV specific medical practices of monitoring an individual’s health status, which I describe as the ‘numbers game’, that position wellbeing as being predicated on clinical indicators, and the use of these ‘numbers’ as surveillance devices with which to enforce treatment use and the medicalised construction of ‘adherence’. By examining these issues, I will argue that satisfaction embedded in lived experiences with HIV in the post-treatment era is not always predicated on the individual’s health status, as indicated by clinical measures, but that this satisfaction is subjectively constituted.

7.2 Medicalisation

I want to firstly clarify the term ‘medicalisation’ in the context of this enquiry. I will draw on the work of writers and researchers who have interrogated the medicalising of the social, as the basis on which to locate my use of the term in examining the medicalisation of wellbeing in the context of HIV and AIDS.

Medicalisation is a concept widely used in the social sciences to refer to the processes by which social phenomena come to be constructed as illnesses (Ballard & Elston, 2005). According to Filc (2004), medicalisation has two aspects: firstly, it de-
socialises illness and disease so to obscure the social processes in their production; and secondly, it explains social phenomena in biomedical terms. In tracing the genealogy of the word ‘medicalisation’, Aronson (2002) submitted that its meaning is “to give a medical character to; involve medicine or medical workers in; to view or interpret in (esp. unnecessarily) medical terms” (p.904). In providing a linguistic definition of medicalisation, he also provided a sociological meaning which contends that medicalisation is the “practice of attaching medical labels to behaviour considered as socially or morally undesirable”. The central premise of these definitions is that by socially constructing a problem or behaviour as a disease or as a medical condition, it invokes the medical gaze which meant that the problem or behaviour could be ameliorated by medically constructed practices. However, the invoking of the medical gaze “had damaged lay person’s capacity to manage matters of health and illness themselves, and, hence, their autonomy” (Ballard & Elston, 2005, p. 231). Zola (1983) noted his concerns with the “medicalizing of daily life”, which refers to a “medicalizing fostered by a certain kind of chemical and surgical success in which the real problems of survival in modern society are trivialized and reduced to treatable medical symptoms, with social problems too often reduced to individual pathologies, all treated symptomatically, with little regard for the larger moral and political consequences” (p.238-9). From this perspective, medicalisation is political for it not only locates disease in the individual body but it problematises the material body in a manner which “exonerates society from any responsibility in the etiology of disease” (Filc, 2004, p.1276) and disregards the “socially or morally undesirable” behaviour, noted earlier by Aronson, as mediated by socio-cultural forces.
Conrad (1992) proposed that the key to medicalisation is the definitional issue informed by socio-cultural processes and resources. He agreed that medicalisation is to define a problem in medical terms by using medical language and epistemology to describe and to understand the problem so that it could be treated within the medical paradigm. In his work with colleagues (Conrad & Schneider, 1980; Kawachi & Conrad, 1996), Conrad argued that medicalisation can occur on three distinct levels – the conceptual, the institutional and the interactional. On the conceptual level, a medical vocabulary or model is used to define a social problem; on the institutional level, an organisation (e.g., a health service provider) adopts the medical approach in its service delivery in treating presenting social problems; and on the interactional level, which refers to the medical encounters between doctors and patients, this is the instance where the doctor defines a social problem as medical by the use of a medical diagnosis and by treating it with medical forms of treatment. It is apparent that these three levels, though discrete as Conrad and colleagues attested, are not isolated from each other in the process of medicalising a problem or behaviour.

7.2.1 Medicalising HIV Living and Subjective Wellbeing

“[Health care providers] look at pure numbers because they’re so used to the old way of things like T cells going from 80 down to 60 and then soon after, you die. Now they’re saying ‘Well, gee, your T cells are 350 and your viral load is undetectable, you should be feeling wonderful.’ And so you think to yourself, ‘Well, I’m supposed to be feeling wonderful – what is wrong with me?’” (Barroso, 2002, p.86)

In examining the construction of wellbeing in the context of HIV, drawing on ideas provided by Conrad on medicalisation as noted previously, the results from
Monitoring technologies are positioned as being indicators of wellbeing in that they are taken to be signifiers of an individual’s subjective experiences with regards to their health. This issue is highlighted by the above extract taken from the research by Barroso (2002) in which the notion of “feeling wonderful” is contested by the individual whose subjective experience does not support the conclusion drawn from his t-cell count and viral load assay. The advances in HIV medical science and the “technologisation” (Davis et al., 2002, p.32) of HIV treatment and management, through which the disease state is made visible and the health of people with HIV quantifiable have the propensity to construct wellbeing within the frame of the medical paradigm. In this context, the resistance to or rejection of the use of anti-HIV treatments and technologies have been problematised as an irrational act, and positioned as detrimental to wellbeing as shaped by medical discourses. It is here that the medical gaze is made visible and medicine can be viewed as a form of social control (Zola, 1972). Zola (1972; 1983) argued that the construction of wellbeing as a goal achievable by medical intervention is problematic, for it treats health in isolation from the complexity of lived experiences and makes the assumption that health and wellbeing are linearly relational. Situating my examination of wellbeing in the context of it being medicalised, I want to explore the implications that privileging medical technologies (the t-cell count and viral load assay) and the strict use of treatments (adherence) have on the participants’ lived experiences, by interrogating the consequences of treatment use (adverse side effects) on their subjectively constructed notion of wellbeing.

In the story that James told of his treatment experience, he recounted the experience of using treatments and negotiating the adverse side effects. James’ story made
visible the paradox embedded in HIV treatment use, as denoted by the pharmakon phenomenon (Montagne, 1996; Persson, 2004), as well as the obligation and commitment he showed despite the negative consequences to his everyday life. At the time of his first interview in 2001, James had stopped taking treatments, for the ‘numbers’ from his t-cell count and viral load assay were ‘healthy’ but he wanted to maintain the option of resuming treatments if necessary.

J: Um…well I, I was encouraged I suppose by my doctor, doctors, when they did come out, to take them. Um, I sort of embraced them whole heartedly, um…and believe, and decided if I was going to take them, it’s going to be a positive thing to do. Um, and um, the first combination I went on to was um, I had severe reaction to but persisted and um, in terms of compliance, I think I was sort of one of the well, very compliant. Didn’t miss a dose despite the fact that for the first you know few weeks anyway, I was practically bed ridden and um never quite got over the um you know, you know um the side effects. They sort of stuck with me until it was sort of obvious that you know I was being over treated. Um

Q: As in given too many drugs?

J: Yeah, I think as in sort of “treating hard, treating early” which was the doctrine of the time, and um, yeah, I don’t think that was necessary. I mean um, I’m sort of paying the price now for that. Um, but at the same time I accept that it’s probably put my um, put me in a fairly good position to sort of you know, maintain you know reasonable health for a longer period. So, it sort of you know like “hate them” and “love them” at the same time. (2001 – first interview)
In spite of his “severe reaction”, the option of resuming treatment if necessary was made visible in James’ second interview in which he positioned the viral load assay as being an important consideration in relation to treatment use.

J: So if I’m, you know if and when I need to start on treatment again (…) I quite like to you know, in most of the time I don’t think you know doesn’t come into my consciousness, you know my thinking that I have HIV, that it’s, that I’m not treating that you know I’ve got a high viral load so they all point to the fact that you know, um my immune system is going to you know suffer eventually and I’m going to need to go back on to treatments that I’ve done a number of regimes, um but the one I go on to will need to um you know be well chosen um that it won’t um cause lipodystrophy which is the main reason why I stopped last time. Um, I mean these things are sort of in the back of my mind but I don’t, most of the time I don’t think about it except I suppose I don’t want to um, I’d much rather get on with stuff, pick up where I was ten years ago (Q: Hm.) um but acknowledge that I’m a completely different person now. (2002 – second interview)

In the context of HIV treatment history, as noted in the previous chapter, political activism made treatments available to people infected with HIV and so when protease inhibitors and the practice of combination therapies were instituted as standard clinical protocol, James “embraced them whole heartedly” and constructed the experience as positive and productive to his health. However, when James spoke
of his persistence with taking treatments even though the adverse side effects had
made him “practically bed ridden”, it could be interpreted that he could not desist
from treatment use, for treatment use was both a political and personal obligation.
James positioned himself as “one of the very compliant”, which illustrated the
embodiment of adherence discourse in spite of the detrimental effects that the
treatments have had on his subjective wellbeing. He could not afford to ‘listen’ to his
own body as it would undermine his position as a compliant subject. Selwyn and
Arnold (1998) argued that the privileging of clinical markers and the emphasis on
adherence has the effect of marginalising lived experiences in ways that affect
subjective wellbeing. The privileging of medical discourses in HIV treatment and
management positioned James as subservient to medical doctrines to the extent that
they disempowered his subjective need for feeling well. It was through the telling of
his story and his analysis that James was able to position the treatments prescribed,
specifically the doses he had to take, as an episode of “over treating”. The
medicalisation of his wellbeing premised on needing to improve his ‘numbers’
through treatments was made visible by his observation of the discursively practice
of “treating hard, treating early” and the possible need to resume treatments as he
“got a high viral load” and his “immune system is going to you know suffer
eventually”. The disembodying experience of treating HIV is typified by the ‘Hit
Hard, Hit Early’ discourse which privileged the clinical markers as indicators for
treatments (Ho, 1995; Portyansky, 1997). Although James acknowledged the early
intervention had helped him to remain healthy within the paradigm of clinic markers,
the benefits attained were tampered with reservations as revealed by the “hate them /
love them” dichotomy. This dichotomy posited by James further emphasises the
tension that exists between the use of treatments in achieving ‘healthy’ clinical markers and the effects they have on subjective lived experiences.

J: Um, but the important thing is being true to yourself and um and finding peace. (...) So yeah, I mean I still draw the distinction between being you know physically well or, or more importantly being well on paper like having results that say everything’s fine, um, and that actually makes you feel physically well seeing that. So I know, I know um you can get fantastic results when you’re on treatments feeling like shit you know, and that’s a distinction as well. Um…yeah so it’s striking a balance. (2002 – second interview)

The “hate them / love them” dichotomy was illustrated in this part of James’ story when he argued that “you can get fantastic results when you’re on treatments [but] feeling like shit”. As noted in Chapter Two, Holzemer (2002) suggested that results from clinical markers are not always reflective of an individual’s lived experience in terms of physical wellbeing and wellness as subjectively defined. Physical wellness as indicated “on paper” did not mean that James necessarily felt better. In this regard, it is useful to examine the meanings ascribed to the ‘numbers’ derived from HIV clinical markers.

7.3 The Numbers Game

What I want to do here is to explore the constructed meanings ascribed to the results from t-cell counts and viral load assays as a way to understand the significance that
these ‘numbers’ have on the manner in which people with HIV make sense of their lived experiences with treatments.

Lisa, a self-identified lesbian in her early 40s who was first interviewed in 2000, received her HIV diagnosis in the mid 1980s. She, like Helen, was one of the first women in Australia to be diagnosed. In contrast to Helen, Lisa contracted HIV through the sharing of injecting equipment and therefore her infection was consistent with the knowledge at the time, which was that injecting drug users were at high risk of contracting the disease. She informed me that she received an AIDS diagnosis when she was very unwell and said that “people thought that (she) was going to fall off the twig” in 1998. When we met for the first interview in 2000, she was well, and the story she told about her improved health related to the results she recently received from the medical monitoring of her t-cells and viral load. I want to present her story with the series of responses she gave to questions about her corporeal health in the course this interview.

L: I suppose…the most major change has been relatively recently where I had seen an increase in my um t-cells due to being on um [drug], one of the protease inhibitors. Not a huge increase but going from hanging-hung around two or three or ten t-cells, and now they’d gone up to 60. And um, it’s probably the first time that I’ve thought um, that it’s given me some hope that I’ve sort of thought, oh well, you know I’m going to really try and keep up taking these tablets because it sort of you know I can, I can see they’re doing some good (…) so I, having seen that increase, it’s given me more of an interest in, in wanting to do something, want to um, more of an interest in the “blood work”. Um…and um…not that that’s my total focus because it’s not um, but it’s just that I’ve been so disappointed for so long
about having such low t-cells that um, I really, it really made me happy to see an increase you know (laughs), however small and um but that’s…as far as the way that I feel I mean that, that, that did make me happy but it’s also it’s I actually feel quite well, um, quite physically well at the moment. And um, so that’s made a difference and when people tell you, “you look well”, then you feel well too (Q: Hm.) you know. (2000 – first interview)

The increase in the t-cell count from a single digit number to 60 signified to Lisa that she has evaded mortal vulnerability when diagnosed with AIDS. The recent t-cell count has given her “some hope” and provided her with encouragement to continue with treatments, for their efficacy was demonstrated in the result. It is interesting and revealing that the increase in t-cells served as an inducement to have “more of an interest in the blood work”. It could be interpreted that for Lisa, the results from her blood work were means through which her subjective sense of health was made visible. A set of favourable results, that is, an increase in t-cells and a decrease in viral load, constitutes a level of health to which people with HIV aspire. Her disappointment to having low t-cells in the past could be read as not reaching the desired outcome from the effort that she made in taking treatments, enduring the side effects and subjecting herself to medical monitoring. The advances and innovations in HIV treatments and management have complicated the ways in which HIV is understood and lived (Persson, Race, & Wakeford, 2003). That is, health and wellbeing are determined by the results from monitoring technologies, rather than by the subjective experience of feeling well, which in turn produces a tension in the subjective experience as illustrated by Barroso (2002). The significant issue here is that Lisa privileged medical discourses and practices on health and wellness as being the gauge by which she compared and located herself in the spectrum of wellness.
Her response positioned herself as a medicalised subject, a position she embodied by the emphasis on the number of t-cells as an indicator of health and the happiness subsequently attained. The authority Lisa placed on the significance of the blood work was further emphasised when she said that she was attending to medical monitoring more regularly for she hope that the next t-cell count would be even better.

L: …I’m going to do it obviously every three months but I just did it a little more regularly at the moment because I keep thinking “ooh maybe it would increase beyond 60” you know. (2000 – first interview)

The value Lisa placed on her t-cell count is not surprising given the use of the t-cell count and the viral load assay, as indicators of health and treatment efficacy, have been established and crucial clinical practices since the emergence of combination therapies (Mellors et al., 1996; O’Brien, Hartigan, Daar, Simberkoff, & Hamilton, 1997; O’Brien et al., 1996; Phillips et al., 2001; Saag, 1997). Furthermore, the results from the t-cell count and the viral load assay are argued to be correlated with the therapeutic success (or failure) of treatments, and are constituted as indicators of disease progression (Brecht, Breitbart, Galietta, Krivo, & Rosenfeld, 2001). The anticipation that “maybe it would increase beyond 60” could be interpreted as Lisa’s hope that she would feel even better or more “happy”, as indicated in her previous response, when she could “see an increase” in the ‘numbers’.

It is in this context that I want to now examine and disrupt the construction of treatment effectiveness as constituent of wellbeing. It has been argued that
favourable ‘numbers’ from the clinical markers, as illustrated in Lisa’s story, can be encouraging, for these numbers make visible the experience of corporeal improvement. However, the subjective experience of ‘feeling better’ cannot be measured by clinical markers. The clinical markers used in conjunction with the combination therapies have been thought to be associated with the subjective wellbeing as experienced by individuals, for the treatments have shown to reduce morbidity (Brecht et al., 2001; Cohen et al., 1998). However, the assumption that a decrement in disease symptoms would convert to improved wellbeing was not shown to be the case. As noted in Chapter Two, the clinical markers are used to interpret individuals as symptom free if they were to have high t-cell counts and low viral loads, which is deficient in the interrogation of health and wellbeing (Holzemer, 2002). Indeed, the construction of wellbeing as determined by the t-cell count has long been contested (Navarre, 1988). Although one study suggested that “better health is related to greater well-being” (Grierson, Thorpe, Saunders, & Pitts, 2004, p.5), the claim was made less convincing by the researchers’ acknowledgement that the relationship is neither clear nor direct. When Lisa was asked what it would mean to her if her t-cells were to further increase beyond 60, her response reflected the ambiguity embedded in the discourse that health and subjective construction of wellbeing are predicated on the clinical markers.

L: Well, I’ve realised that it wouldn’t mean anything (laughs). It would mean something but what would mean, what means more is that I feel well…and, and that’s the main thing. I mean you can’t measure depression in t-cells you know. Um, so just the fact that I know that they’ve gone up, I think that’s enough for me for the moment. (…) But it’s like yeah, it’s good, it’s the first change that I’ve seen in the t-cell rating. And um, and that does
mean something. But in the end, I think it’s the spirit. And I think the spirit only dies when it’s ready, and I don’t think I’m ready. And I don’t feel like I’m going to be ready you know, I’m not planning to go anywhere for quite a while. (2000 – first interview)

Despite the excitement and enthusiasm from an increase in her t-cell count, which in turn produced hope and the real possibility of further improvement in her corporeality, Lisa didn’t position her sense of wellness as predicated on her t-cell count alone. Lisa’s discursive construction of feeling better is to situate her subjective experience outside of the clinical markers; to know that they have increased was clearly desired but an enjoyable lived experience was what she favoured. In emphasising the importance of her subjective experience of feeling well, she suggested “what means more is that I feel well…and, and that’s the main thing” and “it’s the spirit (and) the spirit only dies when it’s ready”. This emphasis is pertinent when she positioned her corporeal health in relations to her experience with depression by stating that “you can’t measure depression in t-cells”. Lisa’s reference to depression, a mental health condition that she has periodically experienced since late teens, is an example that illustrates an increase in t-cells did not mean that she would feel better, for there were other health issues that could be more troubling and undermining of her wellbeing.

In the post-treatment era, it could be argued that the notion of health in the context of HIV is ambiguous, for “HIV health is a complex phenomenon imbued with a variety of meanings and interpretations is widely recognized” (Persson et al., 2003, p.398). The meaning of an increased t-cell count is equivocal in the context of it being an indicator of a restored immune system (Brashers et al., 1999; Siegel & Lekas, 2002), for an individual with an increase in t-cell count and an undetectable viral load assay
could continue to be afflicted with physical ailments (Brashers et al., 1999, p.208).

The definitional complexity of HIV health means that being ‘ill’ or being ‘healthy’ is contestable and cannot be resolved by medico-scientific discourses and practices. This is supported by Persson et al. (2003), who argued that since the breakthroughs in HIV treatments, HIV health is “an intersubjective, transactional web of lived experiences, social discourses and institutional medicine…(that) frequently evoke conflicting understanding of what constitutes HIV health” (p.398). Nonetheless, the clinical indicators do serve an important purpose, for they produce subjective hope and an expectation for further corporeal improvement or treatment success. In spite of this, there is a downside to positioning treatment efficacy as either success or failure. This issue is illustrated in the part of Lisa’s story when she recounted a time in the past when treatments had ‘failed’ her. More troubling still was the intersubjective encounter with her HIV specialist in which, based on the poor results of the clinical markers, she was positioned as an individual for whom medicine could no longer effectively serve.

L: Well I remember um…the reason that I’d change from seeing Dr C was because he, I felt he’d given up on me. He basically said “it’s nutrition, Lisa”, that’s, you just got to concentrate on that and I thought “that’s not good enough”, I want a doctor that gives me hope (Q: Hm.). I want to work with someone who is going to be, not going to be saying, “ooh, just go away and eat properly you know, get yourself a good blender and have lots of protein or whatever” (…) [Dr] C didn’t think I should be walking around um, and they didn’t know why. And that um…changed my perspective about the medical profession. Him saying that as such a specialist in HIV, and I sort of think well, that’s western medicine, but that’s western medicine it’s not all that there is (Q: Hm.). (2000 – first interview)
The impact of positioning treatment efficacy as either success or failure is problematic and counterproductive to the endeavours of individuals who are attempting to make sense of their lives. The event of treatment failure is constructed as a probability in HIV treatment discourses and the implications are well researched and documented (Brashers et al., 2003; Demmer, 2000; Rofes, 1998; Selwyn & Arnold, 1998; Thomas, 1999). The “inability to benefit from the new antiretroviral therapies may be perceived as a sign of personal failure, weakness, or bad choices” (Selwyn & Arnold, 1998, p.900) is an explanation which locates treatment success or its failure in the individual (Race, 2001). It could be interpreted from this explanation that Lisa was positioned as having ‘failed’ to benefit from treatments because of what she was unable to do, be it through personal weakness or through making bad choices. Being positioned as having failed treatments facilitated Lisa’s interpretation of the intersubjective experience with the doctor where she “felt he’d given up on me”. The privileging of the clinical markers as indicators of health and wellbeing positioned Lisa as incapable, for the doctor “didn’t think that I should be walking around”. More significantly, Lisa’s hopefulness was undermined by this doctor, an HIV specialist, who, in response to the absence of favourable results from clinical markers, was unable to infuse the optimism that Lisa needed to attain, and to maintain, a positive sense of wellbeing. The interpretation of being “given up” was constructed as a ‘punishment’ for failing to be a responsible subject. From this perspective, not only do doctors give priority to clinical and laboratory examinations (Meystre-Agustoni, Dubois-Arber, Cochand, & Telenti, 2000) but the clinical markers and the monitoring practices as constituents of HIV medical discourses
could be construed as regimes that produce and regulate medical subjects (Persson et al., 2003).

### 7.4 Clinical Markers as Surveillance Devices

The position of clinical markers as surveillance devices was embodied by Athena, who not only felt the pressure of needing to be routinely monitored, but also argued that the obligation to comply with the monitoring practice had the opposite effect in that she was made to “feel unwell” for applying herself to the practice.

A: 

(…) I thought that going for the tests were um, made me feel unwell when I was going and a fear around that and the impact of getting ones (the numbers) that weren’t so great was really um, put me under pressure (…) I think the first two years I was just re-evaluating everything and starting from scratch in so many ways it felt like, like with job wise and I was also getting tested regularly. And maybe I, yeah, maybe that’s when I did a sense of powerlessness as well. Before that um, so I was getting tested and being really nervous every time I went for a test. I had to confront the fear of needles as well, which I got through well, I’m alright about that now. Um yeah, a sense of powerlessness, I don’t know, I was just trying to cope (…) (2002 – first interview)

Athena’s effort to confront her “fear” in continuing to attend to regular HIV monitoring practices produced an emotionally “depressed” situation as indicated in this part of her story.
A:  (…) but still getting tested, still getting depressed by it all and, grappling with the whole idea of treatments all the way along and, being so frightened by that, yeah. And I think, and then when I got that last test, I just went, stuff it, I’m going to do this on my own. I’m gonna try, I said, I said I’ll try for 6 months to see if I can change the counts myself, then the 6 months just drifted into years, and I re-, and that I was really pushing it away. (2002 – first interview)

When Athena was asked to clarify how she made sense of her monitoring experience that led to her “going to do this on (her) own”, she provided the following response.

A:  It was because the last test that I had was um, the viral load was really high, the t-cells were low and it was like I was looking down the barrel of going down treatments, on to treatments. So I decided that I didn’t want to do that, yeah, I really felt like it was the last resort. And I felt well, that’s right, I had a dream, I woke up, I had this dream and it’s just, it was as if this voice was saying to me as I woke up, so clear “just go along, what’s the point, you’re going to die anyway”. Just in this really passive way. And when I woke up, fuck, shit, no I’m not, right ok, so I started to get massage and pro-biotics and all these things that I wanted to do, that did help me take a sense of control I think, yeah. But then I didn’t get tested after the 6 months, I just went, no, no, no, it’s too scary, I can’t deal with it, I

3 Pro-biotics are nutrition supplements and are “living organisms, which upon ingestion in certain numbers, exert health benefits beyond inherent basic nutrition” (Gionchetti, Rizzello, Venturi, & Campieri, 2000, p.490).
don’t want to get tested any more, the effects on me psychologically are really hard. Don’t want to do it. (2002 – first interview)

The story that Athena told is an important one in its emphasis on the adverse effects that the ‘numbers game’ had on her. The fear of not “getting ones that weren’t so great” was putting her under the pressure of succumbing to treatment use, a proposition she contested and resisted due to her positioning of treatments as the “last resort” as examined in the previous chapter. The aversion to treatments use was manifested in the dream she had in which her future was doomed and hopeless as she was “going to die anyway”. For Athena, the use of treatments is a signifier to deteriorating health or nearing death. More importantly, her story about the medical monitoring practices constructed the clinical markers, and the numbers derived from these practices as disempowering devices, for they produced “a sense of powerlessness”. Her “sense of powerlessness” was produced by being under the medical gaze, and being positioned as a medicalised subject. The results from the monitoring practices are positioned as determinants of her future, if the results “weren’t so great”, which was the case of her last tests, her hitherto successful resistance to treatment use could be compromised, for she did not have the ‘numbers’ to support her cause. For Athena, to be subjected to medical discourse with its privileged practice of remedy through medication was positioned as a loss of power. Disengaging with medical practices as illustrated by her stopping to being monitored could be interpreted as her way of maintaining power. She assumed a “sense of control” by (re)constituting her notion of health maintenance and isolated herself from the monitoring practices that would enforce an option she clearly did not want to take up. The medical construction of health and wellbeing was inconsistent with
Athena’s subjective constituted ideal of wellbeing, for medical discourses on health were unproductive to her subjective needs. Gold and Ridge (2001) in their examination of treatment use, noted that the abandonment of the biomedical approach to management of HIV and AIDS is one way people with HIV contested the discursive practices embedded in this approach, particularly when the question of when to commence treatments is raised. Like some participants in their research, Athena opted for a different approach in her way of managing HIV – “I started to get massage and pro-biotics and all these things that I wanted to do”, for the use of alternative treatments such as massage and pro-biotics, as noted in Chapter Six, is common for people with HIV who preferred to not use pharmacological medications for treating the disease (e.g., Foote-Ardah, 2004). The inadequacy of medical discourses on treatments or the biomedical model, as Gold and Ridge (2001) argued, is that medical discourses attend to the reduction in viral load and improvement in immune functioning, namely the ‘numbers’, and all other features to the lived experiences with HIV and treatments are “deemed to have the status merely of secondary phenomena; they are relegated to the background” (p.705). This is clearly problematic. The attainment of healthy numbers does not occur outside of the social, for the subjective experiences of living with HIV can not, and should not, be marginalised in the management of HIV as medico-scientific phenomenon.

In an era when treatments are privileged, the space between the ideal and the subjective experience, as signified by the ‘numbers’ from the clinical markers, can be destabilising for individuals in their attempts to make sense of their lives and wellbeing. Just as the safer sex messages that aimed to convince us that condoms were fun to use when our subjective experiences informed us otherwise, the medical
discursive construction of high t-cells and low viral loads as indicators of health and wellbeing doesn’t necessarily translate into subjective experiences of health, or indeed, wellbeing. The constant juxtaposing of how we should feel and our subjective realities produces a questioning of our authentic experiences of our material bodies, subjectivities and social practices. We are under the ‘gaze’ of the medico-scientific experts on whose prescriptions we adhere, with the view that by being compliant and responsible subjects we would experience the benefits. The clinical markers serve as surveillance devices under which individuals with HIV are monitored, even in the absence of the medico-scientific expert. I want to draw on Foucault’s discussion of the Panopticon in Discipline and Punish (Foucault, 1995) to help me further my clarification of the clinical markers as surveillance devices. I will draw on the issues that I see as having the most pertinence in my interrogation, which are the effects of this structure in producing the individualisation of health governance and the self-policing subject. Foucault contended that

“the major effect of the Panopticon: to induce in the inmate a state of conscious and permanent visibility that assures the automatic functioning of power. So to arrange things that the surveillance is permanent in its effects, even if it is discontinuous in its action; that the perfection of power should tend to render its actual exercise unnecessary, that this architectural apparatus should be a machine for creating and sustaining a power relation independent of the person who exercises it; in short, that the inmates should be caught up in a power situation of which they are themselves the bearers” (p.201).

Informed by his ideas of the Panopticon’s effects as a surveillance device, it could be argued that the t-cell count and the viral load assay not only made HIV and AIDS visible but they instilled in people with HIV the belief that the visibility of these clinic markers reflect the virus in such a way that it can be monitored and controlled. The clinic markers are positioned as having prognostic power which could predict
disease progression. The construction of the clinic markers as crucial informants to health means that the markers, as surveillance devices, are always at the forefront of individuals’ thinking, as illustrated by Lisa who suggested that an increase in the t-cells “wouldn’t mean anything” but it was equally important for her to know they have increased. The ostensible contradiction in her story signified that the monitoring practice and the clinical markers are deeply embedded in Lisa’s subjective experience with HIV, notwithstanding the limitations identified, that is, ‘they don’t tell you how you feel’. The privileging of the clinical markers in HIV medico-scientific discourses has produced the ‘panopticon’ by which individuals are monitored, and more significantly, responsibility to their own health is assessed and surveyed. Individuals’ behaviours concerning their health care are able to be scrutinised by the clinical experts via the use of the surveillance devices.

The ‘numbers game’ facilitates the intrusion of the medical gaze, through which care needs are controlled and in turn medicalised. People with HIV, as social subjects, are essentialised by the readings from regular monitoring (“the blood work”) they are required to participate. Overt acts of resisting monitoring practices as a strategy to diminish the privileging of clinical markers as indicators of health are subverted by the discursive construction of the markers as critical in the ongoing monitoring of health. The clinical markers make HIV visible and therefore knowable in a way that position people as being responsible for their health without necessitating the presence of the medical gaze. It is here that Foucault’s comment “the perfection of power should tend to render its actual exercise unnecessary” resonates. The power of the clinic markers produces a set of discursively and regulatory practices that inform the lived experiences of HIV, as well as producing a tension between the subjective
experience of wellbeing and the meanings ascribed to particular results from the clinic markers. The quote at the beginning of this chapter between the man with HIV and Navarre (1988) illustrated that his authentic experience of his material body and subjectivity is marginalised by the privileging of the clinical markers as determinants of wellness, and his wellbeing. The clinic markers could be interpreted as instruments by which individuals are expected to monitor their own health in producing themselves as responsible subjects. Race (2001) suggested that HIV monitoring technologies have produced a condition in which people with HIV have become “responsibilized” (p.167) in a way not previously witnessed, for the virus is constructed as an object of specific and individuated management. It is the responsibility of individuals to keep watch over (not unlike the invisible guards in the Panopticon) their viral load to achieve the desired level by yielding to the discursive practices of regular monitoring. Returning to Foucault’s idea, people with HIV “are themselves the bearers” of the regulatory practices, it is as Mills puts it “[t]he individual within the Panopticon is forced to internalise the disciplinary gaze” (2003, p.46). People with HIV have assumed the medical gaze on themselves, they are self-regulating their behaviours by engaging in the practice of ‘self-surveillance’ (Vaz & Bruno, 2003). From this perspective, the power of the clinic markers is firmly established in HIV management regardless of the person who exercises it.

The clinical markers as surveillance devices are operationalised by the medically constructed practice of ‘adherence’ to treatments. Although it is promoted that strict adherence to treatments could lead to desired ‘numbers’ and the prevention of drug

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4 Self-surveillance refers to the attention an individual gives to his or her behaviour “when facing the actuality or virtuality of an immediate or mediated observation by others whose opinion he or she deems as relevant – usually, observers of the same or superior social position.” (Vaz & Bruno, 2003, p.273)
resistance, however, factors to drug resistance are varied and complex. Nevertheless, the act of adherence is essentialised in treatment discourses for it is most amenable to intervention (Chesney, Ickovics, Hecht, Sikipa, & Rabkin, 1999; Walsh, Horne, Dalton, Burgess, & Gazzard, 2001). Is it ‘amenable’ because doctors can ‘do’ something about it by devising strategies and monitoring systems? And if these systems and strategies were to be unsuccessful, is it not possible that the failure could be attributed to the individual for not following the stipulated protocol? The persistence in addressing the issue of adherence is misguided if the attention to changing individuals’ positions towards treatments is devoid of the consideration that the act of taking treatments encompasses a range of psychosocial issues embedded in people’s everyday lives, and the verity of living with adverse side effects from treatments that are uncomfortable and demoralising. As it has been previously argued (Aronson, 2002; Moynihan & Cassels, 2005), certain health conditions are medicalised as “sicknesses”, and “natural processes” into health conditions, for they can be modified by drugs. From this perspective, ‘adherence’ is positioned as a medical issue, for failing to adhere to treatments could produce negative corporeal consequences. Thus the act of taking treatments is discursively constructed as a health concern, which justifies medical interventions to ensure that the practice of adherence is performed correctly.

In the following section, I want to examine the discursive construction of adherence as a medium by which the medicalised subject is produced, and the site on which the contestation and resistance to medicalisation takes place. ‘Adherence’ is positioned as an important and integral constituent in HIV treatment discourses, for its
importance is shaped by the medically constructed ideals of high t-cells and ‘undetectable’ viral loads through treatment use.

7.5 Compliance / Adherence: “Do as you’re told because it’s good for you!”

My endeavour in this chapter to examine the nexus or as Batrouney (1997) suggested, the “intersection” (p.8) between the subjective experiences of living with HIV and HIV as a medico-scientific phenomenon will be further advanced by the examination of the demand for adherence to prescribed medication regimes. In this section I want to address the non-material implications of treatment adherence as a way to understand the manner in which HIV medico-scientific discourses continue to medicalise the behaviours of people with HIV, and the contestation and resistance which occur from people with HIV to the process of being medicalised.

Adherence, or compliance as it was originally described, denotes the practice of taking the treatments for HIV at the prescribed time and with the correct prescribed dose. Successful outcome from treatment use, that is, the suppression of viral load by curtailing the replication process of HIV in the body, demands strict adherence to the prescribed medication regimens (Friedland & Williams, 1999; Hubbard, 2006; Kalichman & Rompa, 2003; McPherson-Baker, Jones, Duran, Klimas, & Schneiderman, 2005; Paterson et al., 2000). Although the term ‘adherence’ is now more commonly used to explicate the act of taking medications within HIV treatment discourses, it is however not unique to HIV medicine⁵, and the shift from the use of

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⁵ For example, it has been used in research into coronary prevention (Russell & Insull Jr., 1981)
'compliance’ to ‘adherence’ needs to be clarified. Compliance was the term used in the first few years after the introduction of protease inhibitors and combination therapies to articulate the act of taking medications efficaciously. Compliance in the context of medication use is a well researched topic, mainly from the professional perspective (Hopkins, Wade, & Weir, 2000), and the socio-political underpinning in its conceptualisation and the implications that this has on individuals have been critiqued (Mullen, 1997; Race, 2001). The term was problematic, for it not only connoted an expectation of obedience (Mullen, 1997), paternalism and the privileging of the medical expert (Marinker, 1997), it disempowered individuals by constructing them as servile subjects to medical discourses (‘follow doctors’ orders’). I am reminded of my subjective experience here of encouraging my friend to persist with AZT even when he had to negotiate adverse side effects ‘because that’s what the doctor prescribed’, as described in Chapter Two. Compliance is a term which could be interpreted as a discursively constructed mechanism to institute control over patients by physicians through the privileging of their expectations, and as an instrument that blames patients for failing to heed their advices and recommendations (Mykhalovskiy, McCoy, & Bresalier, 2003). The recognition of the arduous properties of treatment use – strict dosing practices, the taking of large quantity of drugs each day, and adverse side effects, provoked debates in social science research (Batrouney, 1997; Race, 1997; Race et al., 2001) and in non-medical professions (Sosnov, 1997) concerning its use to describe the treatment practices of people with HIV. In examining the issue of appropriate terminology, Race (1997) asked whether or not ‘compliance’ was the right word, for he argued that “after more than a decade of AIDS activism, it is something of a sad
irony that the term ‘compliant’ is used by doctors, researchers, government and non-government agencies to describe the ‘model’ person using HIV treatment” (p.9). In this context, resistance to the use of the term ‘compliance’ could be interpreted as dis-ease with the positioning of people with HIV needing to be governed by the experts. This issue could be further examined by the use of Foucault’s notion of “biopower”, which could be understood as technologies developed out of the human sciences to analyse, control, regulate and define the human body and its behaviour (Danaher, Schirato, & Webb, 2000); and that the body is docile, which “may be subjected, used, transformed and improved (Foucault, 1995, p.136).

The consequences of constructing people with HIV as either ‘compliant’ or ‘non-compliant’ locate responsibility to treatment success or failure in individuals (Hopkins et al., 2000). In this regard, the compliance discourse does not take into account the multiplicity and complexity of individuals’ subjectivities and their lived experiences. Just as Race (1997) argued that gay men might have resisted ‘compliance’ to safer sex practices at the start of the HIV and AIDS pandemic if the practices had not emerged from the men themselves, the term ‘compliance’ used in treatment discourses produced a fertile ground on which people contested and resisted medical instructions and recommendations. Alternatives have been proposed, for example ‘concordance’\(^6\), but ‘adherence’ is now firmly embedded in HIV treatment discourses as denoted by the vast amount of research conducted by the use of ‘adherence’ in the examination of HIV treatment issues (e.g., Fogarty et

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\(^6\) The term ‘concordance’ was first coined in 1995 to examine reasons for people not taking their medicines as directed (Stevenson, 2004). It was argued to be a more appropriate term than ‘compliance’, for it connoted co-operation and participation by patients in their health care (Rossi, 2000; Stevenson, 2004).
The change in terminology, as Mullen (1997) suggested, would only be meaningful if clinicians assumed a more egalitarian view in their intersubjective encounters with their patients. From this perspective, I argue the linguistic manipulation in terminology has not redressed the exercising of power, particularly when ‘adherence’ continues to be a discursive device to regulate the health practices of people with HIV. This is reflected in research on treatment use, which suggests that “[m]onitoring adherence to combination anti-HIV therapy is a crucial tool in improving compliance and consequently in obtaining a durable suppression of plasma viral load” (Boni, Pontali, De Gol, Pedemonte, & Bassetti, 2000, p.371, my italic). The reading of this declaration is that, notwithstanding the change in the terminology used, the act of taking medications is monitored and the monitoring of the act remains a strategy employed by the clinical experts to ensure that the subjects – people with HIV ‘do what they are told’ so they achieve the medically constructed ideal goal of viral suppression. The compliant subject who ‘does what she or he is told’ is preferred and rewarded, as illustrated in Steve’s story.

### 7.5.1 The Reward for Adherence

In his second interview, Steve, who revealed his “self-fulfilling prophecy” and his fear of particular medications in earlier chapters, recounted a medical encounter in which his commitment and ability to adhere to prescribed treatment regime was rewarded by being invited to participate in a clinical trial for a new drug to redress
one of the adverse side effects – lipodystrophy. This is significant for his propensity to be a compliant subject was rewarded by being gifted with an opportunity to counter an effect from treatments that he dreaded.

S: I went to my doctor’s just for a regular check up and he went “oh, I was going to spend the night looking through all my files” he said “I can have one patient on this, on this trial, you get one each and I can have one. And I was going to look through all my files to see who might be suitable and you’re suitable, so would you do it?” And um, and he told me you know what the possibilities were and I thought yeah. So he was really excited and he raced out to tell the trial nurse because a) and he, not only was I suitable, he told her that this guy is really compliant, he will do everything that you say, he’ll turn up on time, he’ll (laughs), he’ll, he won’t screw up on you, he won’t make your life a misery (laughs). And so it saved him sitting there going through some files to find an appropriate person for that night, so it gave him a free night, and um he was happy to send me off to the trial nurse who was um, confident that I wouldn’t um make her life a misery by not turning up and failing to taking the drugs and things like that (laughs), that I had that conversation with her about it (laughs). Because I said, I said um “oh he was so excited” you know like having found me because he introduced me to her straight away when I said yes. And when I went in for the person, I went and said yeah, he came in and said “oh you know, this guy is perfect because he’ll do things by the letter you know, he’ll do everything right”, so, so that we laughed about that (laughs). (2003 – second interview)

The intersubjective construction of Steve as a ‘compliant’ subject is made available for examination in this medical encounter as well as the privilege extended to him, and I suspect any individual who acts in accordance with endorsed medical practices. Adherence to prescribed treatment regimes as a regulatory device is made tangible
here as Steve was rewarded for his compliance, which was emphasised by him being chosen as the patient his doctor could submit for the clinical trial because “he won’t screw up” or make the medical professional’s “life a misery”. Steve’s doctor not only positioned him as compliant but also responsible. Returning to the previous examination of personal responsibility in the maintenance of health care, Steve is positioned as such an individual for he respects the advice of his doctor and adheres to the discursive practices of health maintenance. Steve, in a response following this story, corroborated and underscored the construction of himself as a compliant subject by stating that “[i]t’s like generally if I commit to something I um, I try to um follow it through as it’s required I guess”. Steve’s commitment is acknowledged by his doctor and this positioned him as a “perfect” drug trial participant “because he’ll do things by the letter...he’ll do everything right”. Just as Steve is privileged and rewarded for his capability to adhere to his prescribed treatments, others who are constituted as unable to do so are marginalised and penalised for their incapability. The import placed on adherence by medical discourses has the potential to produce inequitable practices in the prescribing and dispensing of treatments to people with HIV.

7.5.2 Adherence as a Regulatory Practice

At this juncture, I want to turn my attention to the construction of adherence as a regulatory practice to determine for whom the treatments are made available. As noted previously, the goal of attaining efficacious ‘numbers’ as means to ascertain treatment success or failure produced a contestation between the embodied experiences of HIV and the disembodying consequences of medico-scientific
discourses. The privileging of quantitative identifiers not only has the potentiality to marginalise the human dimensions of living with HIV but it also has the potentiality to marginalise individuals and groups. The t-cell counts and viral load assays as surveillance devices could be constructed as ways an individual’s compliance or adherence to his or her prescribed treatment regime is assessed and regulated. Indeed, the availability of treatments to specific individuals or groups is questioned if these individuals were assessed as less likely to achieve successful adherence (Carrieri et al., 1999; Rothenberg et al., 2003). In this instance, the doctor is positioned as having the power to weigh the benefits of treatments against its complications for people whom he or she positioned as ‘unreliable’ in terms of treatment use (Friedland & Williams, 1999). For example, illicit drug users are less likely to be offered treatments for they are observed to have problems of non-adherence (Arnsten et al., 2001; Carrieri et al., 1999; Crisp, Williams, Timpson, & Ross, 2004; Escaffre et al., 2000; Rothenberg et al., 2003). The doctor is positioned as the “‘general trustee’ of the health interests of the general population” (Crossley, 1998a, p.511-512) whose function is to ensure that individuals are acting in accordance with the socially constructed, and accepted, notion of health, that is, to minimise illness and its associate disabilities as well as to produce responsible subjects.

The provision of treatments has become a contested site, and the medicalising of adherence is political, for it is an instrument through which behaviours are regulated under the pretext of public health concerns. Some researchers that focus on non-adherence issues are alarmed by the implications of the transmission of drug-resistant strain of HIV and the safety of the general public (Fogarty et al., 2002;
Kalichman & Rompa, 2003; Paterson et al., 2000; Wainberg & Friedland, 1998). For whilst adherence is framed as a concern for individuals’ health by aiming to decrease the amount of virus in the blood, as Treisman and Angelino (2004) succinctly summarised, strict adherence is also to make them “less infectious” (p.4). From this perspective, the magnitude of the medical gaze and the exercise of ‘biopower’ are most apparent.

I am not suggesting here that the inequitable practices are malevolent or indeed maliciously discriminating, but the effects of such practices are that people’s capability to adhere to treatment regimes are assessed, and taken into account, by the prescribing doctor in a way that could limit particular individuals’ opportunity to have treatments. The point of concern here is that the cost-benefit issue is grounded on the ‘numbers’ from the clinical markers. If, and this seems to be the case in this instance, the individual is unlikely to attain the desired ‘numbers’ for the reason of non-adherence, treatments are unlikely to be prescribed for fear of drug resistance and the loss of therapeutic choices that could be important later for the individual.

Adherence is constructed as a screening tool for doctors to determine the suitability of individuals to be prescribed treatments, for clinical guidelines have recommended that doctors assess the patients’ adherence before and during treatments (Escaffre et al., 2000). Predictors for adherence are used to “select persons at risk for suboptimal adherence who then could be targeted for intervention to reduce the likelihood of subtherapeutic adherence before therapy is initiated” (Reynolds et al., 2004, P.142, italic original). The construction of people with HIV as ‘compliant’ by doctors thus has great implications on their health care needs, for treatments are given and
withheld in accordance with doctors’ assessment of probable (non)adherence to
prescribed treatments. In spite of research which found that there is no support to the
claim that there is a ‘typical non-compliant’ patient (Wright, 2000), the positioning
of individuals as “good adherers” (Arnsten et al., 2001, p.1422), or alternatively,
‘bad’ adherers invokes a moral frame within which the act of adherence is evaluated.
Furthermore, positioning individuals as either ‘good’ or ‘bad’ adherers operates as a
form medical control over people with HIV that ignores their experiences of
treatments, or defining them in terms of medical discourses (Mykhalovskiy, McCoy,
& Bresalier, 2004). The question needs to be reframed from “why don’t people
adhere?” or “what are the barriers to adherence?” to “what understanding do people
have in making sense of their act of resisting or contesting the use or continual use of
treatments?” This is a very different question, for it is premised on the notion that the
act of resistance or contestation is purposeful and not irrational as shaped by
discourses on adherence.

In this next section, I want to examine the participants’ experiences of treatments.
The ideas presented in the previous chapter in which I examined the meanings
participants ascribed to treatments forestalled this section, but what I want to do here
specifically is to interrogate treatments within the frame of adherence and within the
context of their subjective experiences of living with the adverse side effects, which
in turn produced contestation and resistance to treatments as the privileged means to
establishing health and wellbeing.
7.6 Contesting Adherence: “I don’t have to do what I’m told.”

The importance of adherence to prescribed treatments is established and research findings have shown that adherence to treatment regimes – to take the prescribed amount of medications at the prescribed time – needs to be prompt and accurate at least 95% of the time in order to achieve significant viral load reduction (McPherson-Baker et al., 2005) and to prevent drug resistance (Paterson et al., 2000; Remien et al., 2003). This level of adherence is extremely difficult when put into the context of the general population in which the level of adherence to medications, regardless of illness, is found to be at about 50% (Wright, 2000), yet complete adherence is asserted to be the ideal goal of treatment use (Bangsberg & Deeks, 2002). This goal is insidious for it, as a treatment paradigm, is not only very difficult to achieve but it has the proclivity to discursively position individuals who are unable to achieve complete adherence as having failed to perform the task which would ensure good health, and in turn problematises individuals’ “personalities” for their non-adherence (Penedo et al., 2003; Treisman & Angelino, 2004). Notwithstanding the recognition that the task of adhering to the treatment regimes is particularly difficult, logistically and on the material body – for example, different drugs to be taken at different times of the day, some with food and others without and adverse side effects (Fogarty et al., 2002) – the attention given to some assessments
and strategies, such as MEMS and DAART\textsuperscript{7}, to improve adherence have the effect of disembodying the experiences of living with treatments from the act of taking treatments. These strategies, like the t-cell count and viral load assay, compartmentalise and construct treatment use in medically observable and definable terms. Adherence improvement projects do not eradicate adverse side effects, for they only attend to the ‘remedy’ and not the ‘poison’ effected by the use of treatments as informed by the pharmakon phenomenon. The promotion of adherence to prescribed treatments as a remedy will be undermined by the experiencing of the poison, as every drug used for treating HIV has toxic effects that could jeopardise survival (Powderly, 2002). Medicalising adherence as a regulatory practice and problematising non-adherence have the potentiality of provoking resistance from people to whom this practice is directed.

Research into the ‘non-adherence’ to HIV treatments, of which there are many examples (e.g., Schönnesson, Ross, & Williams, 2004; Siegel, Schrimshaw, & Raveis, 2000; Walsh et al., 2001), has identified adverse treatments side effects as one of the, if not the main reason, for this occurrence. Social research situated in the Australian context (Grierson, Bartos, deVisser, & McDonald, 2000; Grierson, Misson, McDonald, Pitts, & O’Brien, 2002; Grierson et al., 2004) consistently showed that side effects were the nominated reason for ceasing treatment use, changing the current treatment regime, and taking a treatment ‘break’. When the

\textsuperscript{7} Medication Events Monitoring System (MEMS) is an electronic device which monitors adherence through a microprocessor installed in the pill bottle cap that records the time and date when the pill bottle is opened (Samet, Sullivan, Traphagen, & Ickovics, 2001). Directly administered antiretroviral therapy (DAART) is based on the directly observed therapy (DOT) developed for the treatment of tuberculosis; as the name suggests, it requires individuals to be observed in taking treatments to ensure adherence to treatment regimes occurs (Lucas, Flexner, & Moore, 2002). Both the MEMS and the DAART are, in their conceptualisation, surveillance devices of adherence which served to isolate the act of taking treatments from the lived experiences; as strategies, they are inadequate in negotiating with the complex psychosocial and corporeal issues embedded in the act of resisting or forgetting the use of treatments.
attention is turned to Australians with HIV who are not using treatments, the fear of side effects was again presented as the reason for this situation (Gold, Hinchy, & Batrouney, 2000; Gold & Ridge, 2001). Non-adherence to treatment regimes are not “accidents” for they occur regularly and systematically (Meystre-Agustoni et al., 2000, p.720) and people who omit to take one or several drugs of their treatments often do so to avoid particular side effects (Chesney et al., 1999). Unsurprisingly, in light of the research findings presented here, notwithstanding the medical endeavours and projects to improve adherence, people with HIV will act in accordance with their subjective experiences of taking treatments, which might embody the act of not using or discontinuing with treatments and therefore putting themselves at risk of being constructed as a ‘non-adherent’. Although reasons for non-adherence remain poorly understood and research typically focuses on the prevalence and correlates of non-adherence (e.g., injecting drug use and depression) (Siegel et al., 2000), the (mis)conceptualisation of non-adherence continues to be located in individual subjectivity, as exemplified by the summation that the personality characteristics of some individuals not only ‘caused’ HIV infection but these same characteristics reduce their ability to adhere to demanding drug regimes and more difficult for them to tolerate uncomfortable side effects (Treisman & Angelino, 2004). This is a troubling assessment for it discounts the socio-cultural context in which HIV infection occurred, and individuals are made responsible for their infection without the consideration of the socio-political and material constraints that diminish individuals’ ability to protect themselves, and more disturbingly, their inability to tolerate side effects, are positioned as due to their personal characteristics. The causal relationship drawn is problematic for it implies that the ability to tolerate side effects is determined by ‘good’ or ‘bad’ personality
characteristics, which profoundly marginalises and diminishes the significance of adverse side effects in the everyday life, and so negates subjective experiences as reasons for not adhering to treatment regimes. In terms of health and wellness, it would seem that the subjectively constituted ideals are discordant to those embedded in medico-scientific discourses.

The tension that exists between medico-scientific discourses and subjective experiences on issues, such as adherence, needs to be temporally contextualised. Resistance or non-adherence to treatment use, and doubts towards treatments could be explicated by cautions produced from the AZT experience as noted in the previous chapter. Furthermore, treatment use discourses have been challenged due to the variability and changeability of medical opinions. This issue is made visible by James who described, in his first interview, the implications of inconsistency in medical opinions about treatment use depending on available knowledge. He began the story by referring to “a ‘drug de jour’ attitude or um a ‘doctor de jour’”, and when he asked to clarify these descriptors, this is what he had to say.

J: Oh, drug of the day um…sort of doctor of the moment and what we should be doing you know. And that’s sort of like, was sort of like AZT and then the attitude was no, AZT was what’s killing you, um, followed by we need two different sorts. Um, there was um viral load, look at viral load, not at t-cell count um, hit you know, “hit hard, hit early”. Um, what came after that? Oh sort of I suppose this whole um, jungle of, of different treatment options, which dissipated I suppose the activist um side of things. (2001 – first interview)
In reconciling the “hit hard, hit early” recommendation, and adhering strictly to the prescribed treatment regime that proved to be debilitating due to the side effects, James contested the ideals and doctrines embedded in HIV treatment discourses openly and publicly.

J: (...) I remember getting quite um angry at a, at a um, a short course in HIV medicine actually (laughs). Um, saying to the room I suppose, but to the doctors specifically, that you know we believed you when you told us that we should take you know treat hard, treat early and we now believe you when you’re telling us to treat softly, treat later you know. And I think that was actually taken quite, that actually affected them. It was like the trust that, that we hold for, for doctors and particularly ones in this community, um they had to be fairly super human to carry that burden. Um, but when it’s reality of the fact that they you know prescribed certain things that have actually sort of created problems, not you know, not through malice or anything, just through sort of you know um, misinformation I suppose. (2001 – first interview)

James challenging and contesting the ideals embedded in treatment discourses could be interpreted as him contesting the medical gaze. Foucault (1994) argued that the ‘medical gaze’ and the discursive practices of medical perception are socio-historically situated. The way medical knowledge produces particular meanings are informed by certain organising principles that are pertinent at that particular time. James is arguing that the constant changes in HIV treatment knowledge are understandable, for he recognised that the information, which in retrospect, has “created problems” albeit “not through malice or anything, just through misinformation” means that the trust that he has placed in medical discourses on treatment use is compromised. Instead of continuing to allow the ‘medical gaze’ to
position his material body as an object of the medical discipline, he advocated for agency in medical care. Just as Meystre-Agustoni et al. (2000) argued that non-adherence is a way for individuals to take charge of their treatments rather than having to submit to its imperatives, in light of his diminished confidence in medical discourses on treatments, James is taking charge of his own health by recognising that his knowledge and experiences of his material body is ultimately more informing than the diagnoses and prescriptions produced by the medical gaze as illustrated in this part of his story.

J: Which brings me back to um why I think it’s very important that um, everyone has a um, takes a personal interest in the treatments they take because they’re the ones that understand their bodies the most… I mean if you turn up to the doctor and say you know “what will I do” and they are not prepared to sort of like contribute to “this is what I wanna do”. Um, but yeah, I think it’s hard work, it’s not, it’s not, your health is not something that you can um leave to someone else to take care of. (2001 – first interview)

The privileging of his knowledge is important, for at the time of the interview he was not using treatments. After having had previously been on treatments, James decided to stop using treatments because of signs of lipodystrophy which he said “came on quite severely”. The constant assessing of treatment use when compared with the probable experience of side effects is articulate in this part of James’ story.

J: I mean that’s, that’s an ongoing concern every time you know the three month test comes around. The results would be sort of drastic and we have to sort of re-look at combinations. But I think I’m a lot more ready to sort of negotiate the sort of drugs to take now rather
than accept what’s offered. Um, I know the ones [drugs] I don’t want to take, um, I know the ones that have, well, I sensed the ones that have created the most problems. Um, I think experience has um taught me to be a lot more proactive in terms of choosing treatments rather than relying on um, a doctor or doctors to you know calculate the best combination. Um, and I think yeah, so if it happens, I’m sort of ready to you know to um do my homework and come up with um, um, combination but I don’t want to do that until it happens. (2001 – first interview)

The contestation and resistance to treatment use has its base in conflicts between what is required and the experiences situated in the everyday life (Meystre-Agustoni et al., 2000). James is aware that the regular monitoring by use of the clinical markers could affect his treatment-free life. His past experiences have informed him of what is required and more pertinently, the adverse and undesired effects he would have to endure if he were to resume treatments. However, his past experiences have also positioned him where he could contest and negotiate proposed treatments. “I know the ones [drugs] I don’t want to take...I sensed the ones that have created the most problems” means that he has ‘bargaining power’ so that instead of being discursively positioned as needing to ‘comply’ by ‘adhering’ to prescribed treatments, he could dictate and indeed position his doctor as a peer, an equal, in determining “the best combination”; a situation Davis et al. (2002) suggested as a “democratisation of expertise in HIV knowledge production” (p.32). It is argued that in examining adherence issues, it is the individual’s co-operation in following the prescribed treatment regime that concerns most researchers, which makes the conceptualisation of ‘adherence’ and ‘compliance’ irrelevant (Wright, 2000). If the adherence improvement projects are authentically aimed to enhance health and wellness, and therefore wellbeing, it should be apparent that enlisting the co-
operation of individuals by privileging their knowledge of their bodies and needs of
treatments, including the option of not using treatments, would serve productively in
developing treatment strategies that do not position individuals in servitude to the
medically constructed practices.

Dan, in telling his story about his experiences with treatments further clarifies the
significance of adverse side effects in the context of adherence. Dan started
treatments in the early 1990s when his t-cells were decreasing and despite having to
endure the side effects, he demonstrated perseverance by maintaining his prescribed
regime and positioned himself as a “firm believer in…the medical community”. This
is what he had to say.

D: Like my t-cells weren’t dropping rapidly but they were going down
slightly. And I think the attitude back then was, you know, well there
is that question of – is it better to start someone on medications
straight away or is it, is it better to wait till they’re ill, they still didn’t
know in those days. And I volunteered for a quite a few trials through
the (medical centre A) and, and the (medical centre B), maybe I used
myself as a guinea pig I suppose if you want to put it that way. Um,
because I was of the firm, see I was also a firm believer in that, in, in,
for want of a better word, the medical community. That, that they will
find something for this, a treatment, as I said before, not a cure
perhaps but a treatment, and I was always a firm believer in
that…Um, for years I wouldn’t read anything about the disease as
such, I just relied on the doctors to let me know when new
medications come out. And again, that’s only been in the past two
years that I start to take control over that side of it again. Where I said
to myself well, perhaps there is better treatment out there because for
a quite a while I was on ritonavir. For a good two years (…) And um,
I just went off it not because it stopped working but because I just
The interesting aspect of Dan’s story is that he positioned himself as a “firm believer” of medical discourses on the importance of treatments and the need to adhere to the prescribed regime. He made clear that “for years he relied on the doctors” from whom he received the necessary information for health maintenance, including the use of medications, a common situation that is noted by Meystre-Augustoni et al. (2000) who suggested that people do expect their doctors to assume the lead in the area of treatments. The relationship between the health care provider (e.g., doctors, nurses) is a factor that has been highlighted in adherence research (Ickovics & Meade, 2002; Ingersoll & Heckman, 2005; Remien et al., 2003; Roberts & Volberding, 1999), and the conclusion is that a positive relationship between the individual and the provider could effect successful adherence to the prescribed treatment regime.

Notwithstanding the privileged position to which Dan placed in his doctors and the recommendations made, in the end, his subjective experiences with side effects determined how he will use treatments. In his story, Dan does not seem to be an individual who was troubled by needing to adhere to his treatment regime, perhaps to his detriment. He continued to use treatments “[f]or a good two years” in spite of the side effects, but in the end, he was “sick of the side effects”. Dan exercised his personal agency by changing his treatment regime; the change could be interpreted as a negotiation between treatments as resources that were maintaining his health and as the cause of his unwellness. His being “sick of the side effects” would suggest that the weighing of benefits by following the recommendations made, against the
corporal costs, positioned Dan as needing to assess his lived experiences with HIV in the context of treatment use. Dan could be discursively constructed as a ‘compliant subject’ for he unfailingly adhered to the prescribed regime. What is important in his story is that it emphasised that in spite of the assertions made with regards to treatment adherence and the medically constructed health benefits, people with HIV will be informed and make sense of their lived experiences by the knowledge of their corporeal and psychological needs.

The relevance of subjective experiences in the treatment of HIV was noted by Dan in his second interview in 2003. He provided a story that emphasised the need for doctors to “start listening to their patients”.

D:  I’ve done the ASHM [Australasian Society for HIV Medicine] short course in HIV medicine since we um last spoke and learned a lot through that, which was great, it was really good. But one of the things that was interesting that kept coming out of this course was that the doctors are now starting to admit or at least, not admit, what’s the word –

Q: Concede, acknowledge –

D:  Yeah, yeah, well it was more the fact that the doctors that were giving the lectures were advising these other doctors, their fellow doctors, to start listening to their patients more. They’re starting to concede that thing of, ok, well for example, the lipoatrophy, which is a great example, they were always thinking that it was the virus that was doing it, and their patients were saying “well no, it’s not, it’s these drugs” you know, that’s how we felt, the PLWHAs. We felt it was the drugs that were doing it to us, and they were denying that idea. And now at this course, ’cause this is one thing that kept
coming up, guess what, they’re right, it is the drugs, it’s all these DDI and D4T, that’s what causing lipoatrophy, not the virus as we were first thinking. So start listening to your patients more. These are the guys that are on the medications, they know their side effects, don’t you know don’t dispute what they’re saying. (2003 – second interview)

It is interesting to note that the position that Dan took up as a “firm believer in…the medical community” because he “relied on the doctors” in terms of appropriate treatments, is destabilised by the knowledge he gained from the ASHM course. He, as a person with HIV, has to inform doctors with regards to the utility and the appropriateness of prescribed treatments. Similar to James, who positioned himself as having ‘bargaining power’ and positioned his doctor as an equal in the prescribing of treatments, Dan’s assertion that doctors need to “start listening” to their patients illustrates the importance of integrating the subjective experiences of people with HIV in order to understand the positive, as well as the negative, consequences of treatment use. The use of the lipoatrophy example by Dan highlighted the relationship between doctors and people with HIV whose knowledge must be privileged, for he proclaimed that “[t]hese are the guys that are on the medications, they know their side effects, (…) don’t dispute what they’re saying”. In this context, Dan is also positioning the doctors as his equals, for not only he relies on them but they too need to rely on him in determining the most appropriate treatment for him.

Lastly, I want to present Helen’s story on treatments for in telling her story of ceasing treatments, Helen incorporated the issues examined in this chapter – the ‘numbers game’, the negotiation with adverse side effects, resistance to treatments
and personal agency – to determine the best option for her in terms of subjective construction of health and wellness.

H: So I went on a combination of um, AZT, no, not AZT, 3TC and D4T (Q: Hm.). So just the two, I didn’t do a protease inhibitor. I was going to, I was that close to it and then at the last minute, my doctor and I decided to just do the two. And um, within the next blood test my, because my viral load was, it wasn’t that high, it was about 5000 (Q: Hm.) um, so within the next test, my viral load was undetectable and my t-cells improved and they just kept on remaining undetectable and my t-cells went up over those four years to um, 760 I think, 700, nearly 800 was the highest (Q: Hm.). And then I went off them because I felt that I was becoming slightly resistant. The um, twice um, the viral load was, had, was detectable, it was like 50 or 100 or something like that which is still really low but they sort of gone from being undetectable. And I was beginning to feel that I was having side effects like weight loss, um, fat loss I mean on my arms and my face and I didn’t, I felt like why just keep taking them until I became resistant or until I have you know side effects. Um, and I was also getting a bit fatigued, when my prescription ran out, I sometimes would leave it a week or two weeks before I get it refilled. And that happened um a couple of times and I just felt that it was best to go off them rather than trying to persevere with it. So now I’ve gone off, I’ve been off since last October of last year. (2001 – first interview)

A conclusion which could be drawn from the research into adherence and non-adherence noted in this chapter is that it is a complex constellation of issues. The reasons for people with HIV to cease or resist treatment use are multiple and varied. The argument that Helen constructed in supporting her action to cease treatments is subjectively constituted and meaningful. She is aware of the benefits associated with treatment use but she is also wary of the implications and costs associated with their
use. The manner in which she positioned treatments was reflected in her action to not refill her prescription. It was an act which could be interpreted as both a signifier of her ambivalence towards treatments, as represented by her saying that she “just felt that it was best to go off them rather than trying to persevere with it”, and her endeavour to construct and to preserve a subjective notion of wellness. It has been argued that there is an “existential aspect of adherence” and medical practitioners need “to keep in mind that the issues at stake are no less than sickness and death, involving core questions of human existence which cannot be ‘solved’ by medicine or by any other means” (Wright, 2000, p.708). The enterprise of living a fulfilling life is more than living with medically proven effective treatments, for the lived experience with HIV involves questions of meaningfulness in the life that is lived, which not only cannot be medicalised but cannot be solved by medical technologies. Schonnesson (2002) continued with the existential theme by arguing that improved ‘numbers’ do not necessary correlate with an improved quality in lived existence, and that to understand the meaning of living with HIV demands that the interrogation be situated within an existential context. Existential issues such as coherence and meaningfulness in the individual’s life amounts to how he or she makes sense of his or her ‘being’, and to live with HIV, notwithstanding its manageability, is a troubling and destabilising aspect to his or her lived experiences. The medical construction of the ‘responsible subject’ or as Race (2001) posited, the ‘responsibilization’ of individuals does not attend to the Schonnesson’s (2002) notion of “existential responsibility” which refers “to the fact that each individual is the creator to their world, life design, choices and actions and has an awareness of their responsibility” (p.402). It is what I conceive to be the enterprise of living an ‘ethical’ life. By this I
do not mean righteous but rather an authentic\textsuperscript{8} and a subjectively constituted satisfying life. The medicalising of wellbeing through medical technologies and resources do not inevitably produce wellbeing as subjectively satisfying or even authentic.

7.7 Summary

In this chapter I have attended to the medical technologies by which the notion of wellbeing is medicalised and constituted. The ‘numbers game’, the medically constructed practice of ‘adherence’, the adverse side effects that the treatments produced singly and collectively provoked individual consideration as to whether or not living with HIV through medical technologies and material resources is necessarily the manner in which people with HIV want to live in the post-treatment era. What I want to do in the next chapter is to bring the issues raised in the last few chapters to the fore in my project to interrogate the simply phrased but profoundly important question of how people make sense of their lives in a time when living with HIV is normalised, for while it no longer incites the social panic as reflected in the Grim Reaper campaign, the fate of those infected is posited by medical discourses in an optimistic manner, which for some people, is inconsistent with their lived experiences. Notwithstanding the manageability of HIV as a medico-scientific phenomenon, the existential responsibility of constructing an ethical life is, for people with HIV, a way forward into a future that is ‘lit’ rather than ‘bright’.

\textsuperscript{8} By authentic, I position it to mean “self-fulfilment” (Taylor, 1991, p.72) and “being true to the self” (Holt & Griffin, 2003, p.404) as shaped by the available socio-cultural discourses.
Chapter 8: Living a Subjectively Constituted Meaningful and Ethical Life in the Post-Treatment Era

“Medicine cannot by itself determine the quality of life. It can only help people to achieve the state of health that enables them to cultivate the art of life – but in their own way… It implies also the ability for each person to do what he wants to do and become what he wants to become, according to human values that transcend medical judgement.” (Dubos, 1976, p.9 my italic)

8.1 Introduction

“[T]he office of medicine is but to tune this curious harp of man’s body and reduce it to harmony.” (Francis Bacon, 1605)\(^1\)

This thoughtful idea of Francis Bacon could be interpreted as a guiding principle for the practice of medicine. Since Bacon’s time (1561-1626), the advances made in medical sciences have realised the ‘mechanical’ capability needed in order for the material body to be tuned, manipulated and made stronger against what were debilitating or fatal diseases. However, the question here is whether or not “the office of medicine” is able to produce the “harmony” that Bacon posited? I would argue that it has not if the notion of “harmony” is taken to mean that subjective satisfaction as experienced in the social and the psychological domain (existential satisfaction) is predicated on having a healthy material body (corporeal satisfaction). The manner in which I am using existential here is to refer to the sense of coherence and meaningfulness in the lived experiences as subjectively constituted.

\(^1\) “Advancement of Learning – The Second Book”, X.
Elkinton (1966) suggested that the “harmony”, to which Bacon referred, is the ‘quality of life’ that individuals aspire to, that physicians aim to produce and that society places as an ideal. The ‘quality of life’ concept was examined in Chapter Two, and in that chapter I argued that its subjectively constructed meaning is more useful in signifying the ‘good life’ \(^2\) (Holmes, 2005; Zhan, 1992), which denotes subjective existential and corporeal satisfaction, than as a concept by which lived experiences are evaluated. Existential satisfaction is subjective and it is a form of satisfaction that the advances in medical sciences are unable to realise in the same way they could in achieving corporeal satisfaction. In exploring the constitution of the ‘good life’, King (2001) argued that “happiness is a strong predictor of the judged desirability, value, and moral goodness of a life” (p.52). In this context, it made possible to understand that the assumption of a healthy material body will lead to existential satisfaction (as shown in the medicalisation of well-being) is being contested by some people with HIV, as illustrated by their resistance to the use of the anti-HIV treatments discussed in the previous two chapters. As noted in Chapter Six, some research participants contested and resisted the use of treatments due to the associated adverse side effects, and positioned treatments as “feared objects”, “necessary evils” and the “last option”. Elkinton (1966) argued, treatments are sometimes “two-edged weapons” (p.711), which means that successes in treating the corporeal can be compromised by the frustration and dissatisfaction in the existential. From this perspective, the lived experiences of people with HIV in the post-treatment era are embedded with issues that demand for “existential responsibility” (Schönnesson, 2002) which medical sciences cannot address or resolve.

\(^2\) King and Napa (1998) argued that the ‘good life’, as a folk concept, is historically and culturally situated. The concept signifies a life well-lived, which include the importance of happiness, a sense of purpose and a philosophy of life.
Despite the venerable ideals of medical sciences, as illustrated by Bacon, and the capability of medical sciences to prolong life, “HIV-related threats…engender crisis in meaning of life” (Schönnesson & Ross, 1999, p.105), or as Ariss (1997) argued, an “existential crisis” (p.55). Thus, it could be concluded that there are questions and issues about the meaningfulness of life confronting people with HIV which are beyond the manipulation of medical sciences. In this regard, the ‘chance’ of having an extended life needs to be made sense of, particularly when this same ‘chance’ was denied to others. The positioning of surviving HIV and AIDS as a chance occurrence has been explored even before the era of effective treatments (e.g., Remien, Rabkin, Williams, & Katoff, 1992), however, the chance for surviving HIV through treatments needs to be further considered given survival is now positioned as a probability, rather than as a coveted possibility.

In the midst of the buoyancy produced by restored health based on the clinical markers, participants constructed stories with reference to ongoing struggles embedded in living with HIV, as well as their ongoing efforts to make sense of their lives in ways that are subjectively meaningful. It is important to explore subjective existential satisfaction when it has been suggested that the ‘quality of life’ of people with HIV has improved resulting from treatment use (as discussed in Chapter Two). The aim of this chapter is to address the thesis question: ‘How do people constitute a meaningful life in their everyday practices and experiences in the post-treatment era?’ By way of achieving this aim, I will explore the manner in which individuals make sense of their experiences that is subjectively satisfying, meaningful, authentic and ethical.
8.2 Living a Subjectively Constituted Meaningful and Ethical Life

“And while we cannot know in advance the consequences of the choices we make, we can learn to become more ethically intelligent…Ethical integrity requires both the intelligence to understand the present situation as the fruition of former choices, and the courage to engage with it as the arena for the creation of what is to come.” (Batchelor, 1998, p.47)

I want to explore the activities through which a subjectively meaningful and ethical life is constituted. In Chapter Two, I interrogated the ‘quality of life’ concept and argued that, notwithstanding the definitional and conceptual issues, the concept is meaningful when it is subjectively constituted. Informed by this interrogation and the ideas presented, I want to explore the existential issue of survival to which some participants have referred in their endeavours to construct meanings in their lives. It is a difficult issue for some people with HIV, for they embody the opportunity to have an extended life but are also troubled by this same opportunity as illustrated by their ‘survivor’s guilt’. This phenomenon signifies the act of intra-subjective reconciliation. There seems to be a moral imperative and an obligation to take advantage of the opportunity they have been given in spite of the struggles and complexities embedded in living with HIV in the post-treatment era. To locate a subjective meaningful explanation of their continuing survival is to produce an ethical position through which existential satisfaction could be derived. In doing so, I will examine the way people made sense of surviving AIDS; the rejection of the ‘sick role’ within which people have been positioned; and the manner in which post-treatment subjectivities and life in the post-treatment era are constructed and more importantly, lived.
Constructing Survivor’s Guilt as an Subjectively Ethical Experience

In the era when HIV and AIDS were feared because they could not be effectively treated, the goal was to remain uninfected by taking precautions and eliminating identified risks. The concept of ‘Survivor’s Guilt’ as used in HIV discourses (Barrows & Halgin, 1988; Moskowitz, 1989; Stine, 1993) was to describe the experiences of those individuals who managed to evade infection but witnessed the perilous, and more often than not, the mortal fate of others who were infected as they endured and suffered the emotional and corporeal devastation caused by HIV. The experience is described by Odets as the “persistent feelings of guilt for having survived the very calamity to which their loved ones succumbed” (in Stine, 1993, p.326). This would seem an incongruous experience in a situation where to be uninfected was (and still is) desirable, however, if situating the subjective experience within a social context where friends, lovers, life partners were expected to die from HIV infection, it invoked existential questioning of ‘why not me’ and ‘why was I spared’. This is the paradox associated with the ‘Lazarus Syndrome’ in that people who survived have to negotiate the challenges related to their experiences with illness, the ambiguity and uncertainty about the future (Thompson, 2000), and to make sense of their survival.

The ‘survivor’s guilt’ experienced by being spared from HIV infection has resonance in exploring and understanding the existential questioning of people with HIV to whom treatments were made available, or the paradoxical crisis of experiencing improvement from treatments while knowing their experience was not
shared by their peers (Rabkin & Ferrando, 1997; Thomas, 1999). In his first interview, Steve told the story of his partner who died in the same year when the protease inhibitors were introduced and the meanings he produced to make sense of this event.

S: Um, well I can remember reading about it when I first did see it in the paper, I was in a café having a cup of coffee and it said that these medications were going to come out, protease inhibitors and um it really hit me then like “oh fuck he just missed out”. You know like what I probably, 18 months let say, but um because he had actually become too ill, they wouldn’t even put them on, him on them, if they’ve been out a year before that, a year before because he’s too ill, he would have missed out then anyway. But um…oh it was like, I felt very sad about it. Like there was a, there was that, he was that close but it you know, but that close wasn’t good enough for him, yeah. (2002 – first interview)

In the second interview conducted in 2003 with Steve, his experience of being confronted by the deaths of loved ones was again explored and produced the following response.

S: What we experienced, what I was saying was the experience that I had about facing my mortality through friends dying and you know being basically sort of people saying “well yeah you know, you’ll probably die early because of this”, it’s indelibly imprinted and I can’t erase it in my psyche (…) and it is really about not being able to turn that process around to that extend where people go “oh you’ll be around for a while” you know. I think, I don’t think about it because I don’t, you know we’re, we are call human beings because we’re humans being now. (2003 – second interview)
Steve’s story could be interpreted as one in which chance or fate was positioned as the basis that enabled him to survive HIV and AIDS. Although he did not explicitly state a feeling of guilt with reference to his own survival, however, as noted in Chapter Six, he acknowledged that his survival was due to the timely arrival of the protease inhibitors. In this context, his story could be read as one in which he had to negotiate and to reconcile with the situation where treatments did not arrive in time to save his partner. He positioned his survival as one of chance, a chance of which his partner was denied. It could be interpreted here that his story is about the negotiation of an existential challenge, for “it’s indelibly imprinted and I can’t erase it in my psyche”; a challenge which he had to made sense of by locating a subjectively meaningful explanation for his partner’s fate. When he realised that his partner had “just missed out” on the protease inhibitors, he made sense of the situation by positioning his partner as being “too ill” to benefit and that “they (the doctors) wouldn’t even put them on, him on them”. Positioning his partner as being “too ill” also means that his own survival through the available treatments could be differentiated from that of his partner. It could also be read that he was not privileged for having treatments available, for his partner’s situation was different to his. In endeavouring to make sense of his survival as a subjectively ethical experience, Steve aimed to take advantage of his prolonged life by living in the present, for he proclaimed that “we are call human beings because we’re human being now”.

For Ben, the conflict of having effective treatments available to him which preserved his health, while remembering the friends who died because treatments were unavailable, produced a contestation in his subjective experience, as expressed by his use of the “happiness and sadness” binary embedded in his story below.
B: (...) For the last few years, oh it’s been difficult in the way that (laughs), I have a good fortune that I’m still alive but that’s still in the back of my mind “why am I still alive”. But being on the medications as well has I guess made me better. I mean my t-cells have never as high (...) so it’s, for the few years have been a mixture of happiness and sadness. Happiness that I’m alive but sadness that a lot of people are now dead because medications wasn’t available to them and a lot of people sort of literally died from toxicity from different medications which they took. Don’t know whether that sounds, makes any sense. (2000 – first interview)

Ben’s questioning of the coherence of what he said at the end of his story could be interpreted as the contradiction he recognised in the story told. This seeming contradiction or incoherence is reflective of the negotiation he has to confront. This negotiation is significant particularly when his experience of improved health is historically situated within the milieu of surviving and reviving from probable fatality, and knowing his good fortune was not available to people whom he loved and cared for. This is an exemplar of the post-treatment era’s version of ‘survivor’s guilt’. Many individuals feel guilty about their own good fortune for having access to the protease inhibitors and the benefits from medico-scientific advances (Wheeler & Shernoff, 1999). The ‘guilt’ experienced is intensified as they recognise that their survival was somewhat arbitrary. What I mean by arbitrary here is exemplified by Steve’s story about his partner who “missed out” and the chance occurrence of having treatments available at the time when he needed them. The negotiation of ‘survivor’s guilt’ is imbued with a profound existential questioning of the reason for one’s own survival and the death of others. It is epitomised by Ben’s question of “why am I still alive” and Frankl’s (1984) notion of “will to meaning”. Frankl’s
description of his subjective experience of surviving his imprisonment in a concentration camp during the Second World War informed his conceptualisation of his theory logotherapy. His theory focussed “on the meaning of human existence as well as on man’s (sic) search for such a meaning” (p.121) and this striving to find meaning is what Frankl argued to be the “primary motivation” (p.121) in the act of living. Informed by Frankl’s attention to the striving to find life’s meanings and the centrality of this activity in the lives of individuals, I will now explore the constructed meanings some of the research participants used to make sense of their survival of HIV and their effort to constitute an authentic and ethical life.

When asked about the meaning of living with HIV in a time when it is manageable and treatable in his second interview, Eric told the story of his guilt for surviving HIV when others did not. In his story as presented (I recognise Eric’s story is long but I did not want to edit the story and possibly compromise the integrity of his narrative), Eric revealed his experience of survival as a source of conflict in his post-treatment life. His story conveyed the way he made sense of his guilt, his survival, and the way he constructed his longevity meaningfully and ethically. His story is also about the social significance of constructing HIV as a disease that is ordinary and the special status it has in terms of services provided to people with HIV.

E: Um… I, I, you know that term survivor guilt um came into my mind almost straight. Um, and what’s so special about HIV um, so there’s two things: there are, I suppose the survivor guilt is again, as each year goes by and sort of (sigh) it becomes just, it’s just there. You’re taking your, your, your pills and whatever but you know it is just there and there are those trips to the doctor which if, well I probably don’t make any more trips to the doctor in a year maybe than some
people who are HIV negative, um, I mean broadly speaking I suppose that could be true. Um, but there’s still that feeling of I’m here still and there’s you know a significant number of people in my life who aren’t here, um who I would still like to be here, and…I’m trying, I suppose this is the part of, again where I was going to with, some of the sort of feeling around depression, um or my journey is like, I was thinking well, they’re not here, I’m still here, I need to make the best of my life and, and, and that’s sort of, it’s kind of er put it out there that you know I can still live my life to the best of my ability and even um celebrate their lives through my life and you know sort of, twisted as this might sound, sort of live their life, live my life, live their lives through my life a little bit. So it’s like they’ve gone but I can still carry on for them with my life a little bit, yeah. And I can remember clearly thinking that the first um, sort of HIV death I er experienced, um thinking, after I’d been to this person’s funeral, thinking I’ll live my life stronger because they’re not around and because I’ll be living my life a bit for them. Um, and now I realised that sort of such a burden that no one can do that (laughs). But there’s an element of that I suppose and the survivor guilt-y thing “oh well, you know I’m still here so I can do my best”. Um, but then, so that’s, that’s that element of it and then the other part of it which I alluded to was um “so what”! What so special about HIV now? In that again when I go and talk to other groups of people who are not in the HIV sector, um and they say “so, you know why aren’t you a specialist provider for people living with cancer or diabetes or any other sort of life threatening condition?” And I mean, well, when I was first asked that question, I was sort of really kind of thrown back a bit and thought “ooh, yeah, that’s exactly what I think” you know. I’ve never, if someone really asked me what I thought about HIV now and maybe even a few years ago, it’s like “well no, it’s nothing huge, I mean people have had to get over huge other physical um conditions”. The only thing that’s, with this is that, that I’m you know I have supposedly the same condition as a lot other people who I know who died, um, and that has impacted on me in a mental and
emotional way, um which maybe other, and I can identify with that in
the way that other people with other life threatening conditions, can’t.
(2001 –second interview)

In exploring Eric’s story, I want to draw on Frankl’s (1984) emphasis on locating
meaning in an individual’s existence. Similar to the experience of Ben, Eric
struggled with the experience of “survivor guilt”. He survived HIV because of the
treatments but these treatments were not available to “a significant number of people
in my life who aren’t here, um who I would still like to be here”. Given that he is
“still here” and living a life that he did not think he would have, the question of why
he is privileged and the conflict experienced is possibly manifested in the
“depression” he noted or more pertinently the “journey” he has to undertake. To
resolve this intra-subjective conflict, he positioned himself as someone who has “to
make the best of (his) life”. His obligation to live his life to its potential by utilising
all of his ability is his way of remembering and celebrating the lives of his loved
ones. He negotiated his “guilt” by interpreting his opportunity for an extended life as
one which the lives of others could be lived through his and to “carry on for them”.
He reconciled a person’s death, as noted in his story, by determining to live his “life
stronger” so that the loss he experienced is embodied productively and meaningfully.
It could be argued that Eric is positioning himself as an ‘advocate’ of lives that ended
prematurely and senselessly. The senseless death of so many and the trauma afflicted
by HIV and AIDS on gay men in particular, as articulated and analysed by Rofes
(1996; 1998), has to be made meaningful. This is where Frankl’s suggestion of
striving to find concrete meaning in an individual’s life is most salient. Eric
acknowledged that the way he made sense of his subjective experiences relating to
the death of friends is unconventional, for as “twisted as this might sound”, the
discursive embodiment of others’ lives is subjectively constituted as an ethical practice through which not only his survival is made meaningful but that the lives of other were also made meaningful as they helped to construct his subjectivity of which he (and his loved ones) could be proud. The embodiment is a representation of those whom he loved, a concrete meaning in his personal existence.

Eric’s “survivor’s guilt” could also be examined from a different, and perhaps more provocative, perspective. The negotiation of the “guilt” he experienced, as presented in the second part of his story, destabilised the privileged status of HIV. “So what?” and “What so special about HIV now?” Eric rhetorically asked. When challenged by “people who are not in the HIV sector” about the privileged status of HIV, not only does he question the significance of living with HIV but also his subjectivity as a person living with HIV – “well no, it’s nothing huge, I mean people have had to get over huge other physical um conditions”. If HIV, as argued, no longer warrants its privileged status, for it is like “cancer or diabetes or any other sort of life threatening condition”, is it possible for him to continue to position himself differently from others who also have life-threatening conditions or to continue to feel that the “guilt” he experienced is necessary? The change in social significance of HIV infection in the wake of effective treatments (Catalan, Meadows, & Douzenis, 2000), and the normalising of HIV has produced the experience of “living two realities” (Trainor & Ezer, 2000, p.652); the “two realities” is a paradox of appearing healthy but living with an incurable condition. Surviving HIV and AIDS is no longer a remarkable phenomenon but an accepted, and expected, occurrence as shaped by contemporary HIV medical discourses. The implication of normalising HIV is that it undermines survival as a profound and unexpected event for someone like Eric, who not only
witnessed the deaths of loved ones but had anticipated and prepared himself for the same fate. His survival is intensely meaningful and the “guilt” could be constructed as a reminder and a remembrance of loved ones who had not survived. Eric’s experience of “survivor’s guilt”, in this context, does not connote wrong-doing or that his survival is position as an uncomfortable situation, but rather, it is a constituent in the construction of his post-treatment subjectivity. The manner in which Eric positioned himself as having the “same condition” from which many others have died, and that his HIV diagnosis has “impacted on (him) in a mental and emotional way”, could be interpreted as Eric’s attempt to explain the lasting consequence of living through an era when death was the norm and his own survival was questionable. The reflexivity he engaged to make sense of his lived experiences in the post-treatment era by embodying the meaning he constructed to his survival was to resist the normalising of his extraordinary journey. The “guilt” is embodied for it acts as a way to remember the past, to make sense of present and a resource with which to construct a meaningful future.

The embodiment of others’ lives in Eric’s construction of his subjectivity is echoed by Steve, who in telling his stories about his revival from HIV-related illness, and his effort to make sense of the deaths of loved ones as noted earlier, made reference to the “good stuff” that was given to him by friends who died, and the embodying of this “good stuff” into his subjectivity.

S: (…) when someone you love dies, they say here’s all my good stuff, I can’t use it anymore, but if you want to, here it is. You know, that’s the way they hand it over to you (Q: Wow.) (laughs). They, they do, if you’re with someone when they die, you’ll see them if you see their
body (Q: Hm.), that’s the way I see it. And if you really loved them, then you loved that really good stuff about them and you know their awful stuff as well, you know all that crap as well. But they don’t say, “here, I’ll give you that as well”. They say “here’s the good stuff that was me, I can’t use it anymore but I pass it on to you” (…) It’s er um, and what it is my friends who did died, as I said before, they threw me their stuff when I was with them (laughs) (…) And I took it (Q: Hm.). So I changed because of that experience (Q: Hm.) you know, I learned from them. I learned a lot and that and, you know, has that created who I am today you know? Would I be this person now had I not had those experiences? And probably not, so.

Q: I took note of that because it sounds like it’s, the changes you see in yourself are more stemming from the gifts that your friends have given you rather than the drugs.

S: Well the drugs keep me around to um be and be that. The drugs don’t give you that, the drugs don’t give you…you know all of that. They just keep you alive and you then are the person you are. Whereas my friends who have died, and my friends who are alive give me good stuff as well, but the ones who have died you know, really, if you, you know if you’ve been with someone who’d actually died, it’s an amazing experience. And if you can see it in a light where…they’re giving you something um it’s even more amazing experience. So and you’re there just take anything you can get, I mean they really do give it (laughs) (Q: Hm.). You know you can (inaudible) but I feel it. So um you then er, go along and they’d given you something of themselves that you take on and you make it part of yourself. And I think that’s really what’s life is about, that’s the connectedness of existence you know. (2002 – first interview)

Bloom (2001, p.41) suggested that an “integrative” narrative is a discursive device through which individuals construct coherence and to give meaning to their past
experiences, and I would also suggest, to give meaning to present experiences.
Similar to Frankl’s notion of “will to meaning”, the activity of making sense of life
events by constructing coherence and meaning enables individuals to live ethically in
spite of existential questioning of their continual survival. In Steve’s story, he
reconciled the juxtaposition of his survival and the deaths of friends by constructing
his experiences as a situation in which the lives of those whom he loved will
continue to live through him, for they have given him the “good stuff that was
(them)”. Steve constructed this meaningful explanation in making sense of deaths he
witnessed by positioning himself as a ‘product’ of others’ qualities, that is, their
“good stuff”. In his words, their “good stuff…created who (he is) today”. From this
perspective, his survival is made meaningful as there is an ethical purpose. The
purpose is to construct a fulfilling and satisfying life for his friends as well as for
himself.

The duality of the word “integrative” resonates for not only it could mean the
‘joining together’ of experiences to construct a meaningful and coherent whole but it
could also mean the ‘incorporating’ and the embodiment of the non-material selves
of friends he valued. Steve acknowledged the treatments have, as made clear in the
latter part of his story, extended his life, but his subjectivity and arguably the quality
of his lived experiences or his ‘quality of life’ was constituted by the “good stuff”
received from friends who have “given (him) something” that he has to “take on and
you make it part of yourself”. The manner with which Steve concluded his story by
suggesting “that’s really what’s life is about, that’s the connectedness of existence” is
integral to his sense making activity.
I want to explore two issues that emerged from Steve’s story. Firstly, the “connectedness of existence” is informing, for the “good stuff” received from friends could be interpreted as Steve’s way of remembering his past and his friends, which has an affinity with Eric’s construction of guilt as noted previously. Barroso and Powell-Cope (2000), in their project to integrate qualitative research findings on the lived experiences of people with HIV, noted the import of connectedness with others. They suggested that “human connectedness was the emotional support given and received and the sense of belonging that came from social interactions” (p.345). The connectedness through the “good stuff” could also be interpreted as a strategy which Steve employed to preserve the relationships he had with his friends. In doing so, he continued to be emotionally supported by and maintained a sense of belonging with his social network. Although this social network comprised of friends who had died, he maintained a spiritual connection with them. Secondly, which connects with the first issue, Steve’s subjective experiences are shaped by and made understandable through spiritual discourses. Spirituality in the context of health care and coping is crucial (Gall et al., 2005; M. King, Speck, & Thomas, 1999) and specifically in HIV (Ezzy, 2000; Simoni, Martone, & Kerwin, 2002) where it is found to be an important constituent in the enrichment of lived experiences for people with HIV (Coleman, 2003). More pertinent to my present examination of the spirituality which Steve embodied in order make sense of his survival, Carson and Green (1992), argued that “[s]pirituality, specifically the existential aspects of spirituality, holds forth the promise of giving life meaning through allowing individuals to realize experiential values “by experiencing the Good, the True, and the Beautiful, or by knowing one single human being in all his (sic) uniqueness”” (p.217). They further suggested that unlike spirituality founded on religiosity, the existential aspect of spirituality offers a
uniquely human challenge for it is concerned with the individual’s life, and the meaning and significance of that life.

An issue which could be interpreted from the Eric’s and Steve’s stories is that they want to position themselves away from the ‘sick role’. The endeavour to construct a productive and meaningful life means that the ‘sick role’ within which people with HIV were positioned, or within which they positioned themselves, has to be examined. In spite of an absence of a cure, being positioned as sick and being shaped by the discursive and material practices of the sick role, are being contested, resisted and rejected. The activity of engaging positively with the future and constituting themselves as productive subjects necessitates the “de-sickenising” act.

8.4 The “De-Sickenising” Act

As it will be made clear, the title for this section is from Lisa. Her story about the activities of constituting a post-treatment subjectivity is the main focus as it embodies the subjective experiences of contesting and resisting a subject position that is inappropriate or subjectively meaningful. Her story is notable as she has confronted and recovered from imminent death on several occasions, which makes her “de-sickenising” activity all the more remarkable in the context of someone who, by her own suggestion, should not have survived.

In examining Lisa’s act of “de-sickenising” herself, I want to make visible Lisa’s “de-sickenising” process as her way to live a subjectively constituted ethical life in order to turn herself into a productive subject. I want to draw on Foucault’s ideas on
the ‘subject’ and the notion of “subjectification” which is “the way a human being turns him- or herself into a subject…and those processes of self-formation in which the person is active” (Rabinow & Dreyfus, 1991, p.11). Bartos and McDonald (2000) in their attempt to understand the ways meanings of living with HIV are reshaped in the post-treatment era, focussed on “modes of subjectification” (p.300) which they refer to as the ways people work on themselves to make their conduct intelligible not only to themselves but also to others. This framework, Bartos and McDonald argued, is useful for it allowed them to attend to the work performed by people with HIV in managing their subjective illness trajectories, and the ways in which the work is constituted as work on constructing a particular type of HIV or AIDS subject. These are the theoretical bases which inform my analysis of Lisa’s story.

When she was initially interviewed in 2000, her health had improved as indicated by the clinical markers of t-cell count and viral load. She described her excitement of having an increased t-cell count as it was a signifier of positive changes she was experiencing. When asked about how she was living with HIV in recent years, she told the story of “de-sickenising” herself. It was a story in which she used tangible and material markers to illustrate the momentous changes that have happened to her and the changes she has initiated. She began her story by describing the process of removing the “peg” through which she was fed nutrients when unable to swallow.

L: A “peg”, which is a um, it’s balloon shaped thing in your stomach.
And um I get fed, was getting fed, and feeding myself liquid nutrients overnight. (Q: Right.) So I have a drip stand by the bed and um, and that was the way that um I, I got to put on weight, and it saved my

3 PEG – Percutaneous endoscopic gastrostomy is a surgical procedure for feeding individuals who can not swallow due to medical conditions.
life! Apparently they don’t do it that much for people because people, somebody had died when they tried to insert one of them. But um, it certainly worked for me (Q: Hm.). And the interesting thing is I’ve now, I’m now in a process of, what I sort of call “de-sickenising” myself (laughs) (...) because I’m getting that particular plug-peg removed (Q: Ahh.). And um… and I’m doing, I’m doing, at the moment, I’m doing a whole series of things which is removing the presence of the virus or the status of the virus is being altered in my life, my perspective on it. Getting the peg removed, I’m getting my, I’ve had the drip stand removed from the house, and my bed is, as you can see, one of those um adjustable beds which I no longer need (...) I’m sending that back, I’m moving back upstairs. When I first came home from hospital after you know, I told you I lost all that weight, I couldn’t get up the stairs (Q: Hm.). And I had to have a lot help from the community nurses you know with things like you know, toilet supports and things like that and um, I mean I was in a wheelchair when I first came out of hospital and now it’s just a process of um… of change! And um, it’s quite exciting and I feel, I feel strong, I feel strong not just ‘cause I’ve got 60 little t-cells, which is too many to name (laughs) but um, my spirit is not ready to go, and I know that, you know. (2000 – first interview)

The story Lisa told described the positive changes in her corporeal health by situating these changes within the frame of her everyday life. She described the “peg”, a device through which she received nutrients and on which she relied to ensure survival, and the medical equipments in her home that constituted a way of living with HIV which she now positioned as unnecessary in the context of the change in her health. This was illustrated by her declaration, “I’m sending (them) back”. It could also be interpreted that her comment of “moving back upstairs” was a signifier she used to position herself as no longer limited or restricted by HIV, for she previously “couldn’t get up the stairs”. The positive changes were made visible and
tangible by her references to material equipments and her physical capabilities, that is, what she could do. From this perspective, Lisa’s story could be explained by the “restitution narrative”. According to Frank (1995), the restitution narrative “reflects a “natural” desire to get well and stay well” (p.78), for the aim of the ill individual – in this instance, Lisa, is to (re)position herself as an individual with a ‘healthy’ body and a ‘healthy’ life. In her examination of capability and subjectively constituted wellbeing, Sen (1993) argued that “[t]he capability approach to a person’s advantage is concerned with evaluating it in terms of his or her actual ability to achieve various valuable functioning as a part of living” (p.30). Lisa’s description that “(she is) doing a whole series of things which is removing the presence of the virus or the status of the virus” assumed significance when analysed within the context of Sen’s idea.

The change in Lisa’s corporeal health has enabled her to contest the everyday practices of HIV living. The term Lisa used to describe the process – “de-sickenising” is informing and valuable for it signifies the changes she experienced in her everyday life with HIV. The language Lisa used to position her activities is important, for it constructed her subjectivity in the post-treatment era. Alvesson & Sköldberg (2000) argued that constituted subjectivity is a process not a structure, for “[h]ow we speak and how others address us constitutes our subjectivity at any given moment, contingent upon the various discursive fields from which language emanates and in which we find ourselves” (p.164). This idea is pertinent here. The process of “de-sickeninsing (her)self” suggested a (re)positioning of her post-treatment subjectivity. In this context, the discursive constructions of her as sick, incapable, and in need of care have become inappropriate and unproductive.
The “de-sickenising” way of living with HIV in the post-treatment or indeed, Post-AIDS era (Dowsett, 1996; Rofes, 1998), as noted in Chapter Two, is a means through which individuals could make sense and temporally contextualise the changes effected by treatments in the construction of HIV and AIDS. The virus, in spite of the treatments that are available and the effectiveness in its management, will remain to be a significant constituent in the lives of those who are infected. However, living in a perpetual crisis is not feasible, for the lived experiences of improved corporeal health contests the fear and panic which reflected a time in its history, but not the present, and certainly not in resource-rich countries, such as Australia, where treatments are readily available. Although HIV is significant, the centrality of the virus as a constituent in individuals’ subjectivities has to be disrupted, as demonstrated by Lisa in her process of “de-sickenising” herself. It could be interpreted that the material medical objects could be discursively constructed as constraints to her project of constituting a post-treatment subjectivity and an ethical life.

The removal of the material objects from her home is her resistance to the “sick role” to which she has been positioned and a position she no longer considers to be appropriate, for as she later said in the same interview,

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4 I am not using the term strictly within the framework of Parson’s “sick role” (Parsons, 1951). The Social System, in which Parson introduced “sick role”, was “written to explain a relatively complex structural-functional model of society in which social systems are linked to corresponding systems of personality and culture” (Cockerham, 2004, p.14). Parson used the construction of social roles to conceptualised and theorised individuals who are sick by outlining four components to the “sick role” of which two could be regarded as ‘rights’ and the other two as ‘responsibilities’. When individuals are sick they have the rights to be exempt from ‘normal’ social roles and they are not responsible for their conditions. However, they are responsible for getting well and should seek technically competent help and comply with the directions of their treating physicians. Despite its usefulness in making sense of the acute illness experience, it has been critiqued for being inadequate in the chronic illness experience (Bates, 2002; Crossley, 1998a). I will not be appropriating Parsons’ theoretical framework in examining the ‘sick role’ as employed by Lisa but I am aware that some of the issues examined have relevance to or could be analysed by the use of Parsons’ framework.
“that’s what exciting at the moment is that I’m doing these things to sort of get out of that sick role (Q: Hm.), and um, and realised that it is possible to change, and um…that maybe I’ll be lucky enough to find out my purpose here”. (2000 – first interview)

The capability to be “doing these things” is “exciting”, for Lisa is embodying the possibility for change and positioning herself as an active agent, a position she had not considered to be available given her poor state of health in the past. The quality of her lived experiences could be interpreted as having improved due to the changes that were taking place. The meaningfulness of ‘quality of life’, as discussed previously, resonates here in Lisa’s reflexive consideration of her life goal as indicated by her comment “maybe I’ll be lucky enough to find out my purpose here”. It could be interpreted that Lisa’s effort to make sense of her life is to locate a “purpose” in life that is subjectively meaningful. The notion of “will to meaning” is a useful framework with which to understand Lisa’s experience, for it could be argued, and drawing on Frankl’s (1984) work, that Lisa’s ‘quality of life’ in the post-treatment era is predicated on finding the “why to live” in order to negotiate the “how”.

The improvements in her health have meant that the subject position as signified by the “sick role” is no longer appropriate or productive for Lisa, for it is a role from which she is working “to sort of get out”. The discursive construction and material practices of living with HIV have changed from being ‘cared for’ by others to ‘caring for’ oneself. People with HIV are expected to be “responsibilized” (Race, 2001, p.179) in that they are to assume responsibility of their health care needs specifically to achieve an undetectable viral load. It is the “liberal governance” to which Flowers
(2001, p.51) referred when he suggested that people are now responsible for managing their own health, avoiding risks and engaging in healthy behaviours. This is reminiscent of responsibility discourses in the context of contracting and being infected with HIV. Responsibility discourse positions individuals as being ‘blame-able’ for their circumstances and invokes personal incrimination for not acting as responsible subjects. The ‘risky self’ (Ogden, 1995) suggested that the responsibility of preventing health risk or preservation of ongoing health lies squarely on the individual and it is the individual’s responsibility to redress the harm experienced.

The position Lisa assumed in taking responsibility and caring for herself through the “de-sickenising” process could be further elucidated by the work of Crossley (1998), who argued that the absence of a cure for HIV has meant that the knowledge or competence needed by a person living with HIV is not the type of technical or biomedical knowledge that medico-scientific discourses could provide. Crossley contended that the temporal ambiguity associated with post-treatment HIV disease progression has produced a subject position “somewhere between the dependent sick role and the empowered individual” (p.508). From this perspective, in spite of the unresolved issues and problems embedded in living with HIV, Lisa privileged her subjective understanding of her needs in order to be empowered in her endeavour to construct a subject position through which she could live authentically and ethically in a manner that is subjectively valued. It could be further argued that if Lisa were to position herself as being ‘well’, the pertinence of the clinical markers or indeed how she might appear is less relevant than her subjective experiences. For Lisa, the change in her corporeal health demands a subject (re)position which is facilitated by her de-sickenising process. However, as is apparent in the next part of Lisa’s story
about removing herself “out of that sick role”, there is pressure, constructed in the intersubjective space, which she has to work against.

L: (...) Um, it’s interesting, that’s a whole other ball game about how people react to you being HIV and stuff like that. But um, I was just talking about that with someone today about that sort of ah, how people like to ah, keep you in a sick role and disempower you (...) I think the world is full of caretakers (laughs) and um, people would rather keep you in a position where they’re, a lot of people where they’re the provider and it’s a constructed sort of role. I suppose it’s just the basis of what they call co-dependency. Um, and you’re the ‘sick’ one and therefore you can’t, you don’t have any personal power and you can’t make any decisions and um, there’s plenty of power you can have, I believe until the very moment that you die (Q: Hm.), you know. You can have power, you can power just even when you can’t speak (Q: Hm.). Um, and there’s just people, and these are the sort of relationships that I have to sort out along the way and let go of if they can’t be changed so that I can still remain in some sort of a position, some autonomous sort of position which is what, it is my growth. That’s part of my, big part of my being here is to have that emotional independence. (2000 – first interview)

The “de-sickenising” process could also be interpreted as Lisa’s work in reviewing the relationships she has and to re-evaluating them in her project to (re)constitute her subjectivity. The positioning of her in the ‘sick role’ and the disempowerment she experienced is intersubjectively constructed. Just as she is positioned in the sick role, she positioned others as “caretakers” and states that this subject position subjugates her and stymies her endeavour to have the independence she privileges as crucial in her post-treatment subjectivity. Siegel and Lekas (2002) noted that extended survival from treatment use often invokes a review of relationships with others, as
improvement from treatments leads to deliberation about the necessity of maintaining unsatisfying relationships which had previously been retained for fears about health deterioration and the need for support. This issue presented by Siegel and Lekas could produce different interpretations about the integrity and ethics of some people with HIV. If disapprovingly interpreted, some people with HIV could be constructed as ‘users’, for they have taken advantage of others on whose help and support they relied, regardless of the satisfaction level in the relationships. However, if the issue is interpreted as the endeavours of some people with HIV not wanting to ‘deceive’, in that they are rejecting these relationships to which they do not feel committed, then it is a practice of constructing an ethical life. If it is premised that subjectivity is intersubjectively constructed, to construct an ethical life would demand that our intersubjective relationships also be ethical. In her book on ethical relationships, Colegate (2004) premised “that we are always firmly embedded in a network of social and political relationships” and that our “[i]ndividual happiness will always depend on our ability to negotiate these relationships with wisdom and integrity” (p.3). Batchelor (1998) who, from a Buddhist perspective, suggested that although “[w]e were born alone and will die alone…our lives are nonetheless defined through relationships with others” (p.49). Lisa does not want to be reliant on the “caretakers”, for she recognised that it is a “sort of role” constructed intersubjectively by her acknowledgement of it being based on “what they call co-dependency”. To “de-sickenise” is to disrupt the ‘caretaker-sick’ reciprocity on which her previous intersubjective relationships were based. This reciprocity embedded in her intersubjective encounters has the potentiality to comfort or to distress, and it is here that the ethics and politics of these encounters are located, for not only they are sites on which happiness could be produced but they are also avenues through which
power is produced and enacted. The positioning of others as “caretakers” means that Lisa is positioned as having no “personal power”, and this needs to be negotiated as she needs this “personal power” to construct a fulfilling life. The ‘caretaker-sick’ reciprocity is used here by Lisa to make sense of and to (re)constitute her subjectivity as well as for ethical accountability. The position she assumed, which produced the view that “there’s plenty of power you can have, I believe until the very moment that you die” conveys the obligation she has to herself to being ethical as subjectively constituted. The “autonomous sort of position” and the potential for “growth” are embedded in her subjectively constituted ‘quality of life’. The significance and meaning embedded in being “autonomous” relate to her quest for a “purpose”, which is to achieve an “emotional independence” and existential satisfaction. Although having “60 little t-cells, which is too many to name (laughs)” is important to Lisa but the clinical markers do not resolve her “will to meaning”. From this perspective, it could be argued that her aim to construct a subjectively meaningful life is central to her endeavour in making sense of her life, and experiences, in the post-treatment era.

As noted at the start of this chapter, the ‘quality of life’ concept could be used to signify the ‘good life’. The manner in which existential and corporeal satisfaction is valued needs to be contextualised within the subjective ideals of a ‘good life’. A ‘good life’ suggests lived experiences that are subjectively constituted as ethical and meaningful while embodying the challenges as denoted by the difficulties, sadness and guilt embedded in living with HIV in the post-treatment era. What I want to attend to in the next section is how life is lived so that it is subjectively constructed as ‘ethical’ and ‘good’ in spite of the disruptions HIV has produced in forcing unexpected and unwanted changes to life plans.
8.5 The Act of Living is a Piece of Contemporary Art

The playful section title was inspired by James. At the first interview when he was asked to speak about the manner in which he made sense of his life with HIV and fashioned a life(style) in spite of the distress experienced resulting from his infection, James’ narrated this story about how “life lived beautifully is an art”.

J: Yeah, um. Some of it yeah, I suppose yeah, tried to. Um, but ultimately it doesn’t you know, it’s [HIV] not an excuse, it’s not an excuse to sort of not live. It’s um, if anything, it’s um, it’s a prompt or a poke with a big stick to, to get on with it. You know, like to um, to look at yourself, to um look at your you know who you are and that you are going to die ‘cause everyone’s going to die and you know, what the fuck have you done? You know like who the hell are you? Um, what’s the point? You know, all those things that sort of like mull around it at the bottom when you sort of ‘twissing’ around sort of worrying about you know what to wear and when your, you know next job’s going to be and how much money and your car and you know, like your holidays and stuff. And then suddenly you sort of, you know the spectre of death appears and um, you know those things are immaterial whether you like it or not. Um, but yeah, I think you can get, I think if we want to go back to sort of treatments, um, that’s what’s that’s done is it actually managed to put off, like prolonged the period between you know be hit with the news and actually dying to a point where well, I’m not quite sure when that’s going to happen. So I’ve sort of done all this work on accepting my own demise, realising that you know like I’m not particularly sort of you know, there are some quite good things about me as a person but I don’t need to leave any memorials that um, I’m quite you know being you know. Life
beautifully lived is an art in itself, that’s enough. And you know, every sort of like extra year is um, a reward and I’m, I want as many, as many days in that year to feel good just why the days I don’t frustrate me and you know like anger me, um, because they you know, they’re a waste of time. (Long pause) How lucky to be able to indulge in such…sort of complex problems you know. Where so many, so many people in the world are worrying about the next meal and, and you know whether they you know, they’re going to be alive tomorrow you know. Even with you know like I’m unable to actually sort of deal, you know like think about and have time to dwell on sort of metaphysical, metaphysical is that the right word…um, you can tell this is one of my good days… (2001 – first interview)

Foucault’s notion of ethics and the relationship an individual has with him or herself in the constitution of a moral subject as previously noted (Rabinow & Dreyfus, 1991) is salient in James’ story. The disruption caused by a chronic illness experience alters the relationships that individuals have with themselves and with their social worlds, and so for these individuals, the reconstruction of their stories is of central importance (Hydén, 1997; Williams, 1984). The presence of a disruptive chronic disease produces an existential questioning by individuals of the ethicality in their lives, from this perspective, the reconstruction of their stories is a “moral quest” (Hydén, 1995). The moral quest is to locate a place for the illness experience in their stories which enables the individuals to make sense of and to relate it to the values of their life projects. The telling of their stories is more than about their illness experiences, for they pertain to subjective moral aspirations and values.

The opening of James’ story conveys his life project clearly: “ultimately it doesn’t you know, it’s [HIV] not an excuse, it’s not an excuse to sort of not live”. The
distress he experienced from being infected with HIV, and his negotiation with his HIV status in fashioning a life(style) are reflected in this statement. He positioned himself as needing to be ethical by not using HIV as an “excuse” but by constituting himself as a productive subject. This is an important enterprise, for he asked “what the fuck have you done? You know like who the hell are you?”, which suggests that the act of constituting himself as a productive subject might have been ignored in the past. In this context, HIV is constructed as a “prompt” or a “poke” to engage with life and the fear associated with its fatal consequences can no longer be accepted as a reason for inertia and apathy. The idea of ‘getting on with life’ despite living with a chronic disease embedded in James’ story is noted in findings of research on different forms of cancer (e.g., Gurevich, Bishop, Bower, Malka, & Nyhof-Young, 2004; Little & Sayers, 2004; Thomas-MacLean, 2004). “[E]veryone’s going to die” is a discursive device James used to bridge the imagined gap between him and people not infected with HIV. He can not use a possible shortened lifespan to hinder his effort to make something of his life despite living with a chronic and incurable condition. In his “twissing around” concerned by the materiality of a mortal existence, the “spectre of death” renders the concerns with these materialities “immaterial”.

The recognition of treatments as a resource which prolonged his life is constructed as a moral obligation, to himself, to fashion a life through which he could be fulfilled. This fulfilment is not through material goods or “memorials” as he light-heartedly expressed, but to live a “beautiful” life. To live this beautiful life is an “art” for there are no directions or prescriptions; it is a resolution James constructed and centrally positioned in his post-treatment life. It is he who has to locate the meaning that
would make his life worthwhile, in a sense, to locate a subjectively valued ‘quality of life’ has become his life project. Taylor (1991) in his exploration of the authenticity in leading a good life not only suggested that a good life is what each individual seeks in his or her own way but “a certain way of being human that is my way. I am called upon to live my life in this way, and not in imitation of anyone else’s. But this gives a new importance to being true to myself. If I am not, I miss the point of my life, I miss what being human is for me” (p.28-29 italics original). “Being true” as articulated by Taylor is a subjective enterprise, he argued that this is the moral underpinning to the ideal of authenticity, and the journey towards self-fulfilment. From this perspective, James’ project to live a “beautiful” life is to embody all that constitutes his life, that is, to embody the challenges as well as the extended life and the “good days” he has been given, as “a reward”. To be ‘true’ and ‘authentic’ necessitates an ethical positioning of him as being “lucky” as there are others for whom the opportunity to engage with the “metaphysical” is unavailable. He positioned himself as being fortunate and this recognition is important for him in his project of constructing himself as an ethical subject. The way he ended the story “you can tell this is one of my good days” is relational to his apprehension of the ‘not good’ days that “frustrate” and “anger” him. Embodying the impermanence of his lived experiences further emphasises the necessity for him to take pleasure in the present, and to dispense with the detrimental imperative of ideals embedded in notions of what could be or should have been.

Living in the present is important for James and others for whom the centrality of HIV has produced uncertainty in their lived experiences and undermined the take-for-granted position from which life was meant to be engaged. The temporal
orientation to life is disrupted, and the idealised future and the actual present lack the connection that they had previously. What I mean by this is that HIV disrupted or severed the connection between our assumptions that our actions in the present need to be informed by our expectations of how life could or should be in the future. The descriptor of the act of living as not only a piece of art but a piece of contemporary art is to signify that this project is temporally situated in the present. In this context, living a ‘good life’ in the present could be viewed as a strategy to redress the ambiguity and uncertainty embedded in an illness experience that can not be resolved due to the absence of a cure. Following on from the story she told as described in Chapter Seven (in the section titled ‘The Numbers Game’), Lisa narrated this story about ‘living life in the now’.

L: (...) Um, and…I remember being very encouraged by my sister M of like…because I remember coming out after seeing him (an HIV specialist), after he said that, and I was crying, and she was saying “this is it, this is life now!” This is it now you know. And um, not in six months time, not in two years time or five years time or whatever, it’s now!

Q: Which in a way it’s like what you were saying like a moment ago about how…you know, it’s not about the future (L: Yeah.), your life is now.

L: And it’s about the moment, it’s about the quality of the moment (Q: Hm.). Um, and that’s why I’m getting the peg out too because it’s just, I want to be able to wear, I want to be able to wear tight t-shirts, I want to be able to sort of go swimming and not have something hanging off me (Q: Hm.). Um, it served its purpose and I would rather have more quality of life and less time of it than no quality and more of it. You know, I’d rather be able to sort of enhance the
moments and have the moments more special than have lots of dull moments. (2000 – first interview)

Lisa’s story privileges the temporal frame of living life in the present. When her hope was diminished by the medical advice from an HIV specialist (“I felt he’d given up on me. He basically said “it’s nutrition, Lisa””), it was inferred by Lisa as a forecast of her impending demise, she interpreted the advice as a discursive positioning of her as a person without a future. The emphasis on “this is life now! (…) not in six months time, not in two years time or five years time or whatever, it’s now!” produced in the intersubjective space between Lisa and her sister, positioned the act of living as not only to be performed in the present but that the present temporality has to be privileged in order to effectively negotiate the prospect of a ominous future.

Davies (1997) argued that a significant issue confronting people with HIV is their understanding of time; for time is “tacitly understood as the platform from which we live our lives and the means by which control over its course can be exercised” (p.561). She described three forms of temporal orientations: “Living in the future” – the individual continues to focus on the future as the perspective with which he or she engages with the present; “Living in the empty present” – the individual’s belief of imminent death obstructs productive planning for the future; and “Living with the philosophy of the present”5 – the individual embodies the HIV illness experience in a manner that enables him or her to discover new meanings or values embedded in living his or her life in the present temporal frame. I want to draw on Davis’ “living

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5 Ezzy (2000) suggested that this temporal orientation is comparable with the “quest narrative” (Frank, 1995) but there is a significant difference in tone, for the “quest narrative” is heroic, and it positions the individual as endeavouring to overcome the illness he or she is inflicted. The “living with a philosophy of the present” suggests that the individual is not future orientated for it is in the present where life’s meanings are located.
with the philosophy of the present” as the conceptual device with which to further explore Lisa’s story.

In her clarification of “living with the philosophy of the present”, Davis (1997) argued that for some individuals, the loss of take-for-granted-ness embedded in living with HIV could facilitate spiritual growth, and an appreciation of new or different values and meanings in the context of living with an incurable disease. The shift in temporal orientation from future to the present, Davis argued, could mean that for some individuals, they are “freed from the responsibility of having to construct a meaningful long-term plan for his/her life and, subsequently, is enabled to enjoy the present for what it is (for the individual), rather than deliberating upon its implications or possibilities for the future” (p.567). The usefulness of this temporal orientation is that it situates the present as being the temporal space in which lived experiences are given meaning, and arguably, the significance with which to subjectively construct an ethical life. It is from this perspective that Lisa made sense of her lived experiences as told in the second part of her story. Lisa positioned the present temporality as subjectively significant for “it’s about the moment, it’s about the quality of the moment” (an idea that is reminiscent of Steve’s story in Chapter Five), which conveys the act of living is made meaningful when it is lived in the present. In her endeavour to live in the moment, she also gives consideration to the future in that there are a number of activities she has yet to (re)experience such as being “able to wear tight t-shirts, I want to be able to sort of go swimming”. These everyday activities appear to be important markers for Lisa in the context of how her life is to be lived, that is, to be enjoyed. These everyday activities are positioned as indicators of the ‘quality the life’ as subjectively
constituted and desired, for the meaningfulness embedded in these activities signify her privileging of the “quality” in her lived experience. This issue is made apparent in the following point.

The way Lisa ended her story by proclaiming that she “would rather have more quality of life and less time of it than no quality and more of it. You know, I’d rather be able to sort of enhance the moments and have the moments more special than have lots of dull moments” highlights the need for existential satisfaction as much as the need for corporeal satisfaction. More importantly, in her determination to have more “quality” and “less time”, Lisa positioned longevity or an extended life through treatments as less crucial when compared with her preference for a life(style) that she desired. Drawing on Bacon’s idea, as noted at the beginning of this chapter, that the “harmony” can not be produced by “the office of medicine” alone. Medical interventions have extended Lisa’s life as signified by the “peg” in her story, but this extension would only be valuable if her extended life enables her to live in a way that is subjectively meaningful and ethical. Not only does she realise that “it’s about the moment” but she has to live and care for her ‘self’ by having “more quality of life”.

The work of O’Grady (2005) which examined women’s relationships with themselves and specifically, the idea of “friendship with the self” (p.90-91), suggested that “self-love”, which I interpret to also mean integrity, being authentic and ethical to herself, is integral to those who have been subjugated and their projects to enhance “care for the self” (p.90). James’ notion that “life lived beautifully is an art” and Lisa’s project to “enhance the moments” reflect similar and yet multiple and diverse ideas to how life is lived for people with HIV. Has the quality of their lives improved since treatments? This is not as simple of a question to answer as it
appears, for it belies the complexities and the ‘messiness’ of life which can not be answered straightforwardly or without problems, however, locating subjectively meaningful life purposes could be a way towards improving the quality of lived experiences.

Moreover, Lisa’s story, like stories narrated by other research participants presented in this thesis such as Steve, Helen and James, could be interpreted as a story about spiritual growth, as suggested by Davis (1997) noted earlier. The ‘living in the moment’ could also be understood from the Buddhist perspective (Batchelor, 1998), which suggest that the Buddha’s teaching was not something to believe in but an impetus to act. The teaching is not prescriptions or indeed, dogmas but are ideas which offer a way for people to understand the experience of anguish (the HIV illness experience), to reconcile with its origin (“why did it happen to me”), to construct a certain way of living (in the moment) and to embody an awakening from this certain way of living (the meaningfulness of life). This awakening offers a spiritual or philosophical frame within which people, such as Lisa, could practise and live it in their everyday lives. From this perspective, the issues which emerged in the stories presented convey the importance of the ‘meaning of life’ rather than the important but arguably, elusive and thus contested concept of ‘quality of life’ as discussed in Chapter Two. It is by having a meaning for the extended time that people with HIV are given which enables them to construct a meaningful and productive present, and future. The subjective construction of an ethical and a meaningful life facilitates a sense of contentment and the production of a ‘good life’

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6 Batchelor (1998) argued that Buddhism should not be a label by which an individual positions himself or herself. It is in the ‘doing’ and ‘acting on’ the Buddha’s teaching that is important in terms of its significance. It is in this context that the title of his book *Buddhism Without Beliefs* becomes meaningful.
which also enables them to make sense, as well as to make use of their extended longevity, which did not appear to be available when HIV first entered into their lives.

8.6 Summary

In this chapter, drawing on ‘quality of life’ as a conceptual device with which to explore the lived experiences as described in the participants’ stories, I argued that it is the subjectively constructed meanings to which it is ascribed by participants that enabled me to perform a more considered exploration of the quality of the lived experiences in the post-treatment era and to argue that the quality of lived experiences is predicated on it being subjectively meaningful and ethical. The everyday life of people with HIV in the post-treatment era is affected and informed by the meanings and significance ascribed to their extended longevity. This is not so much a material project as it is one which is pervasive in the engagement with life in a time when the struggle with HIV and AIDS is not informed solely by corporeal satisfaction but also by existential satisfaction. I am reminded of James’ encapsulation of his search for meaning as one which “mull around” when he is “twissing around” in preparation for the demands of prosaic life activities. The rhetorical and searching question of “why me” fortified the challenging experience of living with HIV. All research participants have witnessed the death of loved ones, so from this perspective, the unexpected opportunity to live out the lifespan that they thought had been truncated but now has been unexpectedly and fatefully restored can be a conflicted experience. I would argue against the possibility that the profound changes in the lives and subjective experiences of participants could be surmised by
the seemingly simple question of whether or not their ‘quality of life has improved’. This is not to suggest that lives have not been positively changed, or that there is ambivalence in this change, but that these changes are not bounded by measurable or observable constituents. In the subjective realities in which people with HIV live, it is the existential, intangible and unquantifiable constituents which make life meaningful. In their projects to make sense of their lives in the post-treatment era, it is the practice of living a meaningful life that produces an authenticity and ethicality to which they aim which makes the act of living simply, worthwhile.

In the concluding chapter, I will draw together the ideas of this chapter and the preceding chapters to argue that the complexities of living with HIV in the post-treatment era is a continuing process of making sense of living with an incurable disease which has had profound effects on individuals for whom the disease has been integral in their lives.
Chapter 9: Conclusion

We do not receive wisdom, we must discover it for ourselves, after a journey through the wilderness, which no one else can make for us, which no one can spare us, for our wisdom is the point of view from which we come at last to regard the world. – Marcel Proust (The Second Book of Remembrance of Things Past)

9.1 Introduction

This thesis has examined the lived experiences of people with HIV and AIDS in the post-treatment era. It has argued that whilst AIDS-related mortality has decreased since the availability of effective treatments, ‘quality of life’, as subjectively constituted and defined, is an ongoing negotiation that is predicated on people locating meaningfulness in their everyday lives. Despite the decreased threat of failing health and death, people are continuing to be confronted by, and therefore positioned as, having to make sense of complex issues embedded in living with a disease for which there is no cure.

In this chapter, I will summarise the main research findings and highlight the implications of this research. I will also discuss the methodological implications and limitations of this research, and outline suggestions for future research endeavours.
9.2 My Argument in the Thesis

People with HIV have experienced dramatic and monumental changes in their lives since their diagnoses and since the emergence of effective anti-HIV treatments in the mid-1990s. In the course of the thesis I explored the ways participants made sense of their lived experiences in a manner that is subjectively meaningful, particularly when HIV continues to be a significant constituent in their everyday lives in the post-treatment era. The constructed meanings embedded in the participants’ stories and the ways they make sense of their actions and experiences in constituting a subjectively ethical and meaningful life were examined and found to be crucial in their continuing endeavours to live with an incurable disease. The process of people making sense of their lives is an activity with important theoretical and practical implications when situated within the context of aiming to understand the experience of living with HIV.

I began this research study as a part-time PhD candidate in 1999, eighteen years after the first notification of what later became known as AIDS, and approximately three years after the emergence of effective treatments. The study took place during the period of “the high hopes” (see Chapter Two) when effective treatments produced a never before witnessed social phenomenon of people recovering from AIDS-related conditions. It was also a period when HIV monitoring technologies (the t-cell count and the viral load assay) became part of everyday living with HIV. By the use of monitoring technologies, the effectiveness of the treatments is made quantifiable and the health of people with HIV is made measurable. The effective treatments enabled
people to live with HIV, and disrupted the grim and predicable script of people dying from HIV infection.

The excitement, encouragement and hopefulness produced by the treatments made my subjective experiences of hearing stories from people who continue to struggle with the HIV confusing. I began this thesis with the anecdotal account of an individual with HIV who claimed that his experience with HIV was either “be alive or be happy”. I used this account because it typified some of the stories that I have heard in clinical, social and academic settings in which people with HIV narrated accounts of struggles and discomfort with adverse treatment side effects, despite their potential to prolong life. In this regard, the lived experiences of people with HIV and AIDS became of interest to me in my effort to understand the HIV and AIDS experience in the era when treatments were not only available but taken-for-granted in resource-rich countries such as Australia.

Four key questions guided this research study, and the argument in this thesis. These questions were articulated in Chapter One but for convenience, I will repeat them here. They are:

1) How do people with HIV in Sydney, Australia and who have had previous engagement with the HIV/AIDS sector, make sense of their lives and their illness experiences with HIV, in an era when effective treatments for HIV are available?
2) How do people in this group make sense of these treatments in their lived experiences with HIV?
3) How do people in this group negotiate the medicalisation of their lived experiences with HIV, especially the negotiation between doing what is best for them as medically constructed and what is best in terms of how life is subjectively constructed and meaningfully lived?

4) How do people in this group constitute a meaningful life in their everyday practices and experiences in the era of effective treatments?

In my endeavour to address these four key questions, in Chapter Two, I set the scene and provided the context in which this thesis is situated. I provided an account of the identification of the virus and its related condition and a brief history of HIV and AIDS from its discovery in 1981 to the period that I termed the post-treatment era. More relevantly, I discussed the social meanings embedded in HIV infection and the social implications and consequences of living with a “morally repugnant disease” (Miles, 1997, p.481). Whilst there is evidence to suggest that the treatments have produced previously unparalleled results in HIV management, in examining the profound and life saving changes in people’s lives, I noted the implications of treatment use by highlighting the adverse treatment side effects that many people with HIV have to negotiate and accommodate in their everyday lives. HIV medico-scientific discourses have positioned clinical markers obtained by monitoring technologies as means by which health is constructed in the post-treatment era; however, the privileging of the clinical markers as indicators of health produced a contest between the notion of health as medically constructed and as subjectively experienced by people with HIV. In this context, the concept of ‘quality of life’ was interrogated and I argued that it is the subjectively constructed meanings ascribed to this concept that enabled people to determine the quality of their lived experiences.
The notion of ‘quality of life’ or quality of lived experiences was an important focus for my argument. The subjectively constructed meanings embedded in the ‘quality of life’ concept were positioned as a way in which people make sense of lives in the post-treatment era. In spite of the fact that treatments have the potential to effectively treat HIV, they do not redress or resolve difficulties and issues experienced in the social domain.

In Chapters Three and Four, the methodological section of the thesis, I argued for the pertinence and utility of the theoretical framework and the research design that guided the study on which this thesis is based. The research adopted a postmodern epistemology, which privileges perspectivism and divergence of views (Iseke-Barnes, 1997), for there are multiple perspectives from which to understand any social phenomenon, such as the HIV illness experience. From this position, this research holds that there is not one reality but multiple realities in which people with HIV are living. The participants’ stories were positioned as rich materials with which to explore and to theorise the experiences of individuals living with HIV in the post-treatment era.

In Chapter Five, I addressed the first of the key questions by examining the ways in which people make sense of their lives and their illness experiences with HIV in an era when effective treatments are available. I did so by arguing that in order for people to make sense of their contemporary experiences with HIV, they drew on their past experiences as means by which they could compare and delineate the changes that have occurred since the construction of HIV as a chronic disease as a result of effective treatments. I examined stories of interruptions that HIV has caused.
in the lives of people with HIV and the changes they made in their efforts to adjust to the prospect of their lives being shortened as a result of HIV infection. The stories of interruptions were juxtaposed with the “live now, live today” and “a completely different life” stories as a way of illustrating that the life orientation in which people with HIV are now engaging is different to that when HIV was constructed as a fatal disease. It was argued that a significant implication resulting from effective HIV treatment and management was that people with HIV were positioned as having experienced two contradictory life orientations – from preparing for a shortened life to re-engaging with life and new possibilities. In this context, people with HIV are positioning themselves as having to negotiate the aging process; a process that they did not consider would be an issue before the effective treatments. One participant (Eric) narrated a story of having to plan for retirement by being financially secure, and to contend with the expectations and issues that people without HIV in mid-life would have had to deal with. From this perspective, I argued the effective treatments have made it possible for people to reflect and to make sense of their past and present experiences by which a productive future could be contemplated.

The opportunity to reconcile and to make sense of their experiences with HIV, as both a fatal and a chronic disease, and to contemplate or construct a productive future, was made possible by the availability of effective treatments. The constructed meanings participants ascribed to treatments were explored in Chapter Six, which addressed the second key question of how people make sense of treatments in their lived experiences with HIV. Notwithstanding the benefits that treatments could produce in achieving ‘healthy’ clinical markers in terms of high t-cell count and a low, or even undetectable, viral load, the adverse side effects associated with
treatments were a significant issue in individuals’ endeavours to make sense of their lives with HIV. The use of metaphors to make sense of treatments by positioning them as ‘life savers / restorers’, a ‘political / moral obligation’, ‘feared objects’, ‘necessary evils’, and a ‘safety net’ indicated the multiple and varied ways in which people with HIV negotiate treatment use. The different ways in which treatments were metaphorically positioned are the means people employed to make treatments subjectively meaningful and to engage with treatments in a manner that fits the ways they want to live in the post-treatment era. The importance of treatments in participants’ lives is evident by being positioned as ‘life savers or restorers’ and as a ‘safety net’ on which they could rely if and when treatment use became necessary.

However, there are adverse consequences to treatment use and these consequences were made visible by treatments being positioned as ‘feared objects’ and ‘necessary evils’. Furthermore, the positioning of treatments as a ‘political / moral obligation’ makes clear that treatment use has a social context. This context is important for it suggests that treatment use is informed by socio-cultural factors that are not only located within the context of health but also within the context of living with HIV as a medicalised experience. HIV medical discourses positioned individuals as being responsible for their health in that they were ‘obligated’ to take treatments for their infection. The act of resisting or contesting treatment use was positioned as irrational, for it defied accepted practices that were positioned as a means through which a ‘healthy’ state, as medically constructed, is produced. In the post-treatment era, people with HIV are positioned as medicalised subjects, as it is medico-scientific advances that would ensure their survival. However, the privileging of medico-scientific advances has implications for people’s lived experiences, as it is in their
lived experiences that the contestation between health as medically constructed, and health as subjectively experienced, is made most apparent.

The analysis of meanings ascribed to treatments led me to examine the medicalisation of living with HIV in Chapter Seven. It was also the chapter in which the third key question on how people with HIV negotiate the medicalisation of their lived experiences was addressed. The significant finding from the analysis of interview materials contained in this chapter is that in spite of the medico-scientific advances that have produced positive outcomes in HIV treatment and management, the benefits from treatment use and results from monitoring practices do not always reflect the subjective experiences of feeling good. The act of adhering to treatments in aiming to achieve ‘healthy’ results, but at the same time having to endure adverse treatment side effects, has caused some participants to question the utility of treatments as means to construct a subjectively meaningful and healthy life. The privileging of medical practices as means to achieve a healthy state has produced an emphasis on clinical markers and strict adherence to prescribed treatment regimens. The use of clinical markers and the assessment of an individual’s level of adherence to treatments were shown to be surveillance devices by which an individual’s behaviour is regulated. In this context, the individual is positioned as either responsible or irresponsible depending on his or her ability to adhere and to achieve the medically constructed ‘healthy’ numbers. In the everyday life of people with HIV, the issue of treatment adherence and being responsible is complex in terms of the manner in which life is lived as subjectively constructed and defined. One participant (Helen) provided a useful way to understand the way in which people with HIV negotiate between doing what is best for them as medically constructed,
and what is best in terms of how life is subjectively constructed and meaningfully lived. It was interpreted from this participant’s story that although treatment use has made it possible for her to be healthy within the paradigm of clinic markers, the benefits attained were subjectively evaluated with respect to how she feels. Thus, the endeavour of living a fulfilling life is not necessarily predicated on treatment use, for the lived experiences with HIV involve questions of meaningfulness in the life that is lived, which cannot be medicalised or resolved by medical advances and technologies.

The meaningfulness of life was examined in Chapter Eight, in which the key question of how people were able to constitute a meaningful life in their everyday practices and experiences was addressed. The interrogation of the ‘quality of life’ concept in Chapter Two was pertinent in this examination as it illustrated that the meaningfulness of life embedded in the ‘quality of life’ concept is crucial in understanding the way people make sense of their lived experiences. The shift in the life orientation of people with HIV since the emergence of effective treatments (Chapter Five), the multiple and varied ways in which treatments are positioned in people’s lived experiences (Chapter Six), and the awareness derived from appreciating that a satisfying life is achieved by both corporeal and psychological health (Chapter Seven) have enabled people to understand that the act of living with HIV in the post-treatment era is about living a meaningful and ethical life. For some participants, to locate a subjective meaningful explanation of their survival is to produce an ethical position through which existential satisfaction is achieved. Making sense of their survival through treatment use (an opportunity that was denied to others) was a way that people constructed meanings in their lives and life
experiences. The “de-sickenising” process that one participant (Lisa) highlighted as a result of improvement in her health and the moral quest of another participant (James) to live a “beautiful” life as detailed in Chapter Eight, suggest that the everyday life of people with HIV in the post-treatment era is affected and informed by the constructed meanings they ascribed to their extended longevity. It is about being ‘true’ to themselves and the recognition that the act of living with a chronic disease is about engaging with life positively and productively despite the uncertainty embedded in their illness experiences.

The length of time that the eight participants knew of their HIV seropositive status at the time of their interviews ranges from five years to seventeen years. One notable difference between participants who were diagnosed in the 1990s (James and Athena) when compared with the other participants who were diagnosed in the mid to late 1980s (Eric, Lisa, Ben, Helen, Dan and Steve) was in the way participants were positioned in relation to treatments. James and Athena were both diagnosed at the time when new treatments were about to be, or had just became, available and therefore the prospect of their HIV infection being strategically managed was a genuine possibility. In this context, both James and Athena were always positioned as people who could survive and live with HIV. This is in contrast to the experiences of the other participants, who were initially positioned as people who were unlikely to survive HIV, as they were expected to endure the disease progression into AIDS and ultimately, death. The expectation that people diagnosed in the 1980s would not survive HIV infection was exemplified by the stories of two participants – Steve and Dan (Chapter Five), who were positioned by themselves or by others as people who would die from the infection. This difference between James/Athena and others is
significant as it demonstrates the remarkable advances in HIV management and the way in which people were positioned in relation to HIV survival.

Notwithstanding the noted difference, there were many similarities in the lived experiences of the participants regardless of the length of time they have been diagnosed. All participants presented stories of the disruptions caused by HIV, which caused them to confront their shattered assumptions. In this context, HIV is a disruptive element to an individual’s life course, regardless of the length of diagnosis. In order to make sense of their HIV illness experiences, as illustrated by all the participants’ stories, they had to locate meanings in their experiences that enabled them to construct subjectively productive lives.

The analyses presented in Chapters Five to Eight constitute only one possible reading or interpretation of participants’ stories located in the interview materials. Informed by the postmodern epistemology which guided this research, it is not intended as an objective or universalistic account of the lived experiences of people with HIV in the post-treatment era. Rather, it has aimed to demonstrate that the ways people make sense of their illness experiences with HIV is multiply discursively constituted. By doing so, the analyses drew attention to the importance of subjectively constructed meanings, through the act of storytelling, as a useful device for understanding the different ways people make sense of the challenges, difficulties and complexities that are embedded in the HIV illness experience and which have caused profound changes in their lives. The participants’ stories were positioned as resources that helped and guided them through a period of changes not previously encountered in HIV history. Notwithstanding the individuality of participants’ stories, the
knowledge produced and insight gained from their stories could be useful for future research endeavours.

9.3 Implications of this Research

As noted in Chapter Two, many published research papers on HIV and AIDS begin by asserting that the advances made in treatments have reduced morbidity in a taken-for-granted manner. This implies that as a result of treatment availability there is an overall improvement in people’s health and thus their ‘quality of life’. Although the health of the body is important, in the course of the thesis, I argued that the notion of health needs to also encompass the quality of lived experiences as subjectively constituted and defined. There is evidence to suggest that mortality from HIV and AIDS related illnesses has decreased and stabilised since the availability of treatments; however, as I have also argued, people are continuing to be confronted by struggles, problems and challenging issues relating to HIV that undermine their subjectively constructed notion of ‘health’. Indeed, as one participant (Dan) suggested, the availability of treatments has produced new problems for which he was not prepared. Based on the analyses, HIV treatments could be argued as having reduced the incidence of HIV related illnesses, but the psychosocial implications of living with an incurable disease are ongoing issues with which people need to reconcile and negotiate. The implication is that HIV continues to be a disease that produces issues and concerns for some individuals, as the quality of their lived experiences is continuing to be affected by HIV, despite the diminished fear of mortality resulting from effective treatments.
Furthermore, as also noted in Chapter Two, some research studies implied that living with HIV is less complicated because, in spite of a clear definition, the ‘quality of life’ of people with HIV has improved as an outcome from treatment use. Again, some of the stories of participants in this study suggest otherwise, for they are continuing to negotiate, and to make sense of, the struggles and concerns embedded in the HIV illness experience. Informed by poststructuralist ideas on language, which contend that it is unstable and variable in meaning, it is important to be cautious about using ideas such as ‘an improvement in quality of life’ in an unproblematic way when exploring the lived experiences with HIV. The implication of using these ideas unproblematically is that they produce grand narratives about the lived experiences of people with HIV in a way that has the potential to marginalise the subjective experiences of people for whom HIV, and its related monitoring practices and treatments, continue to be issues of concern and causes of distress. In the course of this thesis, I have argued that some participants have been able to make sense of these issues of concern in ways that are subjectively meaningful and productive, and thus are able to engage with life in the post-treatment era positively. However, this should not be construed as an indication of a situation in which their concerns are addressed and resolved, for living with HIV is an ongoing struggle.

In light of the above discussion, my interrogation of the ‘quality of life’ concept (see Chapter Two) has contributed to an understanding of the implications associated with its use as an empirical measure. Notwithstanding its conceptual and definitional issues and difficulties, which have yet to be resolved, the concept has been used as an outcome measure in clinical trials for medication and healthcare interventions. The reification and quantification of ‘quality of life’ devalue the complexity of the
concept by privileging aspects of lived experiences that are measurable and quantifiable. The implication of this is that it repudiates the ‘existential’ aspects of lived experiences and thus weakens the philosophical underpinnings of the concept. It was in this context that I argued that the ‘quality of life’ concept is more useful when it is subjectively defined, for it is the subjectively constructed and ascribed meanings of the concept that are more useful in understanding individual lived experiences than its use as a tool with which to assess outcomes from treatment interventions. From this perspective, the quality of lived experiences in the post-treatment era for people with HIV is predicated on their subjective evaluation of what makes life worthwhile, particularly when it has been suggested that people with HIV have to balance “the (side) effects of treatments against quality of life” (Grierson, Misson, McDonald, Pitts, & O’Brien, 2002, p.xvii, my italics). The story of one participant (Lisa) in Chapter Eight highlighted the need for existential satisfaction as much as the need for corporeal satisfaction, and she suggested that her extended life through treatment use was meaningful when she could lead a preferred and desired life(style). The implication of this research, and what I hope to have contributed, is that the notion of health is multiple and varied, and it is partly subjectively constituted. The way health is positioned in medical discourses only offers a partial understanding of what it means to have ‘good health’. In the context of the ongoing HIV illness experience, the subjectively constructed notion of health is not only premised on having a ‘healthy’ body but also to live a ‘healthy’ life.

From a personal perspective, I argue the research findings have an implication for healthcare workers in HIV clinical settings. In Chapter Two where I presented my story with HIV, I discussed my unease when I worked people with HIV in a clinical
setting who expressed ambivalence or even indifference about the longevity extended to them as a result of treatment use. The implication here was that people with HIV were positioned as, or expected to be, ‘happy’ and ‘grateful’ for their prolonged lives when their lived experiences were filled with challenges and difficulties. Informed by the research process and the opportunity to hear personal stories of lived experiences with HIV, it seems to me that an important consideration for clinicians when addressing complex, ‘messy’ and confronting issues relating to HIV is their willingness, as well as their abilities, to work with seemingly contradictory and confusing stories. As my experience indicated, my subjectivity and subjective experiences with HIV affected the way I engaged with my clients’ stories of difficulties experienced in the post-treatment era. Drawing on findings from this research, it is evident that people are capable of providing accounts of their experiences that can be interpreted as contradictory to, or inconsistent with, dominant socio-cultural discourses and value systems; for example, the act of contesting or resisting the use of treatments that could treat HIV and ensure survival. In this context, clinical proficiency could be enhanced by being aware of the issues embedded in living with HIV in the post-treatment era, for example, effective medical management does not always lead to an improved ‘quality of life’ given there are adverse side effects. By being aware of these issues, clinicians might encourage their clients with HIV to reflect, explore and make sense of their experiences in ways that are subjectively meaningful, and in turn, enable them to assist their clients to negotiate these issues effectively.

Furthermore, the awareness of issues for people with HIV in the post-treatment era could also be extended to clinical work with partners or carers of people with HIV.
Partners and carers of people with HIV are also affected by the changes that have occurred in HIV treatment and management. One participant (Eric) discussed the implications of him having a prolonged life on his partner with whom he was planning to buy a house while another participant (Helen) explored the changes in her family life. In this context, HIV-related issues in the post-treatment era are not only pertinent to people with HIV but also to people who are significant in their lives. The needs and issues for carers and partners of people with HIV in the post-treatment era could be topics for future research.

9.4 Methodological Implications

In the methodology chapters (Chapters Three and Four), I discussed the advantages associated with qualitative research methodology informed by postmodern epistemology in exploring the lived experiences of people with HIV. The use of qualitative research methodology made it possible for me to explore meanings by placing people’s interpretative processes at the centre of the inquiry, and thus enabled me to elucidate the complexities embedded in the HIV illness experience, and to explore how these complexities are negotiated by identifying the multiple and varied ways in which people made sense of, and provided subjectively constructed meanings to, their experiences. I am aware that qualitative methodology has been criticised for the subjective nature of its data collection and analysis (Gubrium & Holstein, 1999; Kvale, 1989), however, it could also be argued that in order to understand subjective illness experiences, we have to discern meanings and interpretations that people construct and ascribe to their unique experiences. It is in the ‘hearing’ of individual stories, which in turn requires uncovering, unravelling,
understanding and explaining of these stories, that, as a researcher, clarity is gained, and through which knowledge is produced. Moreover, as discussed in Chapter Four, although the participant group comprised of only eight people with HIV, the size of the group enabled me to perform intensive analysis of the rich and nuanced materials, which in turn provided an insightful understanding of the lived experiences with HIV in the post-treatment era. From this perspective, the knowledge produced and lesson learned from this research could be used to analyse and draw attention to issues that are pertinent to people with HIV who did not participate in this research. Furthermore, although this research specifically examined the HIV illness experience, I contend that the research findings can inform research into other forms of chronic and potentially life threatening illness (e.g., cancer) as they are about the negotiated understanding of health, illness and the quality of lived experiences.

By conducting the research using a qualitative methodology, the significance of the intersubjective space in which stories are constructed was also highlighted. Riessman (2004b) argued that a research interview is where a “teller convinces a listener who wasn’t there that certain events ‘happened’, (and) that the teller was affected by them” (p.371). Utilising face-to-face interviews to collect research materials is an effective method and the stories produced during the interviews are reflective of the relationships between the participants and the interviewer. I would argue my subjectivity as a gay man, a person who has experiences loss due to AIDS and a clinician who has worked with people with HIV for over fifteen years made it possible for me to establish productive relationships and rapport with the research participants. The rapport that is required in order to have a productive interview and
the effect that rapport has in the interview process were made apparent to me with
all, but especially with two, of the research participants. I want to highlight the
experiences I had with these two participants – Steve and Lisa – to illustrate my
point.

At the end of the first interview when Steve was offered the opportunity to debrief, to
cомment on the interview process, and to raise any issue of concern, he identified
the import of my responses, both verbal and non-verbal, in the construction of his
story. He specifically noted the use of his “self-fulfilling prophecy” as an example to
highlight the pertinence of my responses in his decision to continue with the telling
of this story. Steve was aware of the way in which he could be positioned as a
consequence of his idea, for he acknowledged that “this can sound a little bit airy-
fairy”. However, he said he decided to continue (a process which was invisible to
me) because my responses provided encouragement and a sense of safety for him to
pursue an idea that could be positioned as being peculiar. I expect that this
experience with Steve, on one level, is not unusual in that issues pertaining to rapport
with, and respect for, research participants are (or at least, should be) expectations
and standard practices for any researcher. However, it could be argued that if these
practices were not followed, important stories, such as Steve’s example, could be
silenced. This point was emphasised to me by Steve during the debriefing time when
he made clear that he would not have continued with this story if he had not been
given encouragement to do so or if he had inferred impertinence in my responses.

The other implication from this experience with Steve is that it emphasised the
theoretical position that stories people tell are social constructions as argued in
Chapter Three, for they are produced in an intersubjective space through a joint
effort between the interviewer and the interviewee. In Steve’s example, the joint
effort was made visible by Steve wanting to narrate a particular story, and my
explicit encouragement (supportive comments) and my implicit encouragement (non-
verbal behaviours or cues) that he positioned as being important in his narration. If I
had not made a comment or non-verbally responded in a way that was positively
interpreted by Steve, it could be argued that an alternative story would have emerged
in place of the one that was narrated. Would the alternative story be more informing
or more interesting than the one Steve offered with respect to the research aim?
Clearly it is not a question that can be answered. Indeed, whether or not the
alternative story is more informing or interesting is secondary to the issue of interest
here, that is, the story produced was the one that was available in the particular
context when the interview was conducted, which highlights the notion that stories
are temporally and socially situated.

Lisa was the participant who instigated a third interview and, as I noted in Chapter
Four, the reason she offered for wanting another interview was to have the
opportunity to further expand and clarify issues pertaining to the research. In this
third interview, it was interesting for me to learn from Lisa that the interviews, and
the process of participating in a series of interviews, offered her not only the
opportunity to clarify her ideas about the experiences of living with HIV but was
crucial in her ongoing effort to make sense of her life with HIV, for it was a space in
which another person bore witness to her life and experiences. The presence of a
listener to her story was important, for the listener was positioned by Lisa as a reason
for her to construct a story through which her lived experiences and meanings to
these experiences were articulated. From this perspective, it could be argued that, for
Lisa, a “particular self is constituted through these narratives, occasioned by the presence of a listener, her questions and comments” (Riessman, 2004b, p.371).

Kvale (1996) examined the implications of individuals participating in research interviews and suggested that a research interview could approximate a therapeutic interview in that a “quasi-therapeutic relationship my be promoted through long and repeated interviews with the same subject, where a close personal rapport may develop” (p.155). The possibility of a research interview developing into a therapeutic one should be taken into account in the research design; however, if the interview topics encompass personal and emotional issues that require participants to explore, consider and reflect, as was the case in this research, it is therefore imperative that the interviewer is clear and confident about the purposes and the aims of the interviews. My experiences with Lisa made me aware of the importance of the interview situation whereby it was positioned by Lisa as a device to not only make sense of her experiences but also to validate her experiences.

I want to suggest one methodological issue for inclusion in future research endeavours in light of my experiences and lessons learned from this research. Although I discussed with the participants the content of their interviews, my ideas about the themes and issues identified, and incorporated their ideas during the coding phase (see Chapter Four), I did not share with them my formal analysis. On reflection, my research would have benefited and been enhanced by presenting my preliminary analysis to the participants, and incorporating their feedback and comments back into my analysis as part of the research design. If I had done so, I
contend my analysis would have been influenced by their comments and that I would have been able to offer greater clarity in reflecting their experiences.

9.5 Present Research Limitations and Directions for Future Research

In spite of achieving the research aim, there are some limitations to this thesis and a number of questions raised that might warrant further research.

I discussed in Section 4.3 the size of the sample or participant group in the research and argued that in qualitative research endeavours, the question of the participant group size is a contestable issue and raised a number of issues when determining the participant group size. Although I presented an argument for having a small participant group that was informed by academic research literature, an important issue that needs to be considered is whether or not the participant group reflects a range of people with HIV living in Sydney. In this context, it is important to consider the representativeness of the participants in terms of the research questions. In considering this issue, I need to take into account the procedure and strategies employed in recruiting potential research participants.

It should be noted that the strategy by which participants were recruited yielded a particular sample of people with HIV living in Sydney. The recruitment process of using a purposive sampling approach and the ‘snow-balling’ strategy resulted in only a small section of the Sydney HIV population being approached and contacted (see Section 4.4.2). The ‘snow-balling’ strategy, which included professional colleagues of mine who worked in the HIV sector, meant that people who have no contact with
HIV support or community services might not have been approached. Moreover, the ‘snow-balling’ strategy was reliant on people who were aware of the research project to contact people they knew, which meant that people who were contacted and who eventually became research participants were from a limited number of social networks. This would have an impact on the research findings, for Fisher et al. (2006) noted, people recruited by different strategies and from different sub-groups within the same population (e.g. people with HIV) can produce different research findings. This suggests that the participant group could lack variety with respect to the HIV population in Sydney and thus limit the extent to which the results can be extrapolated beyond this group.

Another issue that I want to discuss with respect to the nature of the participant group is that although none of the eight participants specified the culture with which they most identified, their first language is English. There was one participant (Eric) who was born in a non-English speaking country but has parents whom he identified as English, and lived in England since childhood before migrating to Australia. Another participant (Athena) was born in an English-speaking country in Africa to English parents, but has lived in Australia since childhood. In this context, it could be argued that the participant group lacked cultural diversity and therefore cultural issues relating to HIV in an Australian context were neither raised nor explored.

Furthermore, all eight participants lived in the inner city suburbs of Sydney when they were first interviewed, which means that the stories they narrated were illustrative of people with HIV living in an urban area and so reflect a specific group within the HIV population. This issue could be important, for information and specific services for people with HIV in urban areas of Sydney are more available.
and accessible than for people living in rural areas. From this perspective, I wonder how the stories of people with HIV who do not identify as Anglo-Australian or people living in rural areas of Australia would be different, or similar, to the stories of the people who participated in this research.

Another issue relating to the composition of the participant group is that, despite the concerns and uncertainties relating to adverse treatment side effects raised by the participants, none of them reported failing health or that they were confronting immediate mortality; three participants (Helen, James and Athena) had chosen not to use treatments for they positioned their level of health as being subjectively acceptable or ‘healthy’. The implication is that the stories they narrated were informed by the knowledge that their health was stable and thus they were able to consider and explore how they would construct a productive future. In this context, I wonder if I had interviewed people for whom the treatments had not worked, or for whom the adverse side effects were so severe that they could not be used even when they are needed in order to avert failing health (see Chapter Two), how different their stories would be or what form their narratives would take when compared with the stories of the eight participants interviewed.

Subjective experiences with HIV and the subjectively constructed meanings ascribed to these experiences are shaped by socio-cultural forces. The discourses on which people draw to make sense of their lives through the stories they tell are influenced by the social and cultural contexts in which they are positioned. From this perspective, the issues I noted in the composition of the participant group would suggest that there is a need for future researchers to specifically target people with
HIV from different cultural backgrounds, people with HIV living in non-urban areas and people with HIV for whom the treatments have not been effective in order to further develop our understanding of people’s lived experiences with HIV in the post-treatment era.

In conclusion, in order to assess whether the findings of this study can be extrapolated beyond the specific population studied, further research using a broader population is needed. This should include people who are at different stages of health, people from different social and cultural backgrounds and people who have had no or limited engagement with HIV services.

9.5.1 Where to From Here?

HIV related issues are always changing. The history of HIV has illustrated that, for some people, the issues and concerns they face in the new millennium are different to those they faced in the late 1980s and early 1990s. For this reason, a possible limitation of this research is that the stories collected were from interviews that were conducted between 1999 and 2003, which means that the stories are at least three years old. The reason why I regard this to be a possible limitation is that changes are constantly occurring in the area of HIV in terms of medico-scientific advances, and issues for people in their endeavours to make sense of their lives with HIV and their ongoing negotiation with difficulties embedded in their lived experiences are informed and affected by these changes. At the time of writing this thesis, research into new drug developments for HIV where three widely prescribed HIV drugs are combined into one pill (Frampton & Croom, 2006; Hampton, 2006), and research
into the ongoing effectiveness of treatments in attacking HIV located in different parts of the body (Guadalupe et al., 2006) are constantly producing a ‘shifting ground’ for people with HIV. Living with HIV “is a process of self-reconstruction, of becoming, of realizing oneself in a cultural environment of constantly shifting constructions of illness” (Ariss, 1997, p.55). In this context, the participants’ narrated stories on their HIV illness experiences during the period between 1999 and 2003 could arguably be different to stories they would narrate if they were invited to do so in 2006. The currency of participants’ stories is not problematic, for their stories were reflections of the temporal, socio-cultural and medico-scientific contexts in which they lived; however, my effort in highlighting this issue is to encourage further research into the lived experiences of people with HIV given that people’s experiences are likely to change in accordance with changes in HIV medical sciences.

Despite the benefits of the methodological approach taken which include the facility of interviewing participants more than once, building up relationships with participants, and drawing on research materials from two interviews, there are inherent limitations to the approach that I now want to examine, as well as discussing alternative research methodologies that could address these issues.

In retrospect, it would have been advantageous to position this research as a longitudinal study whereby new issues could be introduced and explored in the follow-up interviews, in order to specifically examine consistencies and changes in participants’ stories over time. The limits that were placed around the follow-up interviews as described in Chapter Four became constraints to what these interviews
could provide. In this context, the research design of this present study could have been improved by positioning the follow-up interviews as ‘new’ interviews with the same participants. Moreover, the present study employed semi-structured in-depth interviews and even though this approach to interviewing provided a ‘space’ in which participants were able to articulate subjectively meaningful issues and concerns, they were also limited by the research issues that had to be covered. In this regard, an unstructured in-depth interview approach could have been useful in allowing participants to raise issues that are particular to their lived experiences with HIV in the post-treatment era.

I have previously discussed the limitations of the research participants group, in that it was comprised of a particular section of the HIV population. Although the present research produced informative findings with regards to the lived experiences of people with HIV living in Sydney, it is based on a small sample group which could limit the potential of findings from this research being generalised to the wider population of people with HIV, not only in Sydney, but in other parts of the country and indeed to other parts of the world. In this context, the applicability of the findings of this research to other populations is a question that needs to be asked. As noted previously, future research endeavours on the ways in which people with HIV negotiate treatment use and quality of life need to include a wider range of people from different backgrounds.

Equally, large scale studies with representative participant groups that utilise a mixed method approach would facilitate generalisability of research findings. This could include a combination of both quantitative and qualitative methods, such as
standardised questionnaires, focus groups and individual interviews. A mixed method approach has the advantages of being able to expand the scope of the research, exploring the complexity embedded in the research topic through different strategies, as well as the extent to which the findings can be generalised across populations.

Large scale studies, such as epidemiological research that aims to investigate determinants of health and make use of both experimental and non-experimental designs, could draw on findings from this research to further explore issues pertaining to the construction of health, wellbeing and treatment decision, as well as the implications adverse treatment side effects have on the quality of people for whom treatments are deemed appropriate and necessary. Large scale studies of people with HIV from different backgrounds would provide the opportunity to examine differences across groups based on factors such as, age, gender, sexuality, current health status, the length of diagnosis and previous or no engagement with HIV services or organisations. In terms of adherence or resistance to treatment use, which was a major focus of the present study, a population group that was not involved but which could have provided valuable information is HIV health care workers (e.g. nurses, mental health workers). Although findings from research that included health care workers informed this research enterprise, conducting in-depth interviews with them or for them to complete standardised questionnaires on issues relating to the research questions could have enhanced the quality of the findings. Furthermore, the advantage of including health care workers in the research is that the findings could be useful for this group of people in their service delivery and provision to people with HIV. This is particularly pertinent in the treatment
adherence issue as the research findings could provide health care workers a different way of working with people with HIV by understanding their subjective experiences with treatment use.

9.6 Concluding Remarks

As my thesis title indicates, it is about the “Lazarus Experience”, an exploration into the lived experiences of people with HIV for whom a shortened life from HIV infection was a likely outcome until the mid 1990s when medico-scientific advances produced profound and inspiring changes. In completing this thesis, I am now able to understand and appreciate the man who reflected on his experience in the post-treatment era as either “be alive or be happy” when it is contextualised within the complex and uncertain issues that people with HIV are continuing to face in their efforts to construct a productive future. What I hope I have contributed through this research is to draw attention to the needs and issues of people with HIV in their ongoing negotiation with a disease for which there is no cure. The interminable vulnerability of people to HIV and AIDS was made apparent during the course of this research when I learned of Lisa’s death. I was troubled and distressed by her death because the challenges she faced and the efforts she made in overcoming these challenges, as illustrated by her stories, were undermined by what was suspected to be an AIDS-related condition\(^1\). Although a productive future is now positioned as being available and people have identified ways in which their lives are made

\(^1\) I learned of the possible cause to her death from a conversation I had with one of Lisa’s friends without disclosing her involvement in this research.
subjectively meaningful, Lisa’s death illustrates the precariousness of living with a
disease that clearly remains to be fatal despite its construction as a chronic disease.
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