Understanding quality of life through Sen's capability framework: An application to people living with HIV/AIDS

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Declaration

The research reported in this thesis is my own
and has not been submitted for a higher degree
at any other university

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Dedication

This thesis is dedicated to my children, Gabriel and Isabella.

Thesis abstract

It is nearly 30 years ago that the Acquired Immune Deficiency Syndrome (AIDS) epidemic officially started. In 2008 an estimated total of 33.4 million people lived worldwide with Human Immunodeficiency Virus (HIV), the virus that causes AIDS. Despite the fact that there is still no cure or vaccine for the HIV virus, important progress has been achieved in treatment for people living with HIV/AIDS (PLWHA) since the mid-1990s, when Highly-Active Antiretroviral Therapy (HAART) was introduced. HAART has proved successful in reducing AIDS-related morbidity and mortality and, therefore, prolonging the life expectancy of PLWHA. In Western democracies such as Australia, HIV/AIDS is considered as a chronic disease that can be managed by most people with the help of regular medical monitoring, adherence to treatment, and access to medical care.

The substantial clinical changes observed since the introduction of HAART open a series of important questions regarding the quality of life of PLWHA. The current quality of life research on PLWHA consist primarily of health related quality of life studies (HRQOL), which investigate the subjective perceptions of PLWHA regarding the impact of their health status, disease, impairment, disability, or treatment primarily on their physical, mental/cognitive, and social functioning. This type of study has received several criticisms, for example the fact of confusing quality of life with perceived health. Another important limit of HRQOL studies is that they focus on PLWHA as patients or clinical cases, rather than as social actors with individual, social and economic rights experiencing freedoms and constraints to fulfil valued social roles and achieve desired social statuses. Lack of research on the experiences of PLWHA as social actors is regrettable because it would offer social scientists and social policy makers relevant information to identify health and social inequalities among PLWHA and to generate a broader and more insightful understanding of their quality of life.

This thesis sets out to address these latter questions by introducing a complementary approach to the investigation of the quality of life of PLWHA known as the ‘capability framework’, which was founded by the economist and philosopher Amartya Sen. This framework suggests that quality of life should be measured by focusing on people’s capabilities, namely their real opportunities to lead the life that they have reason to value. The thesis introduces the capability framework by discussing it in the wider debate around the concept of quality of life. It addresses the operationalisation of its core concept, capabilities, founding it in Sen’s epistemological perspective, ‘positional objectivity’, which is interpreted as a constructivist approach. This is expanded by placing it in a more inclusive and developed constructivist framework, the phenomenological sociology of Alfred Schütz, which requires exploring and making explicit the model of social actor that underpins the operationalisation and measurement of any social science concept. Consequently, the psychological and sociological literature that has investigated the phenomenon of opportunities is reviewed to identify the cognitive, emotional, and meaning-making processes that underpin people’s perception of opportunities. These analyses led to the development of a threefold model of the main components of people’s perception of opportunities and a fourfold model of experiences of opportunities. Both models are empirically tested through a mixed method investigation based on a concurrent nested strategy. The quantitative analysis operationalised the models through a secondary data analysis of the HIV Futures V Survey, an Australian nationwide survey of various clinical and social aspects of the lives of PLWHA. The qualitative analysis explored the factors affecting the perception of opportunities in 29 PLWHA of different socio economic background. The relevance of the results of both analyses to understand the quality of life of PLWHA is discussed against alternative measures and conceptualisations of quality of life.

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INTRODUCTION

It is nearly 30 years ago that the Acquired Immune Deficiency Syndrome (AIDS) epidemic officially started (Klimas, Koneru, O'Brien, & Fletcher, 2008). General awareness of this disease is usually dated back to a report on the occurrence, without identifiable causes, of a rare lung infection (Pneumocystis carinii pneumonia) in five young homosexual men living in Los Angeles, USA, which was published in June 1981 by the Centres for Disease Control in Atlanta (CDC, 1981). The disease was officially named AIDS only one year later, in the summer of 1982. By then a total of 452 cases, from 23 US states, were reported to the CDC and separate reports of the disease occurring in European and African countries were published (Avert, 2010). In 1982 AIDS appeared in Australia too (Whyte, Gold, & Cooper, 1987). From 1981, AIDS-related illnesses have become one of the leading causes of death globally and they are projected to continue as a significant global cause of premature mortality in the coming decades (UNAIDS, 2009). In 2008 an estimated total of 33,4 million men, women, and children under 15 years lived worldwide with Human Immunodeficiency Virus (HIV), the virus that causes AIDS (UNAIDS, 2009). Sub-Saharan Africa is the world region most affected by HIV, comprising over two thirds (71%) of all new infections in 2008 (UNAIDS, 2009). In Australia, to 31 December 2008, an estimated 28,330 people had been diagnosed with HIV infection, 10,348 diagnosed with AIDS, and 6,765 had died (National Centre in HIV Epidemiology and Clinical Research, 2009). Overall, HIV prevalence and epidemiological patterns vary considerably globally and within countries (UNAIDS, 2009).

Despite the fact that there is still no cure or vaccine for the HIV virus, important progress has been achieved in treatment for people living with HIV/AIDS (from here onwards PLWHA) since the mid-1990s, when Highly-Active Antiretroviral Therapy

(HAART) was introduced (Montaner et al., 2010). This therapy consists of a combination of three or more antiretroviral drugs, which are the main type of treatment for HIV/AIDS. HAART has proved successful in slowing the progression of HIV-related conditions and, therefore, prolonging the life expectancy of PLWHA by dramatically contributing to reduce AIDS-related morbidity and mortality (UNAIDS, 2009). However, access to these therapies varies greatly across and within region and countries, determining a very diverse picture of epidemiological patterns across the globe.

In Western democracies, the important and continual advancements in treatments and access to therapies for PLWHA have led to the definition of HIV as a chronic condition (Clarke, 1994). As such, HIV/AIDS is considered as a disease that can be managed by most people with the help of regular medical monitoring, adherence to treatment, and access to medical care (Aidala, Lee, Abramson, Messeri, & Siegler, 2007).

The impact of chronic illness on people's lives and the role of the chronically ill in society have been long debated by sociologists (e.g. Bury, 1982; Freidson, 1970/1988). From a functionalist perspective, it has been suggested that there is no simple role prescription, such as the 'sick role' for acute and temporary illnesses (Parsons, 1964), for people living with chronic conditions (see Bury, 1988). Research based on grounded theory, and so on a symbolic interactionist perspective, has suggested that the experience of chronic conditions is characterised by major uncertainty, which is caused by the disruption of people's every day taken-for-granted assumptions, behaviours and explanatory frameworks (Williams, 2000). As a result, chronic condition has been conceptualised as a "biographical disruption" in people's lives (e.g. Bury, 1982). However, several studies have shown that such biographical disruption can be moderated by factors such as class, age, but also previous experiences.

In particular, especially in older age (Bury, 1997; Bury & Holme, 1991) and amongst disadvantaged segments of society (Cornwell, 1984; Pound, Gompertz, & Ebrahim, 1998), chronic conditions can be perceived as something to be expected, and so have 'biographical continuing' rather than 'biographical disruptive' effects. Carricaburu and Pierret (1995) showed that men who acquired HIV as a result of unsafe sex experienced biographical disruption, whereas men who had lived with haemophilia all their life and acquired HIV through blood infection experienced 'biographical reinforcement'. Finally, some scholars have pointed out that late-modernity and life in Western societies are already characterised by major forms of uncertainty. Consequently, they suggest that chronic conditions may not represent much of a disruption in these contexts, at least comparatively to their experience in different social contexts and times (e.g. Giddens, 1991; Kelly & Field, 1998).

The complexity of the factors involved in defining the experiences of the chronically ill, the controversial conceptualisation of chronic illness in the context of late modernity and Western societies, and its non-unidirectional effects on people's lives open a series of important questions regarding the quality of life of PLWHA. In particular, they suggest the importance of investigating the actual experiences of PLWHA to engage with the prospects that the continual advancements in treatments and access to therapies generates for them, for example returning to work and, more generally, living a fully integrated social life. Specific issues also arise in relation to the possibilities of PLWHA to access treatments for HIV/AIDS, particularly in developing countries. These questions and the analytical complexities tied to the variety of groups and geographical contexts in which PLWHA live would suggest the need to address them using an inclusive perspective that focuses on the social needs and possibilities of PLWHA. However, current quality of life research on PLWHA consist primarily of health related quality of life studies, which investigate the subjective perceptions of

PLWHA regarding the impact of their health status, disease, impairment, disability, or treatment on their physical, mental/cognitive, and social functioning. As such, health-related quality of life tools are primarily used as outcome measures in clinical research, where they are now widely adopted (Shumaker, Ellis, & Naughton, 1997). Despite their widespread use in clinical settings, health-related quality of life measures have been criticised on a variety of grounds. For example, they have been criticised for confusing perceived health with quality of life (Moons, 2004), and for introducing an artificial distinction between parts of life of PLWHA that are influenced by their health issues and parts that are not (e.g. Hunt, 1995, 1997). In particular, such an over-emphasis on the impact of health status on people's quality of life leads to a consideration of health as the most important determinant of people's quality of life whilst diminishing the importance and role of people's living environments (Holmes, 2005; Hunt, 1997). Here, another criticism is raised; health-related quality of life implies a focus on PLWHA primarily as patients or clinical cases, rather than as social actors with individual, social and economic rights experiencing freedoms and constraints to fulfil valued social roles and achieve desired social statuses. Lack of research on the experiences of PLWHA as social actors is regrettable, because it would offer the kind of information needed by social scientists and, ultimately, by social policy makers, to identify and address health and social inequalities in this population. It would therefore help to generate a broader and more insightful understanding of the quality of life of PLWHA.

This thesis sets out to address this latter question by introducing a complementary approach to the investigation of the quality of life of PLWHA known as the 'capability framework', which was founded by the economist and philosopher Amartya Sen. The capability framework was originally developed in the context of the examination of social inequalities (Sen, 1980). Afterwards, in the course of years (Sen, 1985a, 1990, 1992, 1999), Sen has attempted to show the cogency of the notion of

capability also for evaluating other social questions, including quality of life (Sen, 1993a).

The capability framework suggests that quality of life should be measured by focusing on people's capabilities, namely their real opportunities to lead the life that they have reason to value. It criticizes approaches to the measurement of quality of life exclusively based on resources, such as income or, as in the case of health-related quality of life, health status, and mental states, such as satisfaction, happiness, and desire fulfilment. It shows that, in different ways, such approaches fail to provide comprehensive accounts of people's quality of life.

The thesis discusses the capability framework in the wider debate around the concept of quality of life and applies it to investigate some dimensions of the quality of life of PLWHA. To this end, it addresses the operationalisation of its core concept, capabilities, founding it in Sen's epistemological perspective, 'positional objectivity' (Sen, 1993b, 1994). This implies that observations, in the widest sense of this expression – therefore including observations of signs and symbols – can be considered objective in so far as they are accessible to and understandable by others once an extensive specification of the circumstances and mental states that led to them is provided. In this study, it is suggested that Sen's (1993, 1994) positional objectivity perspective can be best understood as an interpretivist epistemological approach. Interpretivist epistemologies share the view that social action is inherently meaningful. This entails that social action has an intentional content that says the kind of action it is and that to understand such an intentional content it is necessary to refer to the system of meanings that generated it (Schwandt, 2000). Consequently, it is proposed that the concept of positional objectivity can be expanded and strengthened by placing it in a more inclusive and developed interpretative framework, which is identified in the phenomenological sociology of Alfred Schütz (1962a, 1972). The main strength of this

phenomenological approach is the fact that it offers a well-developed, although not complete, philosophical and theoretical exploration of the main structures and of the mechanisms that govern people's perceptions in their 'world of daily life', which is called 'life-world' (Schütz, 1962a, 1972; Schütz & Luckmann, 1973). People's life-world is the cognitive and subjective place where the external environment and the others are perceived, so where opportunities, barriers, disadvantage, etc. are experienced. At the epistemological and methodological level, Schütz's phenomenological sociology requires exploring and making explicit the model of social actor that underpins the operationalisation and measurement of any social science concept (Cicourel, 1964), in this case people's opportunities. In other words, it requires making explicit the mechanisms and structures that the social scientist assumes govern the perceptions of social actors in the life-world, with a particular reference to the object being investigated (Giuntoli, 2001; Venturini, 2005). Consequently, the psychological and sociological literature that has investigated the phenomenon of opportunities is reviewed to identify the cognitive, emotional, and meaning-making processes that underpin people's perception of opportunities. These analyses have led to the development of a threefold model of the main components of people's perception of opportunities, and a fourfold model of experiences of opportunities.

A mixed methods nested triangulation strategy (Creswell, 2003) is used to operationalise and empirically test the suggested models (quantitative data), and to further expand the reflection and understanding around the factors that could hinder or help to pursue opportunities among PLWHA (qualitative data). A concurrent nested strategy is characterised by three main characteristics (Creswell, 2003):

- There is no sequence in the implementation of the quantitative and qualitative data collections; they are concurrent, which implies limited interaction between the two datasets during the data collection (Morse,

1991). The quantitative element of this study consists of a secondary data analysis, the data set for which existed and could be accessed at the same time at which the qualitative data analysis was collected and analysed.

- It has a predominant method that guides the project and another that is given less priority and which is nested or embedded within the predominant method. Unlike traditional triangulation, which uses two different methods to cross-validate findings within a single study, nesting implies that the embedded method addresses a different research question than the dominant method or that it seeks information from different levels (Creswell, 2003). In this study, considering that the suggested models of perceived and experienced opportunities offer a priori theoretical frameworks from which research questions and testable hypotheses can be deductively created, the priority is given to the quantitative method (see Morse, 1991). The quantitative method offers an operationalisation of the suggested models of perceived and experienced opportunities through a secondary data analysis of the HIV Futures V Survey, an Australian nationwide survey of various clinical and social aspects of the lives of PLWHA (Grierson, Thorpe, & Pitts, 2006). The qualitative analysis addresses a different, complementary question compared to the secondary data analysis. It aims to explore the lived world of a sample of 29 PLWHA of different socio economic backgrounds in relation to their perceptions of the factors that helped or hindered their experiences of some specific personal and social opportunities. In particular, the data collection and analysis are informed by a thematic approach.

- The quantitative and qualitative components of the study are integrated at the stage of data analysis.

An overview of the thesis chapters is now offered in order to explain the structure of the research project and provide more details on its specific stages.

Chapter I. The first chapter offers a review of the literature on the concept of quality of life that sets the ground for a better understanding of how the capability framework approach to quality of life is positioned in the wider debate on the measurement of this construct. To this end, an historical overview of the development of quality of life in the medical and social sciences literature is offered, followed by a discussion on its definitions and conceptualisations. A particular focus is then given to the measurement of quality of life in PLWHA.

The function of the historical overview is to complement the more theoretical discussions on the definitions and conceptualisations of quality of life by offering an understanding of their origins. It also helps to achieve a better understanding of the origins and of the extent of the overlapping of the concept of quality of life with other relevant concepts such as subjective well-being, happiness, satisfaction, and health.

Chapter II. Chapter II introduces the capability framework by discussing it in the wider debate around the concept of quality of life. It addresses the operationalisation of its core concept, capabilities, founding it in Sen's epistemological perspective, 'positional objectivity', which is interpreted as an interpretivist perspective. This is then expanded by placing it in a more inclusive and developed interpretivist framework, the phenomenological sociology of Alfred Schütz, which requires that any operationalisation of social concepts make explicit the model of the actor on which they are based. This requires addressing the following question: what are the meaning components of the experience of capabilities?

Chapter III. Chapter III addresses the above question by reviewing the psychological and sociological literature that have explored the meaning-making processes involved in people's self evaluation of their own opportunities. These analyses led to propose two models; a threefold model of the main components of people's perception of opportunities, i.e. opportunity availability, opportunity achievability, and opportunity saliency, and a fourfold model of experiences of opportunities, i.e. high capability, low capability, availability disadvantage, and achievability disadvantage.

Chapter IV. Chapter IV offers a first operationalisation of the threefold model of perceived opportunities and of the fourfold model of experienced opportunities. This is achieved by using indicators on housing experiences from the HIV Futures V Survey. The objectives of the analysis are to check the distribution of both the three components of people's perception of opportunities and of the four types of experiences of opportunities in the HIV Futures V sample, and to compare the four experiences of opportunity for adequate housing to alternative, existing indexes of housing.

Chapter V. Chapter V offers a second application of the fourfold model of perceived opportunities. In particular, it checks whether it predicts self-reported well-being after controlling for socio economic, health, cognitive, and behavioural factors. Also, it checks the relationship of the four experiences of the opportunity to enjoy adequate housing with measures of poverty.

Chapter VI. Chapter VI offers an operationalisation of the threefold model of perceived opportunities in relation to the possibility to return to work of PLWHA. In particular, its objectives are to explore whether PLWHA who intended to return to work were in a situation of advantage or disadvantage compared to those who did not intend to return to work. A position of advantage is when there are significantly more respondents who intend to return to work among those having the demographic, socio-

economic, and health factors associated with successful return to work. On the other hand, a position of disadvantage is found if there are significantly fewer.

Chapter VII. Chapter VII offers an analysis of the cognitive and social factors that characterize the perception of opportunities in a sample of PLWHA. This analysis is based on a series of 29 semi-structured interviews that were conducted with HIV positive people living in inner suburbs of Sydney, outer suburbs of Sydney and regional areas of the New South Wales of Australia (Wollongong, Byron Bay, Blue Mountains).

Chapter VIII. In this chapter, I draw conclusions in terms of the theoretical and methodological significance of this research project. The relevance of the results of both analyses to understand the quality of life of PLWHA is discussed. Suggestions for future research into the elicitation of capabilities are made in light of the continued importance that the investigation of the quality of life of PLWHA through capabilities can have both in the social sciences and in the political debate.

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CHAPTER I

QUALITY OF LIFE AND WELL-BEING: CONCEPTUALISATIONS AND MEASUREMENT

The search for 'the good life', of what 'living well' is and of happiness has a long history of interest that, in the Western world, is commonly seen to originate within the works of Greek philosophers living in the fourth century B.C., e.g. Plato, Aristotle and Epicurus (Gilhooly, Gilhooly, & Bowling, 2005). The roots of two main traditions of thought are usually traced back to early Greek philosophers (R. Ryan & Deci, 2001; Waterman, 1993): hedonism, which is the doctrine that pleasure is the good (Gosling, 1998), and eudaimonia, a Greek word the literal sense of which is "'having a good guardian spirit', hence [...] having the life of one who enjoys divine favour [...] a life which is objectively desirable and thereby to have achieved the most worthwhile of conditions available to humans" (Taylor, 1998). Throughout time, within each tradition, different positions were developed in relation to questions such as how pleasure or eudaimonia could be best achieved and what they really consisted of (see, among others, Gosling, 1998; Sorrell 1998).

Some authors have developed classifications of the good life that include the two mentioned traditions started by ancient Greek philosophers, but that also go beyond them by taking into account the philosophical developments that have occurred since then. For example, Smith (1980) distinguished between two forms of the good life: living rightly and living well. These, although not exclusive of one another, refer to different experiences. Living rightly refers to a life led according to accepted and shared values. Living well refers to a life lived according to one's desires. Smith (1980) focused on the concept of living well, which he considered of preliminary importance to the investigation of the good life, and suggested six views of the good life:

1. Maximum gratification of desire views: “living well is primarily a matter of having whatever one wants to have and doing whatever one wants to do” (p. 21)
2. Dominant-end views: “one selects, from the wide array of human goods, one dominant end or cluster of ends, to be pursued to the relative exclusion of other ends” (p. 22)
3. Purpose in life views: life is meaningful when there is “some overarching aim, some *telos*, that transcends one’s life and provides a point or rationale for one’s entire existence” (p. 22)
4. Living up to one’s major expectations: “to live the good life is to have realised one’s serious aspirations to a relatively complete degree” (p. 23).
5. Human flourishing: “One grows toward the good life by progressively actualizing one’s potential for full human functioning” (p. 25).
6. Satisfaction of needs: “Genuine needs are viewed as more or less objective demands of the organism, rather than merely as products of culture or arbitrary desire; and to live well is to be relatively successful in meeting one’s needs” (p. 27).

Clearly, the first and the fifth items include respectively hedonism and eudaimonia.

Brock (1993) distinguished between three main approaches to quality of life: conceptualisations that are dictated by normative ideals, for example religion; conceptualisations that are based on satisfaction of preferences; and, finally, conceptualisations based on people’s direct experiences, in which factors such as joy, pleasure, contentment, and life satisfaction are crucial.

Despite these longstanding traditions of investigation in philosophy, the interest on how to assess the 'goodness' of life, and therefore the use of expressions such as 'quality of life', fully entered the social science disciplines, specifically sociology, psychology and the social policy language only after the Second World War (A. E. Smith, 2000; Veenhoven, 2007a). With regard to the social policy debate, several authors agree that the term quality of life first emerged in the United States during the administrations of the Presidents John Kennedy and Lyndon Johnson (e.g., John & Wright, 2006; Mandzuk & McMillan, 2005). The political agendas during those administrations publicly stated that the good life in America involved more than material affluence and involved a focus on education, manpower, community development, housing, health, and welfare (a discussion of the historical development of quality of life approaches in the social and health sciences will follow in the next section). Since the beginning of the second half of the last century, the number of studies that have used or claimed to have measured the concept of quality of life has grown exponentially (Moons, Budts, & De Geest, 2006; Prutkin & Feinstein, 2002). Despite this wide and growing use of the expression, which spreads across a variety of fields and dedicated publications[1], there is no agreed definition of quality of life (J. Brown, Bowling, & Flynn, 2004). In fact, the expression quality of life has been often used interchangeably with other expressions, particularly well-being, subjective well-being, happiness, life satisfaction, health status and, lately, healthy ageing (Peel, Bartlett, & McClure, 2004). The level of agreement in the literature on how much these terms really are synonyms or rather indicate different states or constructs varies depending on a number of factors. Overall, most literature agrees on the differences between quality of life and happiness (see the reviews and discussions in Veenhoven,

[1] There is a wide range of scientific journals dedicated to the investigation of the quality of life, particularly in health sciences, examples are: Social Indicators Research, Quality of Life Research, Applied Research in Quality of life, Health and Quality of Life Outcomes. The former has a more societal focus, the focus of the others is more on the relationships between health and quality of life.

2000, 2001, 2004), however there is little agreement on the distinction between well-being, subjective well-being, life satisfaction and quality of life. Several authors have attempted to specify whether these concepts should be considered as synonyms or not, however their answers differed depending on the method of their analysis and their specific perspectives on the concept of quality of life itself. For example, in a concept analysis of the expression quality of life, Meeberg (1993) suggested that quality of life should be distinguished from the concept of life satisfaction because quality of life entails an objective assessment by another that one's living conditions are adequate and not life-threatening. The concept of life satisfaction, according to Meeberg (1993), misses such an objective dimension; therefore one could be satisfied with a life that others would consider unappealing on a variety of grounds. Meeberg's (1993) conceptualisation of objectivity implies normative judgements and is consistent with that generally supported in the relevant debate on objective and subjective quality of life (see the relevant section below and, among others, Bowling, 2005). Others have attempted to discriminate between the concepts of quality of life, well-being and life satisfaction undertaking empirical analyses ex post, without preliminarily engaging in a theoretical discussion about what those phenomena were supposed to tap (e.g. A. Spiro, III & Boss, 2000). More recently, Camfield and Skevington (2008) pointed out that Diener (2006), one of the authors that has more strongly contributed to the recent understanding and development of the concept of subjective well-being (e.g. Diener, 1984; Diener, 1994, 2000), has suggested a definition of this concept that presents strong similarities with that of quality of life that The WHOQOL Group suggested about 16 years ago (see The WHOQOL Group, 1995). So, Camfield and Skevington (2008) wonder whether the expression subjective well-being has become redundant and should be dropped[2]. In a recent article titled 'Understanding the diversity of conceptions

[2] The authors had differed opinions on this point, but it was not clear who hold what position (see

of well-being and quality of life', Gasper (2010) suggested that both quality of life and well-being represent abstractions that imply an evaluation about major aspects or the entirety of either a society or of people's lives. The concept of well-being seems to be more often used when the analysis is at the individual level, whereas the concept of quality of life seems to be more used when the analysis is at the level of communities, localities, and societies (Gasper, 2010). Gasper (2010) proposed that the overlapping of the meanings attributed to the two concepts could be explained by the fact that they were developed, autonomously, in different social science disciplines; quality of life more in sociology and social policy, whereas well-being more in psychology.

The above selected examples of discussions around differences and similarities concerning the concepts of quality of life, subjective well-being and life satisfaction showed the need to take an historical perspective on the development of the different definitions and approaches to quality of life and not to focus only on theoretical analyses of the relevant concepts. Consequently, this chapter will first briefly review the literature that has addressed the historical development of the concept of quality of life starting from the second half of last century (the literature reviewed is chiefly American), with a particular focus on the development of this concept in medical studies, psychology, and sociology. This will help to understand when and how the concept started to be used in conjunction with other expressions and will then offer an important basis on which to found a conceptual analysis of the expression. Secondly, to further the understanding of similarities and differences among quality of life and other related concepts, this chapter will offer a brief discussion of the literature that has addressed the question of the definition of quality of life. Thirdly, a conceptual analysis of quality of life based on a taxonomy of the existing approaches to its investigation will be offered. Such a taxonomy will help to better contextualize the capability framework

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Camfield & Skevington, 2008)

approach to quality of life and to explore how quality of life has been conceptualised and measured in health studies, with a particular focus on people living with HIV/AIDS (from now onwards PLWHA). Finally, a discussion of the literature on the quality of life of PLWHA will be offered. In particular, the discussion will focus on the instruments that have been used to measure quality of life in that population and on the findings of the literature in relation to quality of life predictors. The method followed to retrieve the literature is reported in Appendix 1.

An historical overview of approaches to quality of life measurement

In the literature six main streams of studies are identified as precursors of the current conceptualisations of quality of life; they originated in different disciplines:

- the development of measures of functional status, 'quality of survival', and then health-related quality of life in the medical literature (Prutkin & Feinstein, 2002);
- the mental health movement in psychiatry (John & Wright, 2006);
- early psychological studies on well-being and happiness as indicators of mental health (John & Wright, 2006) and on life satisfaction (Cantril, 1965).
- the level of living sociological studies (Ferriss, 2004) and the socio-graphic studies that were undertaken in the United Stated in the forties and fifties (Veenhoven, 2007a);
- the social indicators research movement (Sirgy et al., 2006);
- the Scandinavian studies on welfare.

The use of the expression quality of life and its empirical investigation is usually started with the fifth listed stream of studies, the social indicators research movement

(John & Wright, 2006; Sirgy, et al., 2006). The first four listed streams of research are only indirectly related to quality of life research. Although the expression quality of life was not used in them, they are included in this review because they are presented in the literature as the main first attempts to investigate people's health and, more generally, people's social situation looking over and beyond illness characteristics and economic status (John & Wright, 2006; Prutkin & Feinstein, 2002; Sirgy, et al., 2006). As mentioned above, the expression quality of life recalls the investigation of the goodness of people's lives, a complex phenomenon which is not fully understood by measuring only ill-health or economic status (among others, Campbell, 1976; Campbell, Converse, & Rodgers, 1976; McCall, 1975; Stiglitz, Sen, & Fitoussi, 2009).

Measures of functional status, quality of survival and health-related quality of life

The development of functional measures represented an early attempt in medical studies to steer away from investigations only focused on biologic elements of people's health, both physical and mental, to include measures of functional health status, namely people's ability to perform routinely self-care and complete basic physical activities (Sirgy, et al., 2006). Prutkin and Feinstein (2002) traced back the first functional classification scale for adults to a 1937 study of the Department of Social Welfare of the State of New York in the United States (1937), which intended to examine the medical needs of elderly people receiving public assistance. This study classified older people in four categories: no obvious disability, up and able to get about, homebound, and bedridden. Other, often more sophisticated scales aimed at measuring people's level of independent living and daily living functional capacity were developed in later years. Examples are Zeman's (1947) classification in which patients over 60 years old were classified according to both functional capacity and occupational

skills, and Karnofsky's and Burchenal's (1948) single numerical scale that ranked the performance status of cancer patients from 0 to 100 combining three factors: the ability to carry out normal activities, the need for custodial care, and the need for medical care. Overall, Prutkin and Feinstein (2002) identified over 30 published daily living scales dating from 1945; some of these are still used and some were modified into more sophisticated measures. All these studies measured functional abilities through objective indicators (Prutkin & Feinstein, 2002). Consequently, the investigation of people's behaviours and daily living conditions were undertaken through information collected directly by researchers or clinicians, or through proxies, i.e. health professionals who followed the patients or patients' relatives.

Interest in the patients' own perspectives in the medical literature developed only in the 1960s, when a small number of studies started focusing on the measurement of 'quality of survival' (Prutkin & Feinstein, 2002). This was measured through patient's attitudes, recorded through proxies (as in Eisenberg & Goldenberg, 1966), or batteries of neurological, psychiatric, and psychometric tests to denote the quality of survival of patients who underwent major surgery (as in Logue, Durward, Pratt, Piercy, & Nixon, 1968).

Prutkin and Feinstein (2002) suggested that, as a specific term, the expression quality of life entered the medical literature with an article by Retan and Lewis (1966) on indigent patients receiving haemodialysis. In the same year, Elkinton (1966) published an editorial titled 'Medicine and the quality of life' on Annals of Internal Medicine – the same journal of Retan's and Lewis' (1966) article – in which he questioned whether chronic dialysis provided an acceptable quality of life for patients and proposed that doctors had a more active role in taking decisions on those issues. The concept of quality of life fully entered the medical literature in the 1970s; it was introduced by Medline as a heading in 1975 (Bowling, 2001). In order to focus its

operationalisation, this area of research started to be referred to as ‘health-related quality of life’, an expression which more specifically referred to the impact of health and/or treatment on people’s daily functioning and perceptions of their own physical health, mental health, and social life (Bowling, 2001; Schumaker & Naughton, 1995). Health-related quality of life, which will be further discussed in the section on the conceptualisations of quality of life, has now become an important outcome measures in clinical research (Shumaker, et al., 1997).

The mental health movement and early research on well-being, happiness, and life satisfaction

Similarly to the two previous streams of research, the third and fourth ones also attempted to expand the investigation of people’s conditions by looking beyond respectively mental health illness and experts’ evaluations (social scientists or public officials). However, differently from the two previous streams of research, the mental health movement and the early research on well-being and happiness used subjective indicators, i.e. direct expressions of people regarding their own life situation.

The mental health movement arose from the view that psychiatry needed to look beyond the individual in order to move into genuine preventive work (John & Wright, 2006). In particular, it focused on the social and cultural forces that contributed to psychological distress. The Midtown Manhattan Study (1962), which screened for signs of general psychological distress rather than for specific diagnoses, is an example of an early study from the mental health movement. It was based on the assumption that mental health could be inferred from the absence of symptoms of distress. Jahoda (1958) developed the mental health movement’s premises and proposed to distinguish between mental health, intended as absence of psychiatric disorders, and positive mental

health, intended as the possession of certain psychological characteristics. In particular, Jahoda (1958) identified six empirical indicators of positive mental health:

1. Positive attitudes toward the self.
2. Growth, development, and self-actualisation—including utilisation of abilities, future orientation, concern with work, and so on.
3. Integration, as in a balance of psychic forces, the unifying of one's outlook, and resistance to stress and frustration.
4. Autonomy, as in self-determination, independent behaviour, and, when appropriate, non-conformity.
5. A true perception of reality.
6. Environmental mastery, meaning adequacy in love, work and play, adaptation and adjustment, and the capacity to solve problems.

However, little empirical studies followed Jahoda's theoretical work (Ryff & Singer, 1998; H. R. Spiro, 1980).

John and Wright (2005) and Veenhoven (2007) suggested that Gurin's, Veroff's and Feld's (1960) study represented the first major study in psychology that moved away from identifying cases of specific psychological problems to explore people's own experiences. Using the public survey technique, Gurin et al. (1960) aimed at investigating the mental health of the American population by asking questions that explored a variety of life experiences including people's psychological symptoms, daily experiences, and general feelings. A few years later, Bradburn and Caplovitz (1965) undertook a similar study in which people's experiences were assessed through the investigation of specific positive and negative episodes that had recently occurred in the respondents' lives. In both studies the expressions happiness and (subjective) well-being

were used interchangeably and were considered indicators of people's mental health; also, both concepts were treated as one-dimensional (John & Wright, 2006). However, in a book titled 'The structure of psychological well-being' (Bradburn, 1969), in which the data collected in Bradburn's and Caplovitz's (1965) study was reanalyzed, Bradburn concluded that (subjective) well-being was a two-dimensional construct that consisted of positive and negative affective components. Bradburn (1969) suggested that people's (subjective) well-being consisted of the balance between positive affect and negative affect[3].

Another seminal study aimed at investigating people's general sense of well-being was 'The pattern of human concerns' of Cantril (1965). Differently from Gurin's and colleagues' (1960) and Bradburn's and Caplovitz's (1965) studies, Cantril (1965) conceptualised (subjective) well-being not as the balance between positive affect and negative affect, but rather as a cognitive experience in which individuals compared the perceptions of their current situation to what they expected or desired. Respondents' well-being was elicited by asking them to choose one of the eleven steps of a visual analog of a step ladder of which the lower rung was labelled as 'worst possible life' and the top was labelled 'the best possible life'.

John and Wright (2005) considered Cantril's (1965) study as the "direct heir of the Social Indicators Movement" (p. 53). However, here it is suggested that Cantril's work is better understood as an example of psychological research aimed at investigating people's views on their well-being through subjective indicators. This view is consistent with other scholars' understanding of Cantril's (1965) study (see for example Campbell, 1976; Prutkin & Feinstein, 2002), and with the suggestion that the social indicator movement, at its start, was primarily interested in the development of

[3] Several studies criticised and expanded Bradburn's two-dimensional scale of (subjective) well-being (see among others, Cherlin & Reeder, 1975; Diener & Emmons, 1984).

objective indicators of quality of life (Bauer, 1967; Campbell, 1976; Prutkin & Feinstein, 2002).

Level of living studies, the social indicators movement, and the Scandinavian tradition

Ferriss (2004) and Veenhoven (2007a) suggested respectively the tradition of sociological studies on family living conditions in the United States (which can be traced back to 1918), and socio-graphic investigations such as Ogburn's (1946) portraits of American rural life, as early precursors of quality of life research. Despite the fact that the expression quality of life was not used in these studies (Ferriss, 2004), they focused on wider aspects of people's lives than those offered by mere measures of level and distribution of income. Also, they were concerned with topics, for example living standards and inequality, which then figured as dimensions of quality of life.

Social indicators movement. However, it was not until the 1960s that a strong interest in the development of a set of measures that would provide a fuller description of people's lives developed both at the policy and at the academic level (Campbell, 1976; John & Wright, 2006; Sirgy, et al., 2006). In particular, the focus was on developing new statistical series that would monitor change in public life areas such as education, health, employment, crime, political participation, and population growth and movement (Campbell, 1976). One of the main examples of the work undertaken under the thrust of those concerns is the book titled 'Social indicators' edited by Bauer (1967), in which the potentials of social indicator developments were explored[4]. Bauer, a sociologist, was an associate director of the American space agency NASA, which supported the early development of works on social indicators in an attempt, apparently, to detect and to anticipate the impact and side effects of the American space program on

[4] Noll (2002a) review a number of studies that can be considered important predecessors of modern social indicators research.

U.S. society (Noll, 2002a). Another major work of this kind was that of the Panel on Social Indicators (1969) set up by the American Federal Government (Ferriss, 2004). In these early works, social indicators consisted primarily of objective indicators, namely indicators of events, behaviours, or characteristics of individuals that were meant to be collected and reported through governmental institutions; they did not depend on people's description of their own lives. John and Wright (2005) pointed out that, with the advent of the social indicators movement, in the relevant literature there was a shift from the use of the term 'welfare' to that of 'well-being'. Such a change in terminology was probably due to the fact that the word 'welfare' was too closely associated with existing economic indicators. On the other hand, the expression 'well-being' referred to a wide variety of life characteristics, from basic ones, such as nutrition needs, to spiritual and psychological (John & Wright, 2006).

Overall, the social indicators movement did not succeed in influencing politics and planning and was discontinued in the 1980s, both at the national and international level[5]. However, the social indicators movement did not produce research based only on objective indicators. Studies such as Campbell's, Converse's, and Rodgers' (1976) 'The quality of American life: Perceptions, evaluations, and satisfactions', and Andrew's and Withey's (1976) 'Social indicators of well-being: Americans' perceptions of life quality' aimed at investigating people's own perceptions of their quality of life, similarly to Cantril's (1965) study. Compared to previous studies based on subjective indicators, for example Gurin et al. (1960) and Bradburn and Caplovitz (1965), Campbell's and colleagues' (1976) study did not aim to simply assess people's general satisfaction or freedom from stress in their lives. It also aimed at identifying relevant life domains and exploring people's satisfaction and dissatisfaction in each of them. A

[5] In that period, both the Organisation for Economic Cooperation and Development (OECD) and, in the United States, the administration of the President Reagan terminated their social indicator programs (Bowling, 2005; Hagerty, Vogel, & Møller, 2002).

total of fifteen domains were explored: marriage, family life, health, neighbourhood, friendship, housework, job, life in the United States, city or county, non-work, housing, usefulness of education, standard of living, amount of education, and savings. People were asked a single question about how satisfied they were with each domain. Three questions were also added to elicit people's overall satisfaction with life. These included: Gurin's and colleagues' (1960) question that used the word happiness, one question that used the word satisfaction, and an 'Index of general affect' that was constructed using the semantic differential technique on ten pairs of polar adjectives. Consequently, Campbell and colleagues (1976) distinguished the concept of satisfaction, which implied a cognitive judgement, from the concept of happiness, which implied an emotional state.

Andrew's and Withey's (1976) study built on Campbel's and colleagues' (1976) work by improving the Likert scales used to elicit people's answers (they introduced a 'delighted-terrible' scale, which proved better) and by determining the life domains to be investigated statistically rather than conceptually. Following a complex methodology, Andrew and Withey (1976) identified 12 main life domains to be investigated, which, however, were not substantially different from those that were identified conceptually by Campbel and colleagues (1976): the self, family life, income, amount of fun, house/apartment, doing things with family, time to do things, spare time activities, concern about national government, cost of goods and services, health, and one's job.

It is important to note that in the above studies the expressions quality of life and subjective well-being were used interchangeably. In a later study, Campbell (1981) wrote:

> Psychologists and sociologists throughout the world have experimented with measures of what is variously called 'positive affect', 'quality of life', 'sense of

well-being' – all concerned in essence with what the early philosophers called happiness (p. 12).

The quotation above shows that confusion and overlapping between quality of life and other constructs has characterised this field of research since the start. However, Campbell's (1981) conclusion that all the above mentioned constructs refer to happiness as conceptualised by early philosophers is misleading, because as we saw at the beginning of this chapter, Greek philosophers conceptualised the concept of happiness, intended as the 'good life', at least in two different ways: eudaimonia and hedonism.

Scandinavian tradition. In Europe, quality of life research based on social indicators started independently in the seventies with the Scandinavian welfare research tradition, which consisted of Swedish and Finnish welfare studies (Noll, 2002b). In these studies people's needs or people's resources, rather than people's happiness or people's satisfaction, as in the subjective tradition of American studies, were considered the basic mechanisms of people's welfare. The word 'welfare' in all Scandinavian languages stands for well-being and "relates to both level of living and quality of life" (Allardt, 1993, p. 88). The Swedish level of living survey was the first nationwide welfare study in the Scandinavian tradition. People's level of living consisted of "the individual's resources, the arenas in which they are to be used, and his [sic] most essential living conditions" (Erikson, 1993, p. 74). This study was based on objective indicators.

The second large-scale Scandinavian welfare study was conducted in 1972 by the Research Group for Comparative Sociology at the University of Helsinki (Allardt, 1993). This study was inspired by the Swedish level of living survey, however the intention behind it was to convey a broader sociological picture of the state of well-being in the society compared to the one achievable through the Swedish approach. The

Swedish choices to use objective indicators, and to take people's resources as the focal variable for assessing their welfare, were considered too restrictive. Therefore, firstly a switch from resources to basic needs was suggested with regard to the focal variable. Secondly, subjective together with objective indicators were surveyed (Allardt, 1993). The importance of this comparative study was that "it offered a more comprehensive system of indicators for describing the level of living and the quality of life than the Swedish model" (Allardt, 1993, p. 88). This model investigated three main dimensions of human welfare: having, loving, and being.

In all the reviewed traditions of study of quality of life, this term was used interchangeably with well-being, subjective well-being, happiness, and level of living.

Definitions of quality of life

It was mentioned above that there is not a commonly agreed definition of quality of life (J. Brown, et al., 2004). Some scholars have attempted to define the concept of quality of life by discussing the meanings of the two words 'quality' and 'life'. For example, both McCall (1975) and Michalos (2004) distinguished between the descriptive meaning of the adjective quality, for example when it refers to the distinctive character of a certain object or place, and its evaluative meaning, for example when it refers to the value or worth of things. The first type of meaning of the expression quality implies the use of objective indicators, the second type of meaning implies the use of subjective indicators. McCall (1975) further specified that the adjective quality has to be intended in its evaluative meaning, which implies that things have quality in different degrees and therefore can be compared. Other relevant characteristics of the adjective quality, as used in the expression quality of life, are that it is 'multi-criterial' and type-dependent (McCall, 1975). It is 'multi-criterial' because the applicability of the word quality depends on the presence or absence of a cluster of

other properties, which varies with the object to which quality refers. For example a restaurant can prepare good food but serve it badly. McCall (1975) suggested that the multi-criterial nature of quality gives rise to indeterminacy, because it may be difficult to determine whether a good restaurant that prepares good food served poorly is better or worse than a restaurant that prepares bad food served well. Quality is type-dependent because the criteria that determine the quality of things differ according to their nature; the criteria that define a good wine are different from the criteria that define a good piece of fabric. As for the term 'life', McCall (1975) intends it as life in a society, not the life of a specific individual. This interpretation, however, contrasts with other conceptualisations of quality of life, for example the individual quality of life schedule (McGee, O'Boyle, Hickey, O'Malley, & Joyce, 1991).

Veenhoven (2000) proposed a fourfold typology of quality of life based on the answers to two questions: "quality of *what life*?" and "what *quality* of life?" The answers to these two questions generated two bi-partitions: respectively between 'life chances' and 'life results', and between 'outer' and 'inner' qualities. The cross tabulation of these dichotomies was at the basis of the four types of quality of life: 1) livability of the environment, 2) life-ability of the individual, 3) external utility of life and 4) inner appreciation of life. The concept of livability referred to a fit of the environment with the needs of people (Veenhoven, 1996, 2000). The concept of life-ability of the person referred to inner life-chances, i.e. to "how well we are equipped to cope with the problems of life" (Veenhoven, 2000, p. 4). Veenhoven traced back to this latter quadrant of his fourfold table a few sub-concepts, such as physical and mental health, self-actualisation, which referred to people's ability to acquire new skills for living, and, lastly, art of living, which referred to people having "refined tastes, an ability to enjoy life and an original style of life" (Veenhoven, 2000, p. 9). The concept of external utility of life did not refer to the utilitarian conception of utility, but rather to

the notion that a good life must be good for something more than itself, some higher values. The concept of inner appreciation of life represented the inner outcomes of life and referred to subjective appreciations of life, for example subjective well-being, life satisfaction, and happiness. This model will be further discussed in Chapter 3 in relation to the analysis of the concepts of opportunities and life chances.

Two definitions of quality of life based on the capability framework will be offered in Chapter 3 of this thesis. These definitions will have some of the characteristics of the terms quality and life discussed above and will each represent an example of the two main types of definitions identified below.

Only a few authors have formally attempted to classify the different definitions available in the literature; Farquhar (1995) is the most known and probably only example. Farquhar (1995) proposed a taxonomy of four classes of quality of life definitions: global, component, focused, and combination definitions. Global definitions are all-encompassing and tend to point out the mechanisms that underpin the achievement of full quality of life, for example the degree of satisfaction or dissatisfaction with one's life. Lindstrom's (1992) and the Canadian Centre's for Health Promotion's definitions in Table I-1 are examples of this first class of definitions. Component definitions are those that "break quality of life down into a series of component parts or dimensions, or identify certain characteristics deemed essential to any evaluation of quality of life" (Farquhar, 1995, p. 503); the definition of the Australian Centre on Quality of Life in Table I-1 is an example of this second type. Focused definitions are those that refer to only one or a small number of the components of quality of life, for example definitions of health related quality of life. The definitions of health-related quality of life of the US Department of Health and Human Services Food and Drug Administration (2009) and of Schumaker and Naughton (1995) in Table I-1 are examples of focused definitions. Finally, combination

definitions are those that have characteristics of the first and the second group of definitions at the same time. However, there is space for a second type of combination definitions, i.e. those that consist of the overlapping of focused and component definitions, such as for example the definitions of health-related quality of life reported in Table I-1.

A distinction that is overlooked in the literature is that between definitions of quality of life that refer to other concepts, i.e. well-being, satisfaction, or happiness, and definitions that do not. The first four examples in Table I-1 are of the first type of definitions, the remaining four are examples of the second type.

Table I-1

Examples of definitions of quality of life

Author	Quality of life definition
The WHOQOL Group (1995)	Individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.
Lindstrom, Bengt (1992)	Quality of life is the total existence of an individual, a group or a society.
Canadian Centre for Health Promotion	Quality of life is the degree to which a person enjoys the important possibilities of his or her life.
Lawton (1991)	Quality of life is the multidimensional evaluation, by both intra-personal and socio-economic criteria of the person-environment system of the individual.
US Department of Health and Human Services Food and Drug Administration (2009)	A general concept that implies an evaluation of the impact of all aspects of life on general well-being.
Australian Centre on Quality of life (2010)	Quality of life is both objective and subjective. Each of these two axes comprises several domains which, together, define the total construct. Objective domains are measured through culturally

Author	Quality of life definition
	relevant indices of objective well-being. Subjective domains are measured through questions of satisfaction.
US Department of Health and Human Services Food and Drug Administration (2009)	Health-related quality of life (HRQOL) is a multidomain concept that represents the patient's general perception of the effect of illness and treatment on physical, psychological, and social aspects of life.
Schumaker and Naughton (1995)	HRQOL refers to people's subjective evaluations of the influences of their current health status, health care, and health promoting activities on their ability to achieve and maintain a level of overall functioning that allows them to pursue valued life goals and that is reflected in their general well-being. The domains of functioning that are critical to HRQOL, include: social, physical and cognitive functioning; mobility and self-care; and emotional well-being.

Here it is suggested that definitions of the first type make quality of life a measure of people's advantage (or disadvantage), whereas definitions of the second type make quality of life a measure of people's well-being. By advantage I refer to the position that people have in society comparatively to others. By well-being I refer to the conceptualisations of what makes human beings' life good. This distinction is important because referring to quality of life as a measure of advantage, rather than well-being, changes the theoretical framework within which to understand its function. This question is particularly relevant in the discussion of the choices that underpin the operationalisation of quality of life. Gasper (2010) proposed six dimensions of variations in making quality of life evaluations:

- the scope and focus of quality of life investigations, i.e. what aspects of life are investigated;

- the values that underpin the interpretations of quality of life, i.e. whose values are taken into consideration in quality of life evaluations;
- the methods of measurement and/or observation that are employed, i.e. subjective vs. objective;
- the purposes for which quality of life is investigated, e.g. understanding, acting, praising/condemning, etc.;
- the standpoint of the evaluation, e.g. people themselves or others as proxies;
- the theoretical frameworks employed, e.g. conceptions regarding the nature of being a person.

Within this framework, the distinction between quality of life as a measure of advantage or well-being pertains to the variations in values and particularly in purposes for which quality of life evaluations are undertaken, which are clearly of main importance. Overall, both types of definitions are evidently legitimate. However, here it is suggested that definitions of the second type are more prone to the criticism of redundancy of one of the two concepts, either quality of life or well-being, unless a clear indication is given of the particular aspect of people's well-being that quality of life investigates.

Any analysis of definitions that conceptualise quality of life as a form of well-being rather than advantage should be carried out by distinguishing between indicators and determinants of quality of life (Moons, et al., 2006), and conceptualisations of quality of life and their determinants (Hyde, Wiggins, Higgs, & Blane, 2003). Indicators of quality of life are phenomena, experiences, and events that are investigated to evaluate how much quality of life characterises the experience of people or of a society. Determinants of quality of life are factors that influence the amount of quality of life. Conceptualisations of quality of life consist of statements regarding what quality of life

is and what it consists of (i.e. its constitutive dimensions: control, social life, etc). These distinctions are important because they help to clarify the relationships between quality of life and the other concepts with which it has been used interchangeably, although they are often confused in the literature (Hyde, et al., 2003; Moons, et al., 2006). However, there is no clear cut way to decide whether a certain factor is a determinant, rather than an indicator or a component of quality of life. The same factor, for example poverty, could fall into any of the three categories depending on a variety of factors. Particularly relevant are Gasper's (2010) six dimensions of variation between approaches to quality of life measurement that were mentioned above, which have to be taken into consideration in interpreting the summary of the literature reviewed so far that is proposed in Figure I-1.

Conceptualisations of quality of life

The first relevant distinction in Figure I-1 is the distinction between objective and subjective measures of quality of life. As seen in the previous sections, the debate on whether quality of life refers to a subjective state that, as such, should be evaluated through people's self-reports, or whether it is a life condition that can and/or should be measured through indicators of the environment in which people live and their personal characteristics, has characterised quality of life studies since the start of the social indicators movement and of the Scandinavian studies. It is also a commonly accepted distinction in the taxonomies of quality of life presented in the literature (e.g. J. Brown, et al., 2004; Farquhar, 1995; Guyatt, Veldhuyzen Van Zanten, Feeny, & Patrick, 1989). The vast majority of instruments in the literature uses self-reports and conceptualise quality of life as a subjective state consisting of the gap between an ideal state, which can be a goal, a desire, or a need, and people's current situation. For example, The WHOQOL Group (1995) suggested three levels of questioning in quality of life

research. The first level of questioning investigates people's capacity to function physically (e.g. 'How many hours did you sleep last night?). The second level of questioning consists of people's global evaluations of their functionings (e.g. How well do you sleep?). The third level of questioning consists of people's "highly personalised" (p. 1405) evaluations of their functioning (e.g. How satisfied are you with your sleep?). The WHOQOL Group (1995) suggested that quality of life research is related to the last two types of questions, but not to the first one. Consequently, according to The WHOQOL Group (1995), quality of life is about people's subjective states, not their conditions, and the only way to measure it is through self-reports.

However, as Gasper (2010) pointed out, even though the distinction between subjective and objective measures helps to focus on *how* quality of life is measured, it should not lead to the oversimplification that the choice between subjective and objective measures is merely of methodological nature. *How to measure quality of life* is a value consideration as much as the issues of *who decides* and *what to look at* in its evaluation. Consequently, all of these factors should be taken into consideration in evaluating the spectrum of possibilities available in choosing the methods of measurement of quality of life. To this end, Gasper (2010) suggested that the question of *who decides* is a matter of whether public values or private values are taken into consideration in deciding *what to look at*, i.e. whether people's conditions or their subjective states. Consequently he suggested a three-way cross tabulation of these three questions that generated eight different examples of possible intersections between objective and subjective measures of quality of life (see Gasper, 2010, Box 1 at p. 352). This suggestion differs for focus and outcomes from other classifications previously suggested in the literature. For example, Veenhoven's (2007b) distinguished between objective, mixed, and subjective indicators respectively of the substance and nature of

quality of life investigations. Consequently, he generated a 3 x 3 cross tabulation of possible combinations of indicators of quality of life (see Appendix 2).

In Figure I-1, under objective quality of life, I reported the two traditions of studies that first used objective measures to evaluate people's quality of life. However, other traditions of studies could be added, for example poverty studies, which are indicated as a type of quality of life research by Phillips (2006). Under subjective quality of life I distinguished two main types of studies, generic and population specific measures of quality of life. This distinction reflects that of Farquhar's (1995) between focused and non-focused definitions of quality of life and is discussed in all of the taxonomies of quality of life presented in the literature (e.g. J. Brown, et al., 2004; Guyatt, et al., 1989; Phillips, 2006).

A wide variety of instruments can be included under the box generic quality of life measures, i.e. quality of life measures thought for the population at large (Bowling, 2001). These include national and international indices such as The Australian Unity Well-being Index (Cummins, Eckersley, Pallant, Vugt, & Misajon, 2003) or the WHO quality of life assessment questionnaire (The WHOQOL Group, 1995), but also tools aimed at investigating quality of life at the local level (e.g. Zumbo & Michalos, 2000). Under the population specific group of studies I included gerontological studies (e.g. Bowling, 2005; Bowling, Banister, Sutton, Evans, & Windsor, 2002), and health-related quality of life studies, which will represent the focus of the rest of this discussion.

As it was mentioned above, the concept of health-related quality of life refers to the impact of health and/or treatment on people's daily functioning and to perceptions of their own physical health, mental health, and social life (Bowling, 2001; Schumaker & Naughton, 1995). Such a way to conceptualise quality of life focuses on some of people's roles, for example their jobs, their family roles (e.g. parents, carers), but

excludes other important aspects of people's lives, such as their housing, their surrounding environments, and their incomes (Bowling, 2001). Bowling (2001) suggests that health-related quality of life is a double-sided concept that incorporates positive as well as negative aspects of well-being and life. As such, from a theoretical point of view, it is based on the WHO definition of health: "a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity" (WHO, 1946).

Bowling (2001) and Guyatt et al. (1989) discriminated three types of health-related quality of life measure: generic instruments, disease specific, and utility measures (see Figure I-1). Generic health-related quality of life questionnaires are used to make comparisons between conditions and to evaluate people's physical, mental and social health (Bowling, 2001). Disease specific instruments aim to specifically focus on the severity and clinical outcomes of patients with a specific health condition; they do not allow comparisons between and across different conditions (Guyatt, et al., 1989). Finally, utility measures collect information on the desirability of particular health states or outcomes and attribute to them a value, usually referred to as quality-adjusted life years (QALYs), which is used in cost-utility studies. The concept of QALYs rests on the assumption that "if offered the choice, a rational individual would prefer a life that is shorter but coupled with a satisfactory state of health, to a longer life with a considerable handicap or serious discomfort" (Hunt, 1995, p.207). Utility measures are collected through a number of techniques, including:

- standard gamble, in which people are asked to choose between their own health state and a gamble that they might die immediately or achieve full health status for the remainder of their lives thanks, for example, to a specific treatment (Bowling, 2001);

- trade-off, in which people are asked to consider a health state that is to last for a fixed period of time (Bowling, 2001);
- ad hoc questionnaires, such as the Euroqol or the Rosser Index of Disability (for a review of these instruments see Bowling, 2001).

Overall, the concept of health-related quality of life has been criticised and its usefulness has been questioned on several grounds (e.g. Cummins, 2004; Moons, 2004). Moons (2004) proposes four main criticisms to this construct:

- it artificially discriminates between aspects of people's lives that are affected by their health status and aspects that are not influenced by it (see also Hunt, 1995, 1997);
- it may lead to overestimating the relevance of health-related factors and underestimate the importance of social and environmental factors on people's quality of life (see also Gill & Feinstein, 1994; Hunt, 1997);
- health status should be considered a determinant of quality of life rather than an indicator of it;
- health-related quality of life does not measure quality of life as such, which is best defined in terms of life satisfaction, but rather self-perceived health status and functional abilities.

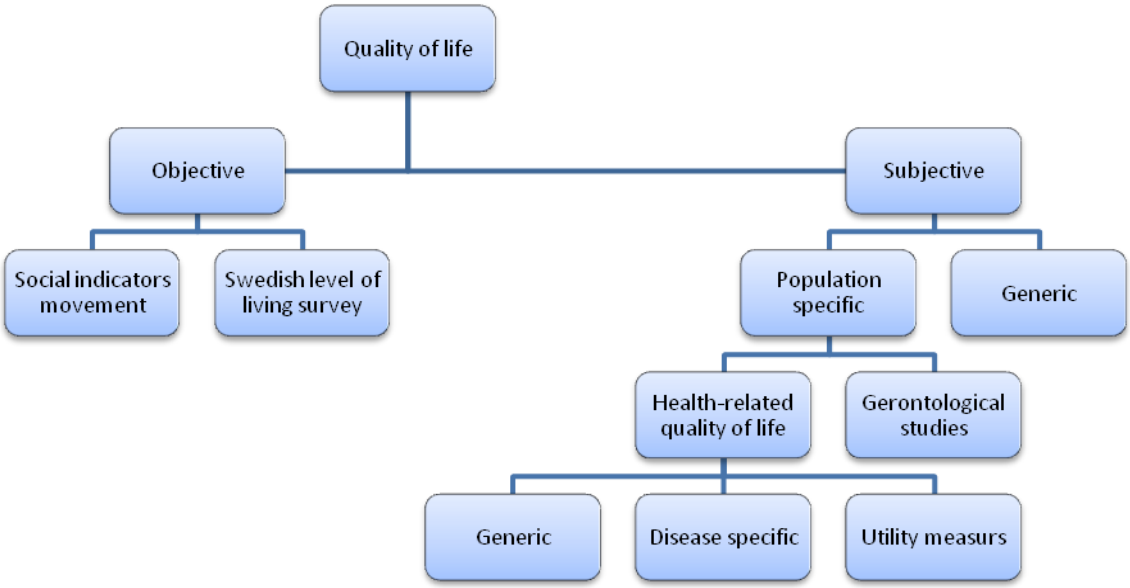
In particular, QALYs have been criticised for the fact that the reliability of the hypothetical and stereotypical judgements completed in games-playing spirit on which they are based is questionable (Skevington & O'Connell, 2003). In fact, the scenarios have limited resemblance to people's everyday life. Also, different techniques generate different values, so their use in cost-effective analyses is invalid (Hunt, 1997). Finally,

because of their cognitive complexity, they tend to exclude the less educated and those who are seriously ill (Skevington & O'Connell, 2003).

The investigation of the quality of life of PLWHA has been largely based on measures of health-related quality of life.

Figure I-1

Taxonomy of quality of life measures



The study of quality of life in people living with HIV/AIDS

In a review of the literature published between 1995 and 2000, Skevington and O'Connell (2003) identified two main research approaches to the investigation of quality of life[6] in PLWHA: economic measures, five main scales were analysed, and self-reported measures of physical and mental health status, of which twelve examples were given (for a review of the psychometric characteristics of these instruments see also Clayson et al., 2006). Skevington and O'Connell (2003) pointed out some important omissions in the reviewed questionnaires. For example, although the majority

[6] Skevington and O'Connell (2003) used the expression quality of life throughout their article; however, given the above discussion, their review should be more correctly defined of measures of health-related quality of life.

of the reviewed instruments measured physical health and physical functionings and some measures of negative mental health, such as distress and worries, only half included cognitive functioning, which is susceptible to change in the conversion to AIDS. Also, although most of the reviewed instruments included a social domain in the form of role-functioning or social support, they did not include other important domains such as relationship with others, sex, concerns about medical care, and financial issues. Finally, Skevington and O'Connell (2003) pointed out that the majority of the instruments for the evaluation of quality of life in PLWHA were developed in the United States thinking of middle- or upper-class male homosexuals. Consequently, given the global spread of HIV/AIDS, these authors pointed out that there is a need to create instruments that are able to tap into different groups of PLWHA, both within a same society and across different societies.

Only a few studies have investigated the factors that influence or enhance quality of life in PLWHA. For example, Kemppainen (2001) investigated the predictors of health related quality of life, as measured through the HIV Symptom Checklist, the Beck Depression Inventory, the HIV-QAM, and two measures of engagement in nursing care, in a convenience sample of 162 hospitalised male and female patients with AIDS. He found that depression was the strongest predictor of decreased quality of life; other important predictors were symptoms, female gender, and involvement in the process of nursing care. Lorenz, Cunningham, Spritzer, & Hays (2006) measured health-related quality of life through two global measures, i.e. overall health and overall quality of life, and found that symptoms were significantly related to health-related quality of life over time. Murri et al. (2003) measured health-related quality of life in a sample of 809 PLWHA using the MOS-HIV questionnaire. They found that, at baseline, low CD4 cell count, hospitalisation during the three months before the enrolment, and symptoms were independently related to the physical health component of the MOS-

HIV. On the other hand, hospitalisation during the three months before the enrolment, symptoms and poor satisfaction with information from providers were independently related to the mental health component of MOS-HIV. The stage of HIV infection, baseline CD4 cells count, physical health and symptom score predicted physical health at six months; while age, baseline mental health status, symptom score and education predicted six-month mental health status. Eller (2001) found that clinical indicators did not predict a substantial portion of the variance in quality of life operationalised through the Sickness Impact Profile, whereas work status, depression, and fatigue were significant predictors. There is scant literature that specifically looks at gender differences (e.g. Cederfjall, Langius-Eklof, Lidman, &Wredling, 2001) and urban/rural differences in the quality of life of PLWHA. In particular, urban/rural differences have been investigated predominantly in developing countries (e.g. Stangl, Wamai, Mermin, Awor, & Bunnell, 2007).

Concluding remarks

The review of the literature on the development of research on quality of life showed that this developed through two major movements in the 1960s and 1970s, one in the social sciences, and one in the medical sciences. The social indicators movement aimed at offering alternative indicators to the mainstream economic ones, particularly GDP, to describe people's lives. In the medical sciences the goal was to move away from evaluations of medical interventions merely based on measures of physical functionings. Overall, quality of life has always presented ambiguities regarding its definition and its relationships with other measures of people's well-being. In the American studies in which the concept was first assessed it was measured through happiness and life satisfaction. The Scandinavian tradition of studies developed different models and used objective indicators too. In the medical sciences a substantial

ambiguity has remained regarding the meaning of quality of life in clinical settings. A significant criticism to health-related quality of life is that it confuses the concept of health with that of quality of life intended as life satisfaction.

Given the confusion that characterise this concept, it is certainly of fundamental importance to be as clear as possible when the concept of quality of life is used, especially when it is operationalised. This chapter has set the ground for a clearer and more informed discussion on the conceptualisation and measurement of quality of life in the capability framework, to which I now turn in the next chapter.

CHAPTER II

THE CAPABILITY APPROACH

In this chapter I will introduce the capability approach. In particular, I will focus on its two main concepts, functionings and capabilities, in order to point out its core features. I will explain how the concepts of well-being and quality of life are conceptualised in this theoretical framework, how they are related to its central concepts, and how it is suggested that they should be measured. The following analysis of the concept of capability focuses on the works of Amartya Sen. The notion of capability that is implied in the other principal version of the capability approach, that of Martha Nussbaum, will be introduced only to the end of clarification.

Core concepts of the capability framework

The capability framework is based on two main concepts: functionings and capabilities.

Functionings

Sen's definition of a functioning is "… an *achievement* [emphasis added] of a person: what he or she manages to do or to be. It reflects, as it were, a part of the 'state' of that person" (Sen, 1985a, p. 10). More specifically, "the concept of functionings reflects the various things a person may value doing or being" (Sen, 1999, p. 75). Such doings and beings can vary from elementary ones, for example being adequately nourished and free from avoidable disease, to very complex activities or personal states, for example being able to take part in the life of the community and having self respect (Sen, 1999).

A functioning has to be distinguished from the resources used to achieve it, to which it is posterior. An achieved valued doing or being involves people's talents and

social environments, which Sen (1985a) calls ‘converting factors’. Converting factors remind us to take into account people’s individual and social characteristics and the ways they might hinder or facilitate certain achievements. Converting factors determine what Sen (1985) calls a person’s ‘utilisation function’, which expresses how people use the resources to which they can have access. People, given their individual and social characteristics, can only have a certain number of ways of using and combining the same resources in a certain context.

A functioning has to be distinguished also from the happiness that that functioning generates, to which it is prior and in a way independent (Sen, 1985a).

Sen claims that functionings reflect the well-being of a person. In Sen’s words, “functionings are constitutive of a person’s being, and an evaluation of well-being has to take the form of an assessment of these constituent elements” (Sen, 1992, p. 39). This claim stands on an intuitive postulate. Basically, that “how well a person is must be a matter of what kind of life he or she is living, and what the person is succeeding in ‘doing’ and ‘being’” (Sen, 1985a, p. 28). So, from this point of view, what we should look for in order to assess the well-being, for example, of PLWHA, is direct information on the actual functionings that they have achieved, i.e. what they do and are through the resources (and their related characteristics) that they can access.

However, Sen introduces a more sophisticated characterisation of achieved functionings that he calls ‘*refined* functioning achievements’ (Sen, 1985a). The refined functioning achievements are the functionings not taken in isolation, but valued against the other functionings within reach of a person. The salient alternatives influence the meaning of the functioning that the person can achieve. One thing is to do something, another is to choose to do something among several possible alternatives (see Sen,

1988, p. 292). The concept of ‘refined functionings’ is similar and introductory to that of capabilities.

Capabilities

Sen defines capabilities as “the alternative combinations of functionings that are feasible for [people] to achieve” (Sen, 1999, p. 75). This concept is interchangeably referred to as “freedom”, and “real opportunities”, as it happens, for example, in the following quotation: “the capability to achieve functionings [...] constitute [a] person’s freedom – the real opportunities – to have well-being” (Sen, 1992, p. 40). Although both facets of the concepts, i.e. freedoms and opportunities, are clearly relevant to its operationalisation, here, for practical reasons, I will be focusing only on the characterisation of capabilities as opportunities. This is because an investigation of the theoretical and methodological frameworks that can help to understand how social actors perceive capabilities as freedoms, rather than as opportunities, need to draw on two very large and different bodies of literature. For example, within psychology, the conceptualisation of capabilities as freedoms implies looking at the literature that has investigated people’s perception of the experience of freedom in general and of freedom of choice in particular, e.g. reactance theory, attribution theory, the psychological phenomenological investigation of people's experience of freedom, social cognitive theory, and national surveys that included questions on perceived freedom. On the other hand, understanding capabilities as opportunities implies looking at a completely different body of research, for example the literature on counterfactual thinking, on life chances, etc. In this thesis capabilities are intended as opportunities and so the focus is on how to operationalise them when so intended. Despite the fact that the understanding of capabilities as freedoms is considered as important, their operationalisation (within

the epistemological framework here suggested) represents another major investigation that is best to pursue in future research.

Overall, the set of all these opportunities, called the capability set, is a measure of people's freedom to achieve those things that they have reason to value and that, therefore, are constitutive of their well-being. Sen, consequently, labels this freedom "well-being freedom" (see Sen, 1992, p. 57). Conceptualising the capability set as a measure of freedom is not in contradiction with what previously stated regarding the need to distinguish between freedoms and opportunities at the level of their operationalisation. In fact, the capability set can well consists of several opportunities which, altogether, give a measure of people's freedom to choose.

People's alternative opportunities to achieve well-being tell us "the kind of 'deal'" (Sen, 1985a, p. 201) that they have compared to others and so contribute to achieve a fuller picture of their well-being. For example, a poor person starving and a rich person fasting may have similar levels of well-being in terms of their actual and current functionings: being undernourished, hungry, forceless and so on. However, an important aspect of their well-being conditions would be missed if their respective real opportunities to pursue alternative functionings would not be taken into account. Whilst the rich person who is fasting can start eating whenever he or she chooses to, the poor starving individual cannot. A focus on capabilities, therefore, helps to focus on information that would otherwise be overlooked in an assessment of well-being exclusively based on functionings, but also on traditional measures such as material resources or mental states (e.g. happiness and satisfaction). In particular, these two latter alternative ways to assess well-being are criticised for two main sets of limits.

On the one hand, studies which focus only on people's resources, for example economic investigations that study well-being solely on the basis of GDP per capita, do

not account for people's different converting factors. Depending on their personal and social characteristics, people can exploit the same goods and resources with very different grades of intensity and for quite different purposes. As a result, such studies fall short when they have to accommodate interpersonal comparisons. Moreover, an exclusive focus on resources leads to a confusion between the concept of well-being and that of being well-off. In fact, a reduction of the concept of "how well a person is doing" to the extent of his or her possessions is open to a "commodity-fetishist" view (Sen, 1985a, p. 23). Resources are not an end in themselves. Their relevance, from Sen's theoretical point of view, arises from the fact that they are *means* for attaining a state of well-being.

On the other hand, Sen (1985a) critically discusses the consequences of evaluating people's well-being based exclusively on three main interpretations of the concept of utility: happiness, desire fulfilment, and choice. I will discuss here his arguments on happiness and desire fulfilment, since those for the interpretation of utility as choice are underpinned by the same theoretical assumptions and draw mainly on technical economical questions. Assessing people's well-being on the basis of their happiness or desire fulfilment entails two main limitations: "physical-condition neglect" and "valuation neglect" (Sen, 1985a, p. 29).

The condition of "physical-condition neglect" is generated by the fact that utility as happiness and desire fulfilment is "fully grounded in the mental attitude of the person" (Sen, 1985a, p. 20). As a consequence, when assessing well-being trough those two measures, the physical condition of a person, for example his or her state of nourishment, shelter, mobility etc., are accounted for only in so far as "they are *indirectly* covered by the mental attitudes of happiness and desire" (Sen, 1985a, p. 21). It can happen that a very poor person who has learnt to come to terms with his or her predicaments and who is easily pleased can claim to have more desire fulfilled and to be

as happy as or even happier than, for example, a certain other wealthy person. Such a phenomenon of adaptation to one's situation is called 'adaptive preferences problem' in the capability framework. In such cases, it seems not at all obvious how it could be claimed that the very poor person is in a better condition than the wealthy individual in terms of how well he or she is doing. From this point of view, the conception of utility as happiness and desire fulfilment raises, according to Sen, concerns with regard to interpersonal comparisons.

The condition of "valuation neglect" refers to the fact that a focus limited on such mental activities as happiness and desire fulfilment leads us to ignore other, equally important mental activities such as stimulation, excitement as well as "the person's own valuational exercise – the mental activity of valuing one kind of life rather than another" (Sen, 1985b, p. 189). Sen points out that valuing is not the same as desiring, "nor is valuing invariably reflected in the amount of pain if the valued object is not obtained" (Sen, 1985a, p. 21). Such a reflective exercise on the kind of life that people value has a crucial role in the understanding and investigation of their well-being. Its centrality follows the capability framework's eudaimonistic conception of well-being.

A eudaimonistic conception of well-being. The concept of eudaimonia was defined in the introduction of Chapter I. Nussbaum (2004) specifies that it refers to "a kind of living that is *active* [emphasis added], inclusive of all that has intrinsic value, and complete, lacking nothing that would make it richer or better" (p. 61). As was mentioned in the previous chapter, the concept of eudaimonia gives prior value to activities rather than psychological states such as pleasure. In this tradition of thought, pleasure (hedonism) is not believed to be identical with happiness, even though a psychological state of pleasure "usually accompanies the unimpeded performance of the activities that constitute happiness" (Nussbaum, 2004, p. 61). The identification of such

activities, of functionings that are valuable for achieving eudaimonia, is an open and debated question in the capability literature.

Lists of valued functionings. Sen has never endorsed a precise list of valued functionings on which to base the evaluation of people's capability set (Robeyns, 2006). Relevant valued functionings, according to Sen (1999), should be developed and decided in accordance with the context under study based on some democratic process and public reasoning. The issue of whether a list of valued functionings is relevant or not and how such a list should be built has been discussed at length in the capability literature (see, Robeyns, 2006). In a nutshell, this question represents one of the major divides between Sen's and Nussbaum's conceptions of the capability framework, as Nussbaum (2000) purported the importance of this kind of lists and suggested one to be used in empirical applications of the framework (see Appendix 3). A recent example of such a list is represented by Vizard's and Burchardt's (2007) list of ten core and valued functionings, which has been developed as a framework for monitoring equality in Britain (see Appendix 3). Because of its theoretical grounding in the international human rights framework and methodological transparency, this list can be particularly relevant to identify relevant areas of investigation to evaluate the quality of life of PLWHA. Robeyns (2005) offers a methodological discussion and a series of steps to follow to identify valuable functioning to use in quality of life research.

Despite the different position between Sen and Nussbaum in relation to the relevance of a fixed list of valued functionings, both authors stress that an eudaimonistic conception of well-being implies a central role for people's freedom of choice (Nussbaum, 2000; Sen, 1988).

Freedom of choice. The activity of choosing does not always come with pleasure, but its importance from the capability framework point of view goes beyond that and it is not diminished by that fact. Such a perspective on the relationship between

freedom of choice and well-being is in contrast with recent empirical findings in the psychological literature on subjective (hedonistic) well-being (among others, Botti & Iyengar, 2004; Schwartz, 2000, 2004). This literature has challenged the importance of freedom of choice and autonomy in relation to people's subjective well-being on at least two grounds. The first ground refers to the general belief that the more options we have the better off we are (Schwartz, 2000, 2004). The second ground refers to the belief that choice carries positive consequences for people's happiness and satisfaction (Botti & Iyengar, 2004; Schwartz, 2004).

There is now a growing amount of literature from psychologists, economists, market and decision making researchers that shows how and why the belief that that the more options we have the better off we are does not always hold (see Botti & Iyengar, 2004; Schwartz, 2004). However, this criticism cannot be extended to the capability approach. In this theoretical framework, in fact, freedom of choice is concerned with "the real opportunity that we have to accomplish *what we value* [emphasis added]" (Sen, 1992, p. 32). By always specifying, in one form or another, that the importance of choice for a good life is related to "what we value", Sen certainly clarifies that the importance of choice in his theoretical framework cannot be understood primarily in quantitative terms; it does not mean the more options the better. We might not value at all possible further choices added to our capability set if they are irrelevant for us. In such a case, on the contrary, we might well have reason to prefer "a peaceful and unbothered life" (Sen, 1992, p. 63).

A long tradition of experimental research shows that individuals who afforded choices demonstrate more enjoyment and higher task performance in their selected activities compared to people to whom choice was denied. Psychological theories such as reactance (Brehm, 1966) and cognitive dissonance (Festinger, 1957) have pointed out that people evaluate the outcome of their choices more, regardless of the fact that their

choices might be incongruent with previous stated preferences, when they believe they have control over them, expect to make those choices, or perceive themselves as having exercised choice. However, a growing body of research (see Botti & Iyengar, 2004) has contended the cultural universality of those outcomes (Iyengar & Lepper, 1999), as well as the limited psychological complexity of the experimental contexts where choosing was performed. This body of research points out that results are quite different in decision contexts where the psychological burdens of making a choice are quite heavy, such as when choosing occurs among unwanted outcomes. In particular, experimental research has shown that when choosing occurs from a set of less preferred options, then choosers experience lower anticipated and experienced satisfaction than non-choosers (Botti & Iyengar, 2004). After all, Candide too, Voltaire's character (Voltaire, 1975), claimed little choice and satisfaction when offered to choose between thirty-six lashes across his back or a dozen bullets in the head. However, as mentioned, the findings of this body of psychological literature, although relevant for hedonistic conceptions of well-being, do not affect the importance of the role of freedom of choice and autonomy in relation to the achievement of eudaimonia. In fact, in the capability framework individuals' freedom represents the "building block" on which to undertake any analysis of human and societal development (Sen, 1999, p. 18). In particular, the "expansion of freedom is viewed […] both as the primary end and as the principal means of development" (Sen, 1999, p. xii). Freedom is considered intrinsically important because "it is a principal determinant of individual initiative and social effectiveness" (Sen, 1999, p. 18), therefore of people's free agency.

Sen (1999, 2002b) recognizes multiple types of freedom and that freedoms are interlinked, so the promotion of certain freedoms, for example education, sparks the raising of others, for example social and economic freedoms. In particular, Sen's

distinguishes between the “process aspect” and the “opportunity aspect” of the notion of freedom.

Process and opportunity aspects of freedom. The ‘process aspect’ of freedom concerns the ways through which people achieve outcomes (i.e. their political liberties, civil freedoms), but also psychological control, since the way in which achievements are obtained might be valuable in itself. The ‘opportunity aspect’ of freedom concerns the real freedoms that people have to lead the life they have reason to value. Therefore, if the process aspect of freedom is concerned with the question of whether the ways in which outcomes are achieved are consistent with fundamental individual liberties, the opportunity aspect is concerned with the *extent* of freedom that people enjoy. As Sen stresses, these two aspects of freedom overlap each other and are interdependent.

There are two other facets of the notion of freedom highlighted by Sen that can be considered a subset of the major distinction between opportunity and process freedom. One is the distinction between “freedom to act” and “freedom to achieve”; the other is the more classical dichotomy between “negative freedom” and “positive freedom”. For “freedom to act” Sen means “a person’s *autonomy* in the form of being able to do what she wants, and her *immunity* from interference by others” (Sen, 2002b, p. 597). For “freedom to achieve” he means “what a person is free to have or to achieve – on the basis of her own actions and those of others” (Sen, 2002b, p. 597). Evidently the opportunity aspect of freedom is more concerned with the “freedom to achieve”, while the process aspect of freedom with the “freedom to act”. The distinction between “freedom to achieve” and “freedom to act” is also related to the other, more classical dichotomy between ‘negative’ and ‘positive’ freedoms. The expression ‘negative freedom’ has been defined in several different ways, as well as the term ‘positive freedom’. Definitions of freedom are mostly “concerned with one aspect of the freedom to achieve, namely, the aspect of freedom from the limitations imposed by the world

outside (as opposed to ‘inside’ oneself)” (Sen, 2002b, p. 586). There are definitions, however, which are mainly connected with the freedom to act, therefore with people’s autonomy and immunity from interference by others. The concept of positive freedom can refer both to the freedom to achieve in general and to the “freedom to achieve insofar as it relates to influences working within oneself” (Sen, 2002b, p. 586). What is important to point out here is that the capability approach suggests a more inclusive definition of positive freedom. Positive freedom, in fact, is defined by Sen “as the person’s ability to do the things in question *taking everything into account*, including external as well as internal limitations” (Sen, 2002b, p. 586). Therefore, elements of internal and external limitations should be accounted for in any assessment of people’s well-being. With regard to internal limitations, a variety of psychological constructs can help to explain people’s experiences of positive freedom (see Chapter III for a revision of some). With regard to people’s external limitations, the sociological and political science analyses of the concepts of opportunities and life chances can be helpful to understand the social mechanisms that constrain people’s freedom to act. The mentioned psychological and the sociological constructs will be discussed in Chapter III, where a model of perceived opportunities will be offered and their exploration will become relevant.

Well-being and agency. Sen (1985b) points out that the pursuit of well-being, namely of functionings that generate eudaimonia, is one dimension only of human beings’ behaviour. “Values other than the pursuit of well-being may figure prominently in a person’s assessment of choices” (Sen, 1985b, p. 203). These other goals and values take the name of *agency* goals and values. The concepts of agency and well-being are conceptually distinct, but certainly not independent of each other (Sen, 1985b, 1992). In order to better explain the concept agency the following example can be helpful. Consider a medical doctor who decides to give up his or her well set-up practice in

Sydney to go on a mission to medically assist sick children in some politically unstable underdeveloped country. By taking such a decision that doctor could pursue goals and objectives, for example social justice that might not be directly connected with wanting to promote his or her own personal well-being. At the same time, the intensity and level of involvement with that choice might not be confined at all by the extent to which his or her personal well-being is advanced. In fact, as a consequence of his or her choice that doctor might be kidnapped by some group of local rebels, or suffer from some local infectious disease, all events that can be considered detrimental for his or her own well-being intended as specified above. In the hypothesis that these last accidents occur to the doctor, the fact that he or she would score quite low in terms of achieved functionings in those circumstances, because of being secluded in a jail or ill in a bed, cannot be accounted as a reflection of a failure of evaluation or action. We can assume that the capability set of the doctor gave him or her plenty of good opportunities to achieve well-being, it happens that, totally legitimately and rationally, she decided otherwise. This is another reason why the well-being aspect of individuals should be assessed not only in terms of actual achievements, but also in terms of freedom to achieve.

The concept of quality of life in the capability framework

The way in which the concept of quality of life is discussed and operationalised in the capability framework is discussed in relation to both Sen's and Nussbaum's works. Other scholars' contributions to the operationalisation of this concept will be reviewed last.

The concept of quality of life in Sen's work

Sen has never directly dealt, on a theoretical and methodological basis, with the issue of quality of life and its measurement as such, certainly not with that same depth

of analysis and insight which his readers and students are used to. For example, despite the fact that Sen has been co-editor with Martha Nussbaum of an important book titled 'The quality of life' (Nussbaum & Sen, 1993), his contribution in that book was titled 'Capability and Well-Being' and in the entire text the expression quality of life appears, if I have not miscounted, one time only in the following passage: "The [capability] approach is based on a view of living as a combination of various 'doings and beings', with quality of life to be assessed in terms of the capability to achieve valuable functionings" (Sen, 1993a, p. 31). Also, the term quality of life does not appear in the list of some of the social issues to which Sen has attempted to apply the capability approach (see note 1 in Sen, 1993a). The expression quality of life is not listed in the subject index of one of his most important works, "Inequality re-examined" (Sen, 1992), even though it appears here and there in the text. It is listed in the subject index of one of the empirical studies in which the capability framework has found an application (Sen, 1999), but not in others (e.g. Dreze & Sen, 2002). The expression "well-being," to give a benchmark, is listed in the subject index of all his cited works.

Sen uses the expression quality of life in two ways. On the one hand, the expression quality of life is used to refer to the corresponding and independent field of study. In this case, Sen intends to stress that this field of study has evolved in such a way as to embrace a wider informational basis compared to that typically adopted in economic development studies, which often only focus on GDP per capita. This happens, for example, in the following passage:

> It should […] be noted here that the freedom-centered perspective has a generic similarity to the common concern with 'quality of life', which too concentrates on the way human life goes (perhaps even the choices one has) and not just on the resources or income that a person commands (Sen, 1999, p. 24).

On the other hand, Sen refers to the notion of ‘quality of life’ as the specific concept that assesses the well-being of individuals. In this meaning, it is suggested that quality of life is best evaluated in the informational space given by the capability set. However, this definition seems to equate the concept of quality of life to that of well-being.

Gasper (2004) discusses Sen’s concept of quality of life by referring to two sets of core distinctions within the capability framework, namely *agency* and *well-being*, and *achieved functionings* and *potential functionings*. Table II-1 shows Gasper’s (2004) proposal; the first column shows that the concept of standard of living (Sen, 1987) is a subset of the more general concept of well-being. Standard of living refers to that particular type of condition of individuals that takes into consideration only those influences on the well-being that come from people’s own life. This implies the exclusion of any influences that are the outcome of ‘sympathy’ (Sen, 1987), namely improvements in an individual’s well-being that follow the good that others experience. An example of such an improvement is given by a good deed; in this case the provision of help to another individual might have the effect to promote the well-being not only of the person who enjoys the help, but also of the helper through the experience of the reduction of the other individual’s misery. On the other hand, the concept of well-being contemplates all the positive and negative influences that are generated both internally and externally of people’s own life. The second column, refer to the pursuit of goals and values that are not necessarily and directly related to the improvement of well-being and, consequently, are agency related.

Table II-1

A fourfold table of two core distinctions of the capability approach: well-being/agency and achievement/freedom

	Well-being	Agency
Achievement	Well-being achievement Standard of Living (exclude sympathy)	Agency achievement
Freedom	Well-being freedom Standard of Living Freedom (exclude sympathy)	Agency freedom

On the basis of Table II-1, Gasper (2004) suggested that the term ‘quality of life’ in Sen’s view might fit the agency column or represents an evaluative summing-up of agency achievements and well-being achievements, or, even, of the all table. However, by saying this, Gasper misses two points. First of all, he disregards Sen’s main focus on capabilities, in other words on the last row of table 1. Gasper’s main interest, in fact, is in developing theoretically the analysis of that table in terms of the contrast between columns, not between achievement and freedom to achieve, as Sen does (Gasper, 2004). At the same time, by pointing out the possibility that the domain of analysis of the notion of ‘quality of life’ might be the agency column or also the whole table, Gasper underestimates a potential methodological problem in such an assessment. This consists of the fact that those two ways of operationalising the notion of quality of life imply mixing potentials and achievements, two conceptually different things.

An alternative interpretation of the concept of quality of life in the capability framework is suggested in Table II-2. This assumes that Sen’s defines quality of life as a measure concerned with individuals’ well-being. The originality of Sen’s contribution rests on the theoretical effort aimed at identifying a category of analysis for quality of life that would be able to give an evaluation of people’s well-being which is as

comprehensive as possible. Therefore, according to this interpretation of Sen's works, the concept of quality of life is not to be found in the comparison between the columns of Table II-2, in other words by analysing that table horizontally, but in the well-being column. From this point of view, the concept of quality of life can be seen as the most complex and articulated form of evaluation of well-being conceived in the capability framework. If I can use the metaphor of a scale, then the concept of standard of living is the most restricted form of evaluation of individuals' well-being; it consists of an objective assessment of people's financial circumstances, e.g. their income and assets, and represents the lowest end of the scale. The concept of 'well-being' represents a more comprehensive form of assessment of individuals' well-being, since it is concerned with assessing people's perceptions, both emotionally and cognitively, of their own circumstances, from their work environment, social life etc. to their life as a whole; it represents the middle point of the scale. The concept of quality of life represents the most comprehensive form of assessment of individuals' well-being; it consists of both subjective and objective assessments of people's own circumstances. Subjective assessments of quality of life are identical to well-being evaluations, so the two expressions can be and are usually used interchangeably. Objective assessments of quality of life differ from standard of living because they do not only focus on people's income, but include their housing and wider environment, e.g. the level of environmental pollution, the availability of public/private transport, etc.

Table II-2

An original interpretation of the concept of quality of life in the capability framework

		Well-being	**Agency**
Direction of the level of generality of the different concepts of well-being assessment	**Achievement**	Quality of life achievement ↑ Well-being achievement ↑ Standard of Living achievement	Agency achievement
	Freedom	Quality of life freedom ↑ Well-being freedom ↑ Standard of Living freedom	Agency Freedom

I think that this interpretation does not contradict the eudaimonistic conception of well-being on which the capability framework is based, since, as mentioned above, the concept of eudaimonia gives prior value to activities, therefore to all those dimensions that can be traced back to individuals as rational agents, not primarily as passive receiver of contextual circumstances (as it is when undertaking living of standard evaluations). Such an interpretation is valid for both the quadrants well-being achievements and well-being freedom.

An alternative interpretation of quality of life in the capability framework would imply relating this concept not to that of well-being, but rather to that of ‘advantage’. The concept of advantage refers to “a person’s real opportunities compared with others” (Sen, 1985a, p. 5). As evident, the word advantage seems to be a synonym of capabilities; so it could be argued that investigating quality of life using the capability framework implies investigating people’s advantage (or disadvantage) in society, rather

than their well-being. Here, it is suggested that both interpretations are legitimate and in line with the current types of definitions of quality of life (see Chapter I). However, the consequences of framing the investigation of quality of life in one concept rather than the other concept are yet to be explored and understood in the literature.

The concept of quality of life in Nussbaum's work

Nussbaum (2000) discusses the concept of quality of life both in relation to individuals and societies. With regard to the quality of life of individuals, she points out that:

> The central question asked by the capabilities approach is not, 'How satisfied is Vasanti?'[1] or even 'How much in the way of resources is she able to command?' It is, instead, 'What is Vasanti actually able to do and to be?' (p. 71).

Evidently, the focal variable chosen in order to assess individuals' quality of life is their opportunity freedom. As already mentioned, Nussbaum suggests referring to a universal list of capabilities when applying the capability approach to political purposes. Therefore, referring to that list, she further suggests that the capability approach should ask:

> Is the person capable of this, or not? We ask not only about the person's satisfaction with what she does, but about what she does, and what she is in a position to do (what her opportunities and liberties are). And we ask not just about the resources that are sitting around, but about how those do or do not go to work, enabling Vasanti to function in a fully human way" (Nussbaum, 2000, p. 71).

The assessment of quality of life at a macro level of analysis bears similar characteristics; however Nussbaum's description of the questions to be asked shows

[1] Vasanti is the name of one of the subjects studied by Nussbaum (Nussbaum, 2000).

also clearer elements of similarity with the concept of empowerment. This refers to the enhancement of "an individual's or group's capacity to make choices and transform those choices into desired actions and outcomes" (Alsop & Heinsohn, 2005, p. 5)

> How well have the people of the country been enabled to perform the central human functions?' and, 'Have they been put in a position of mere human subsistence with respect to the functions, or have they been enabled to live well?' (Nussbaum, 1995, p. 87).

Nussbaum's descriptions of the aims of an analysis of people's quality of life based on the capability framework offer us some interesting insights. They show that even though the capability framework does not recognize as a focal variable, for example, people's satisfaction with one's functioning, however it does not rule out the possibility that that variable can be meaningful in assessing people's quality of life. People's satisfaction, for example, can be used in quality of life assessment as far as it gives information on what their opportunity and liberties are. However, when it comes to deriving a methodology to reach that goal, Nussbaum too falls short of providing one.

Measurement of the capability framework

In discussing the measurement of capabilities, Comim (2008) suggested that both qualitative and quantitative indicators can provide important information for their measurement. In particular, he identified four questions that any operationalisation of the capability framework should take into account: the valuational foundation of the capability framework, its counterfactual nature, human diversity, and objectivity. The valuational foundation refers to the need to identify the functioning that people have reason to value and their weighting; it implies the question of the list of valuable functioning that was mentioned above. The question of human diversity refers to the need to use the tenets of the capability framework as empirical hypothesis and to use

people's characteristics and socioeconomic background, i.e. their diversity factors, as control variables. Objectivity refers to the need to avoid the adaptive preference problem, which was mentioned above, and therefore the need to move towards objective assessments of people's opportunities. The counterfactual nature of the approach refers to the nature of opportunities as potentials, so not actualities that can be observed, but possibilities that can be inferred as ready available if people would engage with them. This question partly implies that of agency and people's autonomous choice that was mentioned above; in fact, it requires understanding whether people do not pursue certain options for autonomous choice or rather because those options are not there for them to choose. The first two questions do not offer major challenges to the operationalisation of the concept of capabilities. The questions of what are the relevant domains for the evaluation of quality of life and of relevant control factors to account for in the analysis of quality of life have characterised this field of research since its start (see Chapter I and also Alkire, 2002). The last two questions, objectivity and the counterfactual nature of the capability framework are the most challenging for its operationalisation and will be the object of the remaining of this chapter and the following.

Both the questions of objectivity and of the counterfactual nature of capabilities are related to the issue of the type of data that are used to elicit and analyse them. Sen suggests that there are three main sources of data for the application of the capability approach: market purchase data, responses to questionnaires, and non-market observations of personal status. The main problem with both the observation of people's functioning and the use of questionnaires is the risk to elicit data affected by the adaptive problem. To this end, Sen (1993b, 1994, 2002a) suggests that questionnaires and observation of people's functionings should be undertaken within a specific epistemological perspective, which he calls 'positional objectivity'. The concept of

positional objectivity has a central role in Sen's perspective on the role of subjective and objective indicators in quality of life research, and I will now discuss it.

The concept of positional objectivity Sen argues that "the idea of objectivity requires explicit acceptance and extensive use of variability of observations with the position of the observer" (Sen, 1994, p. 115). By pointing this out he suggests considering positionality "as a parametric feature of objectivity" (Sen, 1994, p. 115) and, consequently, disentangling the idea of positional perspective from that of subjectivity. This leads Sen to question "the tradition of seeing objectivity in the form of invariance with respect to individual observers and their positions" (Sen, 1993c, p. 126), of which one of the main interpreters is Thomas Nagel (1986). As an alternative to this classical perspective on objectivity Sen suggests distinguishing between the concept of "positional objectivity", "which is a claim regarding the objectivity of observations from a certain position" (Sen, 1994, p. 115), and "transpositional objectivity", which draws on but goes beyond different positional observations, since it consists of synthesizing, in some coherent way, different views from distinct positions (see Sen, 1993c; Sen, 1994). The main characteristic of the concept of positional objectivity is that a certain observation, in the widest sense of this expression – therefore including observations of signs and symbols – can be considered objective in so far as it is accessible to and understandable by others once an extensive specification of the circumstances and mental states that led to it is provided (see Sen, 1993c, 1994). In the positivistic tradition, the concept of positional objectivity evidently overlaps with that of subjectivity, since "every view or opinion could be made positionally objective by some appropriately thorough specification of positional parameters" (Sen, 1993c, p. 137). The extension of the overlap varies according to the kind and amount of mental tendencies

and other individual features that are accounted for in deciding what can be considered positional objectivity.

Both the concept of positional objectivity and that one of transpositional objectivity draw on an interpretivist view of knowledge. Sen does not claim, in fact, that observations consist of the direct access to some ontological reality, but rather that they depend and are the outcome of the positional conditions of the observers, which in turn can be influenced by the results of observations (see Sen, 1994, p. 116). This means that the positional characteristics of a certain observation need to be analyzed in order to understand and explain the content of the observation. Outside such an analytical approach and focus on the positional conditions that generate observations, the risk of a possibly defective use of knowledge is quite probable. Sen brings the example of statistics based on self reported morbidity. If we should rely on self reported assessments of morbidity, then the United States is far less healthy, as a country, than Bihar, which is an Indian state with medical and educational facilities of the lowest level. This latter state, in fact, has far lower rates of reported morbidity than the United States. However, as Sen points out, there is:

> Much evidence that people in states that provide more education and better medical and health facilities are in a better position to diagnose and perceive their own particular illnesses than are people in less advantaged states where there is less awareness of treatable conditions (Sen, 2002a, p. 861).

In general terms, Sen suggests always analyzing and interpreting the statistics on self perception by taking note of contextual factors. He is suggesting somehow to interpret, to comprehend self assessment data. The comprehension of their meaning should be undertaken by referring to the positional factors that are beyond them. However, since Sen does not develop his epistemological perspective, questions such as: what factors should be considered as relevant?, why knowledge is positional?, and

what is the role of the social actors' common sense constructs compared to the social scientist's theories in accounting for the statistics on self perception?, do not find any answers. Nevertheless, I believe this interpretivist element of Sen's approach to be the keystone on which it is possible to build a sound ground for the operationalisation of functionings and capabilities in survey research, both by means of subjective and objective indicators. In order to do this, however, it is necessary to place the idea of positional objectivity within a more inclusive and developed interpretivist framework, such as one of the theoretical frameworks that belong to the interpretive paradigm.

The phenomenological sociology of Alfred Schütz

With the expression 'interpretive paradigm' I mean to refer to those schools of thought – phenomenological sociology, symbolic interactionism, and ethnomethodology – which have their foundation in the sociology of Max Weber and that, beyond their distinctive theoretical characteristics, share the common assumption of the impossibility of a form of knowledge that does not imply a cognitive process of comprehension of meanings. In particular, I suggest that, among those schools of thought, the phenomenological sociology founded by Alfred Schütz (Schütz, 1962a, 1972; Schütz & Luckmann, 1973) represents the most suitable theoretical framework for developing an interpretivist foundation of the capability framework. Consequently, that is the theoretical framework within which I will develop my approach to the operationalisation of the capability approach. I will introduce and discuss that theoretical framework in more depth in Chapter III. For now, I limit myself to specifying the reasons for which I believe that that theoretical framework offers the most solid interpretivist ground for the operationalisation of the capability approach.

There are at least three main reasons behind my suggestion. Firstly, even though the phenomenological sociology assumes the process of comprehension of meaning as a

constitutive element of both the everyday and the scientific knowledge, compared to the ethnomethodological approach to social science, it does not imply a dissolution of social science as an independent and external form of knowledge compared to the everyday common sense of the layman (Muzzetto, 1997). Secondly, compared to symbolic interactionism, it offers an understanding of the way in which social actors construct their 'natural attitude', namely their belief in reality and the social world, as well as the ways in which meanings are constructed in the social world. Thirdly, compared to approaches such as grounded theory (Strauss & Corbin, 1990), it offers a complex theoretical framework within which it is possible to conceptualize and ground the relationship between scientific theory and empirical findings.

Drawing on the theoretical framework of the phenomenological sociology of Schütz means to look first for a clarification of the condition of possibility of capabilities, both from a cognitive and a social point of view. This means investigating what factors affect, both cognitively and socially, the social actors' perception of opportunities, as well as of their freedom of choice. These questions will be addressed in the next chapter. Here I will keep discussing the consequences of placing the idea of positional objectivity within the more inclusive and developed interpretivist framework represented by phenomenological sociology.

Within the phenomenological framework, the issue of adaptive preferences would not be considered a potential source of biases for people's assessments, but the object of comprehension. In particular, Sen's suggestion to always analyse and interpret the statistics on self perception by taking note of the contextual factors behind them could be fully embraced by grounding it within Schütz's complex analysis of the 'multiple realities' of which the social world consists and, particularly, of the relationships between the everyday life world and the scientific formal world. In the phenomenological approach, in fact, the traditional topics of the methodology of social

research are addressed and developed within the theoretical framework offered by the analysis of the possible relationships between the layman's everyday life world and the scientist's formal world (Giuntoli, 2001). Questions that do not find any answer in Sen's epistemological reflections, in particular: what contextual factors should be considered as relevant in interpreting the statistics on self perception?, and what is the role of the social actors' common sense constructs compared to the social scientist's theories in accounting for the statistics on self perception?, would find theoretically underpinned answers in the phenomenological framework. The meaning of the distributions and statistics on self perception in general, and of capabilities in particular, would neither be self disclosed in the data matrix, nor found only in the analysis of the data on the basis of the social scientist's formalised knowledge – as Sen suggests –, nor found in the analysis of people's perspective and their contextual circumstances alone, as ethnomethodology suggests. Schütz's analysis of the relationships between the everyday life world and the scientific formal world, and the methodological literature that developed from it (Cicourel, 1964), suggest that the meaning of statistics and distributions of data, no matter if of primary or secondary data, should be looked for in the combined analysis of the information contained in the statistics, people's contextual circumstances and common sense constructs, and the social scientist's scientific knowledge formalised in his or her ideal types. To this end, it is fundamental that the social scientist makes explicit the model of the actor that underpins the collection first, and the analysis then, of the data to be studied. In the last analysis, this is my suggestion, that the phenomenological sociology offers a theoretical framework that strengthens the epistemological and theoretical foundations of the capability approach. A sound epistemological and theoretical foundation enables us to address Sen's worries about self assessed data in a comprehensive, theoretically underpinned way that allows us to take into consideration the role of the knowledge of both the responders' and the

social scientist's in accounting for the elicited data. In this way, Sen's intention to achieve an objective criterion of well-being that does not ignore the personal features which differentiate social actors can be fully embraced.

Overall, the interpretivist element of the capability approach has not been pointed out and developed in any of the contributions of the capability literature that have addressed the question of the operationalisation of the capability framework. For example, Teschl & Comim (2005) and Comim (2005) critically addressed the phenomenon of adaptive preferences and its consequences on the operationalisation of the capability framework from a completely different perspective. They discussed Kahneman's concept of 'objective happiness' (Kahneman, 1999), which consists of a methodological attempt, by means of instant measures of hedonic and affective experiences, to bypass people's tendency towards various forms of adaptation to their situation, for example the phenomenon of the 'satisfaction treadmill'. This phenomenon consists of people's tendency to feel less satisfied than they previously expected once a certain desired goal is achieved. The objective happiness approach implies a theoretical and methodological focus on time rather than meaning. However, it is not by trying to neutralize the time factor that a more objective picture of the situation of the individuals' well-being will be reached. No matter how small is the fraction of time in which a certain behaviour is elicited, that behaviour, unless it is a mechanical reflex, is still a production of meaning and as such should be addressed.

Within an interpretivist perspective, questionnaires generate "defective" outcomes (Sen, 1985a, p. 47) when they are used as a technology to neutralize the subject, rather than as a means to elicit their constructs. From this point of view, the objective happiness approach, despite being based on subjective answers, attempts to neutralize as much as possible the individuals' cognition and reflective nature, since these are elements that are considered sources of bias. This characteristic of the

objective happiness (Gasper, 2005) approach resembles the positivistic attempts to exclude as much as possible the influences of the subject from the purity of the data.

In other contributions of the capability literature, such as Gasper (2005), the concepts of subjectivity and objectivity respectively mean feeling or non feeling related indicators of well-being. Such a distinction, even though heuristically valid, does not address the central question of the kind of information on which the interpretation of those indicators should be founded.

Operationalisation of the capability framework

According to Nussbaum and Glover (Nussbaum, 1995), the Human Development Reports of the United Nations Development Program represent the most important examples of research projects that collects information and rank nations in accordance with the principles of the capability framework. However, there is no consensus in the community of scholars who study and apply this framework on how much the Human Development Reports actually represents an operationalisation of the capability approach (Comim, 2008). At the individual level of analysis, the Scandinavian welfare research tradition (Allardt, 1993; Erikson, 1993) has been suggested as another example of research program that, in accordance with the capability framework, investigated original dimensions of quality of life, such as loving and caring. However, those dimensions were investigated in the informational space of achieved functionings, not in that of capabilities.

Overall, the vast majority of studies that have operationalised[2] the capability framework have focused on people's functionings. Although the originality of the capability framework consists primarily on the concept of capabilities, as Sen (Sen,

[2] The concept of operationalisation is here intended in the classic meaning of this expression in social research: the development of specific operations through which a concept is transformed into a measurable variable (Babbie, 2002). In survey research this includes the wording of questionnaire items.

1985a) points out, the complex information that is required in order to assess them is not ready available and might be difficult to collect. Consequently, most scholars, Sen included, have applied the capability framework by evaluating people's well-being and quality of life in the informational space of their achieved functionings (e.g. Brandolini & D'alessio, 1998; Chiappero Martinetti, 2000; Roche, 2008). In such cases, the capability framework still offers two original contributions; its eudaimonistic nature and a certain emphasis on the need of more objective ways to assess people's quality of life.

It is worth mentioning that, although capabilities are individual characteristics, Sen has always operationalised them using macro-level variables, such as average education level and life expectancy (e.g. Dreze & Sen, 2002; Kynch & Sen, 1983; Sen, 1999), and has not provided examples of their operationalisation at the micro-level of people's direct experiences. I suggest that the choice of indicators of capabilities and, therefore, the decision regarding the type of data to be used for their investigation, can be best understood referring to a proximal-distal continuum of indicators of capabilities. In particular, it is useful to look at such proximal-distal continuum in relation to a time scale (see, for example, Green & Tones, 1999). Examples of distal indicators of capabilities are those used by Sen in his empirical analyses. In this case, capabilities consist of life-chances, that is they indicate how likely individuals with different characteristics are to experience a certain outcome. Examples are the proportion of children from poor backgrounds that experience poverty in adulthood, or who graduate from university, or the mortality risks of children of different socio economic backgrounds (see, for example, Fabian Society, 2005; F. Field, 2010). This type of indicators is relevant to compare people's capabilities across time or different countries. However, they are not as useful to evaluate the efficacy of social policy interventions aimed at expanding people's capabilities, specifically those implemented at the community level, or the capabilities that characterise specific social groups. In fact, the

effects of interventions aimed at expanding the capabilities of specific groups may generate effects on distal indicators, specifically the epidemiological ones, after many years and may be influenced by a wealth of other factors difficult to control. When the concept of capabilities is operationalised using distal indicators, the originality of the capability framework is not at the measurement level; life chances is indeed a well-known concept that has a long tradition in sociology (see the discussion of this concept in the next chapter). On the contrary, its originality consists of its emphasis on the importance of issues of distributive justice in the assessment of quality of life. Proximal indicators, by which I mean indicators of capabilities at the micro-level of analysis, i.e. at the level of people's experiences, seem to be the best option when one intends to assess what opportunities are available to specific groups of people. In particular, it can be expected that changes in proximal indicators of capabilities are more likely to be due to the direct impact of specific interventions aimed at expanding people's capabilities, specifically those run at the community level.

There is a growing literature that attempts to operationalise capabilities using proximal indicators (see Chiappero-Martinetti & Roche, 2009; Samman, 2007; Burcahrdt & Vizard, 2011). For example, Ruta, Camfield and Donaldson (2006) suggested to assess quality of life by evaluating the gap between desires and capabilities through a measure of utility. Although legitimate, it is not clear how such a proposal would escape the physical-conditions and valuation neglects limits that were mentioned in Chapter II. Another example consists of a series of studies that had as a specific focus the operationalisation of capabilities in survey research (Anand & Hees, 2003; Anand et al., 2009; Anand, Hunter, & Smith, 2005; Anand & van Hees, 2006). These studies are particularly relevant in relation to the focus of this thesis, which is on proximal indicators of capabilities, specifically when this concept is intended as opportunities. In those studies, Anand and colleagues (2003, 2009, 2005) have not offered a discussion of

the frameworks, either epistemological (e.g. the issue of positional objectivity) or theoretical (e.g. what model of social actor is implied in their analyses), which guided their choice of indicators of capabilities. As it was discussed above, conceptualising capabilities as freedoms rather than opportunities is not indifferent as it implies referring to different bodies of research and theoretical frameworks when it comes to their operationalisation. Anand and colleagues (2009) conceptualised capabilities as freedoms, however, questions such as what freedoms are, what model of the actor is implied by a certain way of understanding and eliciting freedoms (i.e. what cognitive, emotional, agency characteristics does a certain way to understand freedom implies), have not been addressed. In a first attempt to elicit capabilities, Anand and colleagues (2005) conceptualised capabilities as opportunities, but, in this case too, the authors did not specify their understanding of what opportunities are and how these should be elicited. Anand et al. (2005) and Anand et al. (2009) simply followed a procedure of selection of face valid indicators of capabilities from the British Household Panel Survey. This was the only warrant given regarding why the suggested items should be considered as indicators of respectively opportunities and freedoms, rather than anything else. Within the epistemological stance that is here taken, the lack of more specific theoretical and methodological warrants to underpin the operationalisation of capabilities, either as opportunities or freedoms, represents a substantial limit of these studies. Although this is a common approach in mainstream survey research, it implies that researchers use their commonsensical understanding of the concepts being operationalised and that such an understanding, which is taken for granted and never made explicit, is shared by anyone else, in particular study participants and readers of the study. Within the interpretivist epistemological framework of Schütz's works, particularly as developed by Cicourel (1964), researchers are asked to make explicit their understanding of the concepts being investigated by indicating what model of

social actor they implicitly rest on. This helps to make more transparent and therefore more open to scientific discussion the operationalisation and measurement of any concept in the social sciences, capabilities included. These questions will be taken up in the next chapter, where the cognitive and meaning-making elements involved in people's perception of opportunities will be investigated.

Concluding remarks

This chapter has introduced the two core concepts of the capability framework, functionings and capabilities, and has offered a discussion of how the concept of quality of life has been discussed in it. Questions related to the measurement of capabilities intended as opportunities were discussed. In particular, it was suggested that referring to the concept of proximal-distal continuum of indicators could be of help when choosing the level of analysis and the type of indicators to operationalise capabilities. It was also suggested that the Sen's (1993c, 1994) concept of positional objectivity represented a keystone on which to build the operationalisation of functionings and capabilities, both by means of subjective and objective indicators. Positional objectivity was interpreted as an interpretivist perspective that could be strengthened by referring to the far more developed theoretical framework of the phenomenology of Alfred Schütz. This approach asks researchers to make explicit the model of the actor that is implied by the operationalisation of the concepts to be investigated. Consequently, in the next chapter, I will explore and elaborate the psychological and sociological literature on people's perception of opportunities, which will set the basis for a proposal on how to operationalise and elicit the concept of opportunities.

CHAPTER III

THE PERCEPTION OF OPPORTUNITIES

In this chapter, I aim at investigating the literature that can help us to identify and understand the underlying mechanisms by which people construct the meaning of their experience of opportunities in everyday life. My goal is to address the concept of opportunity in a 'content free' manner. By this I mean that, in this chapter, I do not study one or more specific types of opportunities, therefore, I do not try to answer questions such as: "*why* social actors experience more X opportunities in such and such a situation and not in this other one?", but rather I focus on the following more basic questions: "*what* are the main components and processes that characterize the experience of opportunities in people's everyday life?", "*what* cognitive mechanisms (consciously held beliefs and opinions), affective mechanisms (emotional tone and feeling), motivational mechanisms (disposition for action) and evaluative mechanisms (positive or negative) tend to characterize the experiences of opportunities in people's everyday life?", and "*what* social processes tend to affect those components and processes?". I believe that without first answering these latter questions, without first achieving an understanding of the foundations of the phenomenon of opportunity, every attempt to operationalise it in quality of life survey research will fall short of providing a sound theoretical and methodological basis.

In order to answer those questions I first examine how the phenomenon of opportunities has been conceptualised and operationalised in quality of life research. I then build on the findings from the quality of life studies by reviewing the main studies that have addressed the conceptualisation and operationalisation of opportunities in psychology and sociology. The consequences of each approach for the operationalisation of the concept of opportunities are pointed out and discussed.

The concept of opportunity in quality of life research

It is probably possible to identify an indirect reference to the concept of opportunity, intended as possibilities, in any quality of life index that is available in the literature. Nevertheless, only a very limited number of scholars referred to opportunities in defining or conceptualising quality of life. An example is Lehman (1995), who proposed that:

> The quality-of-life concept encompasses what a person is capable of doing (functional status), access to resources and *opportunities* to use these abilities to pursue interests, and sense of wellbeing. The former two dimensions are often referred to as objective quality of life and the latter as subjective quality of life (p. 94, emphasis added)

Lehman (1995) seemed to consider the investigation of opportunities as achievable through objective indicators; however, he did not discuss how to do this. Here I will discuss three main studies that have used and discussed the concept of opportunities in quality of life research: Patrick and Erickson (1988), Veenhoven (2000, 2006), and Omodei and Wearing (1990). I use the discussions undertaken in these studies to identify some crucial characteristics of the concept of opportunity, which I then further develop.

Patrick and Erickson (1988) defined health related quality of life as "the value assigned to the duration of life as modified by the *social opportunities*, perceptions, functional states, and impairments that are influenced by disease, injuries, treatments, or policy" (p. 104, emphasis added), where the value assigned to the duration of life varied between 0.0 and 1.0. They suggested that, at the top of the continuum of health-related quality of life there is "*the opportunity* or *potential* for an optimal state of health for an individual or a group" (p. 105, emphasis added). Patrick and Erickson (1988) referred to

opportunity and potential as elusive concepts to measure, and suggested to intend them in terms of either handicap or resilience. The concept of handicap was used as a synonym of disadvantage: "when a person with disease or disability is denied the opportunities generally available in a community for the fundamental elements of living [they previously mentioned social access to the environment, to education and training, and to employment], he or she experiences a disadvantage" (p. 105). They defined disadvantage as a social phenomenon that needs to be assessed relatively to others through three stages of measurement. First, by assessing the social norm or average status of the group to which a person belongs, so for example the average unemployment rate of people aged 16-64. Second, by identifying people with health problems which prevent to work or limit them in their job options. Third, by assessing the opportunities for achieving the normative status, so for example "the *availability* of employment, or the labour force participation rate of disabled people compared with that of persons with no disability" (p. 106, emphasis added). Patrick and Erickson (1988) did not specify further the implications of assessing people's opportunities, but concluded that "more direct approaches to identifying who is unable to obtain employment, education, housing, or insurance because of health are needed to assess the opportunity of individuals and groups with health-related problems" (p. 106).

Patrick and Erickson (1988) defined resilience as the capacity to cope or withstand stress, so people's capacity to maintain emotional equilibrium after having experience a major stress[1]. They then suggested the use of measures of coping as a way to evaluate people's capacity to deal with stress. Here stress and resilience are considered as factors that can affect certain dimensions of quality of life as measured

[1] There are other definitions of resilience in the literature. For example, Norris, Tracy, and Galea (2009) suggested that the concept of resilience should be distinguished from that of 'resistance' and that it is better described as some people's capacity to 'bounce back' to the state of well-being that preceded a significant stress. So, it refers to some people's capacity to quickly regain their original level of well-being and functioning after these worsened because of some major distress.

through opportunities; however, they do not add anything to the understanding of opportunities as such.

As mentioned in Chapter I, Veenhoven (2000, 2006) distinguished between the concepts of "opportunity for a good life" and "the good life itself". This distinction represents "the difference between potentiality and actuality" (Veenhoven, 2000, p. 3), which are referred to respectively with the expressions 'life chances' and 'life results'. Veenhoven (2000) specified that the concept of life chances was to be intended in a more inclusive way compared to the classical sociological meaning of 'environmental opportunities', which he labelled environment 'livability' and defined as a fit of people's environment with their needs (Veenhoven, 1996, 2000). Therefore, Veenhoven (2000) identified a second dimension of the concept of life chances, that of 'life-ability', which he referred to as 'inner life-chances', namely "how well we are equipped to cope with the problems of life" (Veenhoven, 2000, p. 4). In a recent article, Veenhoven (2010) suggested that the concept of capabilities shares with that of life chances the fact of having a double meaning: freedom from external restrains and personal skills. He then suggested that this characteristic of both the concept of life chances and capabilities represents a limit for at least two main reasons: the fact that the concepts are too wide and generic, and that their dual nature is such that one loses sight of the interrelations between environmental demands and personal skills. Consequently, he suggested focusing on one element only of each concept; in particular he analysed that of life-ability.

Veenhoven's (2010) analysis highlighted the need, which was pointed out in the previous chapter, to clearly distinguish between the concept of opportunities and that of freedom when operationalising capabilities. Because in this thesis the concept of capabilities is intended as opportunities, Veenhoven's (1996, 2000, 2010) works leave unanswered questions such as whether opportunities can be actually defined as life

chances and, if so, whether individuals' inner qualities[2] can be considered as opportunities.

The final work that I would like to discuss here, that of Omodei and Wearing (1990), concerns the investigation of the elements of congruence between telic and autotelic theories of subjective well-being.

Autotelic theories of well-being locate the origin of positive human experience in the activities involved in the attainment of certain end states, which can be either the satisfaction of needs or the achievement of particular goals (Diener, 1984; Omodei & Wearing, 1990). An example is Csikszentmihalyi's (1985, 1991) theory of 'flow'. The concept of flow or involvement refers to those particular types of experiences that are intrinsically motivated and generate positive affect even though they do not present any obvious extrinsic rewards.

Telic theories find the origin of well-being in the achievement of desired end states – which can consists of either needs (e.g. Maslow, 1954) or goals (e.g. Klinger, 1977) – rather than in the movement towards those end states, in the activities involved in the achievement of those end states. Omodei and Wearing (1990) highlighted two major points of convergence between telic and autotelic theories of subjective well-being:

- both positions acknowledge the importance of the alternative approach as representing an independent account of the origins of well-being, and
- both suggest that people are more likely to allow themselves to become involved in activities that they perceive to be likely to meet their needs.

[2] The concept of inner qualities is one of the two elements – the other is outer qualitites – of the second dichotomy at the basis of Veenhoven's 1996 fourfold typology of quality of life concepts (see Chapter I). The first dichotomy is life-chances/life results.

The second point of convergence is of central importance and it introduces us to the discussion of two relevant analyses on the topic of the perception of opportunities. In fact, Omodei and Wearing (1990) offer a theoretically underpinned hypothesis about the causal relationship between perceived opportunities for need satisfaction and involvement, and a first theoretical analysis of the cognitive nature of perceived opportunities.

Omodei's and Wearing's (1990) hypothesis about the causal relationship between perceived opportunities for need satisfaction and involvement was conceived in the following terms: "the *perceived potential* [emphasis added] for need satisfaction leads to involvement" (Omodei & Wearing, 1990, p. 763). Such a relationship is based on Omodei's and Wearing's analysis of Csikszentmihalyi's (1985) concept of "flow" or "involvement", and Schachtel's (1959) concept of 'allocentric perception', namely "a perceptual mode in which the environment is openly examined for its own sake and not for its potential to meet an individual's need" (Omodei & Wearing, 1990, p. 763). On the basis of their discussion of the works of those two authors, Omodei and Wearing suggested that "the *perception of opportunities* [emphasis added] for need satisfaction leads to both (a) the experience of involvement and (b) behaviour that results in the satisfaction of needs" (Omodei & Wearing, 1990, p. 763). This means that "need satisfaction and involvement are conceptually distinct sources of well-being that overlap empirically because they share a common source in the perception of opportunities [emphasis added] for need satisfaction" (Omodei & Wearing, 1990, p. 763). Omodei and Wearing (1990) focused the rest of their work on the investigation of the strength of the relationships between need satisfaction and involvement, not on the analysis of the processes behind the perception of opportunities. Nevertheless, their work offers a first theoretical perspective on the cognitive nature of such a perception.

First of all, Omodei and Wearing used the concept of potential as a synonym of opportunity and referred to both these concepts with the meaning of "to be likely". Secondly, they considered perceptions of opportunities as expectancies (Omodei & Wearing, 1990). Such expectancies were described as having "implicit aspects of awareness" (p. 768) and consequently were not considered suitable for surveys based on self-reports, since they were deemed to be "relatively unavailable to conscious report" (p. 768). For the reasons that I will discuss later on in this chapter, when I analyse a theoretical perspective on the perception of opportunities developed outside the well-being/quality of life debate, it is totally plausible to suggest a relationship between the perception of opportunities and expectancies. However, such a perspective on the perception of opportunities raises a few questions for which Omodei's and Wearing's (1990) article does not provide answers: To which type of expectancies does the perception of opportunities correspond, and why? Does the methodological problem of the perception of opportunities as expectancies unavailable to conscious report always apply? I answer those questions later on in this chapter in the context of the discussion of some of the properties of the perceptions of opportunities as expectancies.

The concept of opportunity in psychology

Counterfactual thinking represents the main field of research in psychology that has investigated how people construct possible scenarios, alternative options, and available opportunities.

Counterfactual thoughts are mental rehearsals in which a certain event is negated and alternative possible outcomes are imagined instead. Counterfactual thoughts can be generated on purpose, by means of conditional questions of the kind: "what would have been if…", or can be generated automatically. In this latter case counterfactual thoughts

spontaneously pop up in people's mind regardless of an external input or an internal conscious intent (Roese, 1997).

The research on counterfactual thoughts has focused in particular on automatic counterfactual thoughts. It has tried to answer two questions with regard to them: what triggers such mental rehearsals? And what affects their content? (Roese & Olson, 1995).

In a review article, Roese (1997) pointed out that there are two main determinants of counterfactual thinking: negative emotional states and perceived closeness – both in terms of time and of physical distance – to a possible outcome. Another determinant can be the affective involvement with the outcome in question (Meyers-Levy & Maheswaran, 1992). In other words, counterfactual thoughts are triggered by negative emotional experiences, when an alternative course of outcomes has been near missed, and when people feel emotionally involved with an outcome (Roese, 1997).

Once a counterfactual thinking process has been switched on by one of the activation factors just mentioned, the actual content of the counterfactual inferences can vary. In general terms, however, the content of single counterfactual thoughts can have only two directions. They can be upward, when the imagined alternative to reality is better than the experienced event, or downward, when the imagined alternative to reality is worse than the experienced event. Upward counterfactual thoughts tend to loom larger than downward counterfactual thoughts (Botti & Iyengar, 2004; Brenner, Rottenstreich, & Sood, 1999).

Some variables have been found to affect the content of counterfactual thoughts (Roese, 1997). The most important determinants of the content of counterfactual thoughts are antecedent normality and antecedent controllability (Roese, 1997). Antecedent normality refers to the fact that the content of counterfactual thoughts

usually tends to restore the normal state of affairs (e.g. expected behaviours) that has been altered by some negative event. In other words, in thinking of alternative events people tend to return abnormal elements to their normal or default status (Kahneman & Miller, 1986). Antecedent controllability refers to the fact that it seems that people tend to generate counterfactual thoughts about controllable rather than uncontrollable antecedents.

There are two main theoretical perspectives underpinning the research on counterfactual thinking: norm theory (Kahneman & Miller, 1986), and a motivational perspective (Roese & Olson, 1995).

The motivational perspective suggests that motivational variables can influence the generation of counterfactual thoughts. Examples of relevant motivational variables are personal involvement with an action or event and the valence of the outcomes of that event or action. So, for example, outcomes that generate negative affects not only motivate avoidance behaviours, but also cognitive attempts to mentally avoid those negative affects by means of the production of counterfactual thoughts (Roese & Olson, 1995).

Norm theory is more focused on describing the cognitive processes underlying reactions to specific events without reference to motivational determinants. It aims at describing the judgmental processes that resist an explanation within a theoretical framework only based on the retrieval of memory representations of past experiences. Therefore, if compared with other social judgment theories, its main characteristic is that it assumes that people's comparison standards, or *norms*, are not only the outcome of "precomputed schemas and frames of reference" (Kahneman & Miller, 1986, p. 136). Norm theory states, in fact, that people's comparison standards can also be computed on-line, after an event, as outcomes of counterfactual thinking. This could occur, for

example, when an event generates surprise. The experience of surprise might be the outcome of the comparison of the experienced event not with previous memorised experiences, but with an alternative to the reality which is constructed on-line when the experience of the event occurs. Kahneman (1986) brought the example of the surprise that family friends might experience in not seeing a certain relative crying at the funeral of a family member for whom the affection of that relative was renown. In this case the surprise occurs even though no one has ever seen that relative cry in the past, both in general and at other funerals. That surprise is generated by an alternative to the fact of not crying that must be constructed momentarily, rather than be recalled from the memory (Kahneman, 1986)

Norm theory suggests that people, when engaged in counterfactual thinking, construct alternatives to events by maintaining some features of the event constant and letting other features vary. The features that are held constant are perceived as difficult to mutate (e.g. gravity), therefore are called immutable features. The features that are able to be varied are perceived as mutable (e.g. effort), and therefore are called mutable features. When an event is characterised by the presence of several mutable features then it is easier for the generation of counterfactual thoughts to occur. When, on the contrary, there is absence or paucity of mutable features, then counterfactual thoughts will be less available. Therefore, according to the norm theory, “an abnormal event is one that has highly available alternatives, whether retrieved or constructed; a normal event mainly evokes representations that resemble it” (Kahneman & Miller, 1986, p. 137). Representation refers to judgemental standards, namely *norms*. In summary, events are more or less normal depending on the above mentioned *mutability* of the elements of the reality. The more mutable elements there are, the more is the likelihood that several alternative realities can be generated in mental counterfactual rehearsals and, consequently, that an event is perceived as abnormal.

As it is evident from the above discussion, counterfactual thinking is a mental process very much tied to people's expectations. As mentioned, the generation and the content of counterfactual thoughts depend on whether or not people expect certain aspects of an event or of a circumstance to be mutable and normal. In other words the generation of counterfactual thoughts depends on whether or not people expect certain aspects of a situation to be under their control and agency and typical. Generation of counterfactual thoughts can help to elicit opportunities in survey research. With regard to this, I suggest that engaging respondents with ad hoc scenarios that aim at the generation of counterfactual thoughts with regard to the interviewees' status quo, as well as administering questionnaire items worded counterfactually on specific questions can help with the elicitation of the perceived availability of opportunities of people own making. In fact, if the respondents could generate many counterfactual alternatives to their status quo, then it would mean that there are many courses of action potentially under their control that they cannot pursue given their current circumstances. According to norm theory, we can expect that a normal event or circumstance to mainly evoke representations that resemble them, while an abnormal event generates many counterfactual alternatives.

An example of such scenarios can be found in the 'target-constrained' mental simulations mentioned by Kahneman (1995). Mental simulation "is a form of elaborative thinking in which one imagines the unfolding of a sequence of events, from an initial counterfactual starting point to some outcome" (Kahneman, 1995, p. 378). More in particular:

> the goal of target constrained simulations is to discover scenarios that lead to the target outcome or to assess the availability of such scenarios … An outcome may be judged impossible if attempts to imagine scenarios leading to it end in

failure; it will be judged inevitable if all scenarios that come to mind produce it (Kahneman, 1995, p. 379).

The concept of opportunity in sociology

Two main streams of research are investigated here in relation to conceptualisation of opportunities: the reflection within social-movement theory on the 'structure of political opportunities' (McAdam, 1982), and the phenomenological analysis of opportunities by Schütz (1962c). This latter study allows us to refer to the wider literature on the concept of life-chances, specifically as developed in the Weberian tradition of class analysis.

Structural and perceived opportunities in social-movement theory

Sociologists and political scientists have long engaged in the study of the factors that determine uprisings and revolutions (Della Porta & Diani, 2006). Two main factors have been identified at the basis of collective action: structural opportunities, e.g. state breakdown, diminished control, etc., and perceived opportunities, i.e. activists' belief that an opportunity exists that they have the power to bring about change. Kurzman (1996) identifies three main traditions of analyses with regard to the relationships between structural and perceived analyses:

- The Tocquevillean tradition, which focuses on cases in which the opportunity structure and perceptions agree; so it suggests that activists rise up if they perceive the State breakdown.
- The critical-mass approach, which focuses on mismatches between structural opportunities and perceived opportunities in which activists perceive opportunities for action even when there are no reasons to think that these exist.

- The Marxist tradition, which focuses on mismatches between structural opportunities and perceived opportunities in which activists fail to perceive opportunities for change. False consciousness and ideological hegemony are the identified causes for the masking of opportunities or the deflection of activists' attention from them.

These traditions of studies are interesting in relation to the analysis here undertaken because they offer different perspectives on how people calculate[3] their opportunities. The Tocquevillean tradition implies that people calculate their opportunities primarily on the basis of changes in the State (Kurzman, 1996), whereas the critical-mass approach implies that individuals calculate opportunities for action not simply in terms of changes in the structure of the State, but primarily in terms of strength of the opposition to the State. In particular, Kurzaman (1996) discussed the case of the Iranian revolution and showed how, in that case, people's perceptions of the opposition strength "proved self-fulfilling: the balance of forces had indeed tilted toward the opposition, and perceptions proved stronger than the state structure" (p. 165).

An important characteristic of both the Tocquevillean and the critical-mass traditions is that they imply that activists follow rational decisions. This assumption distinguishes these approaches from others, such as the collective-behaviour school of analysis (Blumer, 1969), which focused more on the irrational, emotive protest behaviour. On the other hand, the Marxian tradition emphasises the relationship between cultural and social forces and people's perceptions. One important aspect of the above traditions of studies is that they address the question of how people perceive opportunities in a group or movement context. In order to understand whether the

[3] Kurzman (1996) usese the verb 'calculate' rather than 'perceive' in his article. This is to stress the fact that social actors identify opportunities on the basis of rational decisions.

insight gained from such analysis extend also to people's behaviour outside specific group dynamics.

Overall, the reviewed sociological literature on 'structural' and 'cognitive' opportunities suggests that *having* an opportunity mostly requires the presence of clear structural conditions as well as the presence of cognitive components. Nevertheless, the reviewed literature also suggested that, at times, the strenght of people's belief in the saliency and achievability of a valued opportunity can be at the basis of the develoment of a strong *empowrement* process (see Chapter II for a definition of empowerment) that can lead masses of people to change the societal structure and generate opportunities that were not otherwise present. This is an important element that entails that, in the context of social groups or movements, the perception of opportunities is not only a necessary component of *having* opportunities, but, at times, can also be a sufficient cause for their generation".

I now turn to investigate Schütz (1962) phenomenological analysis of subjective opportunities.

Objective and subjective opportunities in phenomenological research

In his work titled 'Equality and the Meaning Structure of the Social World', in the context of a discussion of the concept of equality, Schütz (Schütz, 1962c) offered an analysis of the concept of opportunity. He suggested that the term opportunity, as much as that of equality, permits a twofold interpretation: 'objective opportunities' and 'subjective opportunities'. According to Schütz, objective opportunities consist of all the roles and statuses that are open to the choice of social actors in a certain social system. Each social role and status carries a set of socially approved *expectations* that "any incumbent of the role is expected to fulfil" (Schütz, 1962c, p. 269). That set of expectations can be generated by some specific social institution, such as a government

office, or they can originate in the mores and traditions of a specific social group. Examples of the first type of objective opportunities are the roles and status associated with any job position. Examples of the second type of objective opportunities are the roles and statuses associated with concepts such as a “credible person”, or a “credible day-labourer” (A. Smith, 1976), to which Sen refers when he brings examples of some capabilities for which income as a category of analysis does not provide any information.

In the subjective sense, the concept of opportunity refers to the meaning that the term opportunity “has for the individual who in objective terms would be eligible to avail himself [sic] of an opportunity” (Schütz, 1962c, p. 271), namely it refers to the subjective meanings of those roles and statuses. In order to fully discuss Schütz’s distinction between subjective and objective opportunities, I need to analyze those two concepts separately. I will start with the concept of objective opportunities and I then turn to the analysis of the concept of subjective opportunities.

The concept of objective opportunities, a more comprehensive definition. While the distinction between subjective and objective opportunities seems very promising, the definition that Schütz offers of the concept of objective opportunity appears to be too restrictive, since not every opportunity can be immediately translated into a social role that is normatively defined in the society. It is worth pointing out that Schütz proposed his analysis of the concepts of objective and subjective opportunities not in the context of a discussion of the concept of opportunity in general, but rather in the conceptually narrower context of the discussion of the concept of equal opportunity (Schütz, 1962). As a consequence, his definition of objective opportunity covered only opportunities related to people’s social mobility, such as their job, careers patterns, civil rights and achievable statuses. Such a definition of objective opportunities is not

comprehensive enough to include both the types of opportunities that emerged from the discussion in the previous section:

1) Opportunities that are generated by the social system, independently and beyond people's control and agency. Examples of this type of opportunity includes one's job, civil rights, access to services, which are all generated by institutions and mostly, but not necessarily correspond to specific, normatively stated social roles.

2) Opportunities that are of people's own making, namely the generation of which is directly under people's control and agency. Examples of this type of opportunities include actions or projects of actions that individuals construe in their everyday life for the realisation of their goals or the satisfaction of their needs. Those opportunities, which can be as simple as saving money for a specific purpose, or making specific arrangements to get to do or experience something, often do not translate into normatively stated social roles.

Nevertheless, in other writings, Schütz referred to the mentioned distinction between opportunities that are of social actors' own making and opportunities that are socially generated (e.g. Schutz, 1951). Also, his analysis of subjective opportunities, which I discuss shortly, is comprehensive enough to include a wide variety of opportunities, not only the subset implicit in his definition of objective opportunities. Consequently, I suggest that it is possible to expand Schütz's definition of the concept of objective opportunity to make it more comprehensive.

I propose that the most important aspect of Schütz's definition of objective opportunities is that it focuses on the way their meaning is constructed. Objective opportunities are possibilities for performing actions or achieving goals that are generated by the social system, independently and beyond people's control and agency. This means that the set of expectancies that they carry with them is defined normatively,

by some social institution. The strong points of this way of defining objective opportunities are that it certainly addresses the main focus of Schütz's paper (1962), and that it allows us to clearly differentiate between objective and subjective opportunities, subjective opportunities being people's perception of objective ones. As mentioned, the main weak point is that, since it focuses only on opportunities that are normatively generated, it does not include opportunities that cannot be immediately translated into social roles and statuses. In order to overcome this limit, I suggest hinging the definition of objective opportunities on the following more inclusive criterion. I suggest focusing on the "direction" of the expectancies that are tied to opportunities, namely on whether they concern one individual's own behaviour or the behaviour of others, rather than on their "origin", namely on whether they are defined by a social institution or not. From this point of view, objective opportunities consist of possibilities that carry with them expectations, either of an individual or a social group, about the availability or attainability, for certain other subjects, of actions or experiences that are believed to be in those subjects' power to generate. This definition of objective opportunities includes both possibilities that translate into social roles and statuses and possibilities that do not.

The concept of objectivity, as it is used in the above definition, overlaps with the concept of positional objectivity that we discussed in the previous chapter. From this point of view, a certain opportunity can be considered objective in so far as it is accessible to and understandable by others once an extensive specification of the circumstances and mental states that led to it is provided (Sen, 1993, 1994). As pointed out in Chapter II, the concept of positional objectivity overlaps with that of subjectivity, since "every view or opinion could be made positionally objective by some appropriately thorough specification of positional parameters" (Sen, 1993, p. 137). As a consequence, the more inclusive definition of the concept of objective opportunities that I have suggested comes at the price of a fuzzier distinction with the concept of

subjective opportunities. Nevertheless, the concept of objective opportunities so redefined offers the possibility to discuss the full range of opportunities that are open to the choice of social actors.

Having discussed and expanded the concept of objective opportunities, I can now turn to Schütz's analysis of how social actors make sense of those types of opportunities in their everyday life experience. Schütz addresses in particular two questions:

1) What are objective opportunities from a subjective point of view?

2) What are the conditions of their existence from a subjective point of view?

In the following section, I discuss Schütz's analysis of the concept of subjective opportunities. The expression subjective opportunities is only a shorthand that stands for people's subjective perception of opportunities. Schütz's approach to social actors' subjective perception of objective opportunities, despite being framed around his conceptualisation, is comprehensive enough to allow the full range of opportunities that was pointed out above to be addressed.

The concept of subjective opportunities. As I mentioned, in the subjective sense the concept of opportunity refers to the meaning that the term opportunity "has for the individual who in objective terms would be eligible to avail himself of an opportunity" (Schütz, 1962c, p. 271). This definition of subjective opportunities is general enough to address my revised definition of objective opportunities. In particular, Schütz points out that "such an individual experiences what we have defined in the objective sense as an opportunity, as a *possibility* for self-realisation that stands to his choice, as a *chance* given to him, as a *likelihood* of attaining his goals in terms of his private definition of his situation within the group" (Schütz, 1962c, pp. 271-272, all emphases added). Schütz used three different words to define what a subjective

opportunity is, namely “chance”, “possibility”, and “likelihood”. However, he stated that he preferred the term chance, which is the “technical term coined by Max Weber … despite the fact that the English translators Talcott Parsons and M. Henderson have rendered it for reasons explained by them by ‘probability‘ and sometimes by ‘likelihood’” (Schütz, 1962c, p. 272, note 30). Schütz did not give any explanation of why he preferred the term chance to the others. However, for the reasons that I now turn to discuss, the fact that he preferred to refer to subjective opportunities as chances represents a very important point.

Chances and life chances. Schütz’s preference for the word ‘chance’, which was originally used by Weber, can be explained thanks to Wallimann’s, Tatsis’s, and Zito’s (1977) discussion of the different translations of the word chance given by various scholars in the context of Weber’s definition of power: Parson (1968) translated it with probability, Bendinx (1962) with possibility, Blau (1963) with ability, whilst others maintained the original word chance (e.g. Aron, 1964; Gerth & Mills, 1946; Schütz, 1962c). However, Wallimann and colleagues (1977) pointed out that Weber (1922/1972) did not use the German word *Wahrscheinlichkeit*, i.e. probability, neither *Gelegenheit*, i.e. opportunity, nor the French *probabilité* in defining power. They thereofore argued that the same word chance should be maintained in any English translations, specifically because the word in German has the same meaning than in English. With regard to this, they mentioned that the word chance referred “not only to luck, opportunity, or fortune, but additionally, [to] that quality associated with the giveness of the social environment” (p. 233). So, the word chance did not have only “the random characteristics we associate with probability, nor with the fortuity of ‘opportunity’” (p. 233), but also some characteristics of social structure.

Although Wallimann’s et al. (1977) discussion focused specifically on Weber’s (1922/1972) use of the word chance in his definition of power, their understanding of

this word finds confirmation in the work of other scholars. For example, Dahrendof (1979) suggested that the concept of chance in Weber's writings in general did not refer to "random probability" (p. 64) or to "the empirical generalisation of observations" (p. 72). It rather referred to "structurally determined probability" (p. 65), namely probability anchored in social relationships. In order to better explain what this means it is worth quoting Dahrendorf (1979) in full:

> For Weber the probability of sequences of action postulated in the concept of chance is not merely an observed and thus calculable probability, but it is a probability which is invariably anchored in given structural conditions. Thus, chance means probability on the grounds of causal relations, or structurally determined probability (p. 65).

From this point of view, "probability for Weber was a logical, not a frequency matter. Perhaps the term 'likelihood', rather than probability, would be closer to his intention" (Abel & Cockerham, 1993, p. 553). However, both Dahrendorf (1979) and Abel (1993) kept using the word probability as a synonym for chance, even though each time they qualified its restricted meaning. Roth and Wittich, who edited an edition of Economy and Society in the 1990s (Weber, 1992), pointed out that they translated the word chance with probability because it was used interchangeably with *Wahrscheinlichkeit* (probability). However, because the concept of probability implies the possibility of numerical statements, and in most cases in which Weber used the word chance numerical statements were not possible, they also used the term likelihood. This allowed maintaining the distinction between degrees of probability implied by the word chance without assuming the mathematical characteristics of the full concept of probability.

With regard to the expression 'life chances', Dahrendorf (1979) pointed out that its meaning remained ambiguous in Weber's writings. However, he suggested that it

was best understood as “the crystallised probability of finding satisfaction for interests, wants and needs, thus the probability of the occurrence of events which bring about satisfaction” (p. 73). Such a definition refers to people’s probability to achieve valued goals, a probability that is anchored in socio economic conditions as well as in rights, norms, and social relationships, i.e. the probability that others will respond in a certain manner[4].

Indeed, the expression life chances is often used interchangeably with the word opportunities in the literature (e.g. Wright, 2005). Dahrendof (1979), who in certain passages seemed to suggest that people’s life chances are nothing else than opportunities for people’s growth, wishes and hopes that are provided by their social conditions, specified that:

> It may appear that life chances are simply opportunities in the sense of alternatives to choose from. The more of these alternatives a person has (or so one might think), the greater are his possibilities and thus his life chances. This, however, would be a deceptively foreshortened, indeed a mistaken, understanding of the concept which we have in mind (p. 30).

Dahrendorf (1979) suggested that life chances were rather a function of both people’s ‘options’, which are “possibilities of choice, or alternatives of actions given in social structure” (p. 30), and ‘ligatures’, which are the bonds and allegiances that characterise people’s experience as a consequence of their social positions and roles. People’s options and ligatures varied throughout time, for example pre-modern societies were characterised by strong ligatures and little choice, whereas modernity determined the expansion of choices, although often “by the disruption of linkages” (p.31). By this

[4] Wright (2005) mentioned three main types of resources that can shape people’s life chances: capital and labour, human capital, and cultural capital. The first is particularly emphasised in the Marxist tradition of class analysis. The weberian tradition refers to both capital and labour and human capital, i.e. people’s skills and knowledge. The Bourdieuian tradition is the most inclusive one and refers to both capital and labour, human capital, and cultural capital.

Dahrendorf (1979) meant that in modern society people can do things wherever they belong in the social structure; for example, “the worker can vote Conservative, the old lady wear a mini-skirt, and the villager spend his holidays in Mallorca” (p. 31).

This definition of life chances discriminates between opportunities and life chances by stressing that the former is a function of the latter. In particular, opportunities are a necessary, but not sufficient element of life chances, the other being linkages. Life chances are therefore understood as people’s likelihood to experience different outcomes in life, whereas opportunities, as in Sen’s works, are available valued options open to people’s choice.

Objective and subjective chances. Dahrendorf (1979) further pointed out that the concept of chances in Weber’s writings had both an objective facet and a subjective facet. The concept of objective chances referred to structurally anchored probabilities of the occurrence of events. The concept of subjective chances referred to subjectively anchored probabilities of the occurrence of events, namely to probabilities anchored in the individuals’ beliefs, values and attitudes. Weber’s (1978) analysis covered predominantly the concept of objective chances. He discussed the structural conditions that have a causal relationship with the probability of satisfying the needs and interests of social groups and of individuals. In particular, Weber identified relevant structural conditions in the social phenomena of power, authority, rights and laws (see Weber, 1978, vol. 1). However, we do not find in his writings any in depth discussion of the concept of subjective chances, namely of what are the structures of meaning that have a causal relationship with the probability that a certain individual will construct the belief of a certain event.

Dahrendorf (1979), in his analysis of Weber’s use of the word chance, disregarded the analysis of subjective chances, since he was more interested in the meaning and the characteristics of the concept of objective chances. It is in Schütz’s

analysis of the concept of subjective opportunities that we find an in-depth analysis of the several experience components that have a causal relationship with the construction of the meaning of subjective chances: the *cognitive* component (consciously held beliefs and opinions), the *affective* component (emotional tone and feeling), the *motivational* component (disposition for action) and the *evaluative* component (positive or negative). In order to discuss such an analysis I first need to introduce some of Schütz's more basic concepts, namely: *typification*, *stock of knowledge at hand*, and *systems of relevances*.

A phenomenological description of opportunities

The concept of typification. The concept of typification refers to the conceptual process by means of which social actors (scientists included) organize their knowledge of the social and outer world. Social actors' knowledge is deemed to be organised not in terms of the unique characteristics of the percepts, but in terms of their typical features. This means that the outer world, both the social and the physical one, "is from the outset experienced not as an arrangement of individual and unique objects dispersed in space and time, but as 'mountains', 'trees', 'animals', 'fellow men'" (Schutz, 1951, pp. 166-167). Those typifications are both socially derived and fruit of our own experiences. In particular, they are handed down to us by means of the "typifying medium *par excellence*, namely, common language" (Schutz, 1951, p. 167).

In the psychological literature there have been a few attempts to classify social actors' types of knowledge. For example, Anderson (1976, 1983) has distinguished between 'declarative knowledge' and 'procedural knowledge'. Declarative knowledge consists of social actors' beliefs and factual information. Procedural knowledge consists of social actors' awareness of rules and strategies, which then operate on declarative knowledge. The concept of declarative knowledge can be further broken down into the

concepts of ‘episodic memory’ and ‘semantic memory’. Episodic memory is autobiographical in nature and stores the specific context in which it was acquired, while the semantic memory is more abstract and context free.

The concept of stock of knowledge at hand. Social actors’ ‘stock of knowledge at hand’ consists of both declarative and procedural knowledge. In particular, procedural knowledge consists of those particular typifications that Schütz (1951) called the ‘recipes’ that guide people’s behaviour in their everyday life. Social actors’ stock of knowledge at hand presents two fundamental characteristics:

1) Those zones of it that are in connection with the theoretical or the practical problem with which people are concerned at a given time are taken for granted. In other words, people naturally believe that the knowledge related to the aspect of the everyday world with which they are dealing at any time is “simply ‘given’ and ‘given-as-it-appears-to-me’ – that is, as I or others whom I trust have experienced and interpreted it” (Schütz, 1962e, p. 124). For example, people do not question the fact that tomorrow the sun will rise again. To the end of calling my friends and family I simply take for granted the fact that if I pick up the phone and dial their number I will be able to speak with them, given that they are at home and not talking over the phone with someone else. I do not need to question that knowledge or to be familiar with the way telephones and communication networks work.

2) That “all knowledge taken for granted has a highly socialised structure, that is, it is assumed to be taken for granted not only by *me* but by *us*, by “*everyone*” (meaning “everyone who belongs to us”)” (Schutz, 1951, p. 167). This highly socialised structure gives the typifications of the stock of knowledge at hand “an *objective* [emphasis added] and anonymous

character: it is conceived as being independent of my personal biographical circumstances" (Schutz, 1951, p. 167).

The concept of systems of relevances The concept of relevance refers to the *current interest* that is at the basis of social actors' construction of a particular typification. For example, the fact that the perception of a certain rock in the middle of the desert is typified primarily as the Australian icon called Uluru, rather than, among other possibilities, as an obstacle in one's way, depends on the individual's interest at hand, which determines what aspect of perceptions are relevant for the ongoing action. Schütz identified three types of relevances, which he called respectively 'topical relevances', 'motivational relevances', and 'interpretative relevances'.

Topical relevances. The concept of topical relevance refers to what is at the centre of our attention at any time. There are two processes in particular that determine what becomes thematic in our flow of consciousness at every particular time (Bergson, 1913). Schütz called those two processes respectively 'imposed relevances' and 'intrinsic relevances'. The concept of imposed relevances refers to topics that become thematic in people's flow of consciousness despite the fact that they are not necessarily connected with interests that they choose. Examples are diseases, bereavements and so on. From a psychological point of view the concept of imposed relevances refers to events or situations that strike our attention. It is worth quoting Schütz in full on this point:

> Imposed upon us as relevant are situations and events which are not connected with interests chosen by us, which do not originate in acts of our discretion, and which we have to take just as they are, without any power to modify them by our spontaneous activities except by transforming the relevances thus imposed into intrinsic relevances. (Schütz, 1962b, p. 127)

Intrinsic relevances refer to things that become thematic in people's flow of consciousness as an outcome of their chosen interests. For example, the fact of choosing to perform a certain action makes thematic a certain number of means to reach the chosen goal. From a psychological point of view the concept of intrinsic relevances refers to the outcome of voluntary attention processes.

Interpretative relevances Once something becomes at the centre of people's attention, they start to interpret it, to make sense of it. In order to do this people refer to their stock of knowledge at hand. However, not all of previous knowledge, not all of the typologies stored in people's memory are relevant in order to interpret each singular topic at the centre of attention. The only types and knowledge that are relevant for the purpose of making sense of topical relevances are those interrelated on the basis of their sameness, likeness, or similarity (see Schütz, 1970, p. 36). Therefore, the concept of interpretative relevance refers to those aspects of the stock of knowledge that become of interest to interpret, to make sense of a certain topic thanks to their *compatibility* with it.

Motivational relevances Schütz (1970) identified two other types of motivational relevances, which he called 'in order to motives' and 'because motives'.

In-order-to motives present two levels of complexity. Firstly, they refer to the motives that are behind people's decision to go ahead with a certain action. Let us assume that some percept, for example the view in the distance of a young woman in the street, strikes my attention because she looks like my friend X. That percept, because of the doubt that it generates, becomes thematic in my flow of consciousness and I start to interpret it. The phenomenon of interpretation leads to the selection from my stock of knowledge of a few problematic possibilities, in this case two in particular: either that is my friend X, or she is only a stranger. In this example the motive which is of paramount relevance for all my future actions related to that first percept is finding out whether the young woman in the distance is my friend X. However, in order to

reach the main goal, there are also other examples of in-order-to motives. For example, I can try to catch up with her. In order to do so, I might have to accelerate my steps. In order to walk faster and faster, I will have to put my heavy bag on my shoulders as a backpack, perhaps quit a cigarette and so on.

In-order-to motives, however, are only one facet of the general concept of motive. To follow up with the previous example, I may want to verify whether the individual who I saw in the street is my friend or not for a variety of reasons. For example, I may need her opinion on something. My belief in her wisdom is an example of what Schütz calls 'because motives'. My belief is in fact "motivationally relevant for phantasying the paramount project which in turn becomes (in the way of in-order-to) motivationally relevant for each single step to be taken in order to actualize the projected state of affairs" (Schütz, 1970, p. 50).

Now, my belief in my friend's wisdom is also motivationally relevant for the limits up to which I keep interpreting my percept of the young woman. What is a "reasonably likely" interpretation of my percept will partly depend on the intensity of my belief. My belief in her wisdom is also at the very basis of the establishment of what information is selected in my flow of consciousness. Instead of the two alternatives 'that young woman is either my friend X or a stranger', I could have come up with very different alternatives such as, for example: 'that young woman over there is either French or Italian'. The reason why the two above discussed possibilities became thematic in my flow of consciousness, and not others, is also tied to the 'because motives'.

Now that I have introduced some of Schütz's main concepts with regard to the aim of my discussion, I can fully introduce his analysis of the concept of subjective opportunities.

Subjective opportunities: A threefold model of their perception

Schütz offers an analysis of the conditions under which subjective opportunities as subjective chances exist. It is worth quoting Schütz (Schütz, 1962c) in full on this point.

> This subjective chance exists, however, from the subjective viewpoint of the objectively qualified individual, only under certain conditions:
>
> 1) the individual has to be aware of the existence of such a chance;
> 2) the chance has to be within his reach, compatible with his private system of relevances, and has to fit into his situation as defined by him;
> 3) the objectively defined typifications of role expectations have to be, if not congruent, then at least consistent with the individual's self-typification, in other words, he has to be convinced that he can live up to the requirements of his position;
> 4) the role for which the individual is eligible has to be compatible with all the other social roles in which he is involved with a part of his personality. (p. 272)

The above analysis is based on the structural elements of the life-world that were discussed above. These structures represent a sort of sextant for the researcher; they indicate relevant areas of investigation in relation to any object being studied. In particular, Schütz's analysis includes elements that were already mentioned in the other approaches to the investigation of subjective and structural opportunities while expanding on them. For example, the concept of chance specifies how subjective opportunities are 'calculated' in a rational way.

I suggest that those questions can be more clearly discussed by classifying them under three main components:

- opportunity availability,
- opportunity achievability,
- opportunity saliency.

Such a threefold model of main components of people's perception of opportunities allows us to distinguish between:

1) People who enjoy and people who don't enjoy a certain valued functionings, for example being nourished, because they have or have not the opportunity to pursue it, e.g. because there is a famine.
2) People who can afford to buy food and people who have available opportunities to nourish themselves in their social environment, for example there are food shops and restaurants, but who are undernourished because they cannot afford to buy food.
3) People who have available opportunities to nourish themselves, can afford to do it, and nourish themselves and people who decide not to, because for example they want to fast for political or religious reasons.

These three components of people's perception of opportunities can be compared to other proposals available in the literature. For example, Alkire (2007) referred to Alsop's and Heinsohn's (2005) work on the operationalisation of the concept of emporwment as a good example of how the concept of capabilities could be operationalised. In particular, Alsop's and Heinsohn's (2005) suggested that:

> Degrees of empowerment can be measured by assessing (1) whether a person has the opportunity to make a choice, (2) whether a person actually uses the opportunity to choose, and (3) once the choice is made, whether it brings the desired outcome (p. 7).

I suggest that the first point of Alsop's and Heinsohn's (2005) proposal for the operationalisation of degrees of empowerment refers to the concept of availability of the threefold model here suggested, and the second point to the concept of saliency. However, there is no reference to the concept of achievability, unless this is included under the first point. Compared to Alsop's and Heinsohn's (2005) suggestion, the proposed threefold model makes explicit all of the cognitive processes that intervene between the two factors of which Alsop and Heinshon suggested empowerment consists: opportunity structure, i.e. the formal and informal context in which people live, and agency, i.e. people's ability to make meaningful choices. Also, the model here proposed specifically refers to the perception of opportunities, which is the way in which capabilities are intended, and it is theoretically ground.

It is worth to point out that the threefold model of opportunity perception does not include the third point of Alsop's and Heinsohn's (2005) proposal. This is because the evaluation of the consequences of an opportunity is a cognitive phenomenon that follows the actual engagement with it; so it does not need to be included in a model of perception of opportunities. As discussed, the focus of such a model is on the cognitive factors that lead people to perceive options as relevant opportunities.

I now turn to discuss each single component of the threefold model more in depth.

Availability. The concept of availability refers to the fact that a given option is perceived as available to a certain individual; this means that such an individual does not experience any forms of ignorance in relation to the given option, i.e. neither forms of passive ignorance, i.e. not knowing of the existence of such an option, nor forms of active ignorance, i.e. ignoring such an option because it is considered a taboo. This issue presents two facets, depending on whether we are dealing with opportunities the

constitution of which is under or beyond the social actors' control and agency. However, both facets are influenced by two questions:

- people's knowledge or non-knowledge, namely ignorance of opportunities;
- people's beliefs regarding the existence of such options (see the above discussion on structural and subjective opportunities).

Opportunities beyond social actors' control and agency possess the characteristics of "social facts" (Durkheim, 1965), and so they are perceived as external by the social actors. This implies that they exist; they are available in the subject's perspective as far as the social actors are aware of their existence. Consequently, the investigation of different types of ignorance (Smithson, 1989) can help to identify the reasons for which some opportunities might not be perceived as available. To this end it is relevant to introduce the distinction between the action of ignoring something, which is an active concept, and being ignorant of something that, on the contrary, is a passive concept (Smithson, 1989).

The availability of opportunities under people's control and agency has to be assessed by accounting for the processes and factors that affect the mental construction of projects of action. From this point of view, it is relevant to ascertain people's acts of ignoring something, which consist of stating the irrelevance of some information, event or experience. The act of ignoring something consists of three phenomena: untopicality, taboo, and undecidability (Smithson, 1989). For example, certain courses of actions could be unavailable to certain individuals or groups of people because they are considered taboos. I will expand on these questions in Chapter VII.

From the point of view of the operationalisation of the concept of opportunity in questionnaire items, this means that it is important to ascertain whether the respondents know that a certain objective opportunity is subject to their choice and what they know

about the set of social expectations tied to it. A technique that uses open ended questions to survey people's opportunities, regardless of whether they are beyond or under people's control and agency, can be borrowed from the cross cultural research on the perception of employment possibilities (Tyler & Sundberg, 1991). It consists of asking respondents to list all of the occupations they know (Tyler & Sundberg, 1991). This same technique has also been used to assess people's perception of possibilities for free time activities, places in which one might live, and persons known.

An alternative to this technique, which uses close-ended questions, is to provide the respondents with a prepared list of opportunities, for example employment positions or free time activities, with which the researcher knows most or all of the respondents are familiar. Such a list can be used to make cards on which the opportunities are printed. In this case respondents can be asked at first to divide the cards into two piles, namely cards that represents employment positions or leisure activities that the subjects know to be present in their environment and cards that represents employment positions or leisure activities that the subjects ignore.

Achievability. By 'achievability' I mean that the subject has to perceive the opportunity, regardless of its kind, as within his reach. In Schütz's words, the individual "has to be convinced that he can live up to the requirements of his position" (Schütz, 1962c, p. 272).

In order for an opportunity to be considered within one's reach the subject has to perceive:

3) that he or she has the means, both personal and material, necessary to pursue the opportunity;

4) that no internal or external hindrances work against him or her. This second point refers to the concept of process freedom that was mentioned in Chapter II.

With regard to the operationalisation of people's perception of opportunity achievability, this could be achieved using further prompts following the questions mentioned in the preceding section to elicit people's perception of opportunity availability. For example, once information on a specific topic has been collected in a face to face interview – in the previous section known occupations and free time activities were mentioned as examples – respondents could be asked to indicate the options that they regard as possibilities for themselves and they may be also asked to provide reasons for their choices (Tyler & Sundberg, 1991). Alternatively, using a close-ended questions technique, respondents could be asked to sort the cards that they were given to indicate the jobs or free time activities they were aware of (see example in the previous section) into positive and negative sets according to whether they saw the options in question as a personal possibility.

People's judgment about whether they have the characteristics or the personal skills to fulfil a certain role or to realize a certain action can be influenced by several psychological mechanisms, for examples: "expectancy of helplessness" (Martin E. P. Seligman, 1975), "self-efficacy belief" (Bandura, 1986, 2000, 2001, 1995), "perception of control" (Perlmuter & Monty, 1979; Martin E.P. Seligman & Miller, 1979), social support (Helgeson, 2003; Hupcey, 1998), social capital, health locus of control (e.g. Lefcourt, 1976), and risk assessment (Slovic, 1987). Their relevance rests in the fact that they can help to understand the contingencies that hinder or facilitate the perception of opportunities in certain individuals and groups as opposed to others. Other scholars who study the capability approach have referred to some of these psychological mechanisms in an attempt to construct a multidimensional measure of human agency

(Alkire & Chiappero Martinetti, 2006). I will now briefly introduce each of those concepts, which, in this context, should be considered as mediators of people's perception of opportunity achievability, not as sources of indicators for them. Their empirical investigation is usually undertaken through a variety of questionnaires or scales that can be found in the relevant literature and for which there are already several tests of validity and reliability.

Helplessness. The concept of people's helplessness refers to the expectancy of not having control over any outcomes (Martin E. P. Seligman, 1975). Helplessness is a learned state produced by the exposure to bad life experiences. It is the outcome of a particular "attributional style". Seligman (1975) pointed out that people's way of explaining events can be rated along three dimensions: 1) 'personalisation', which consists of internal vs. external attributions; 2) 'pervasiveness', which consists of specific vs. universal attributions; and 3) 'permanence', which consists of temporary vs. permanent attributions. The most pessimistic explanatory style is internal, universal and permanent; it is correlated with the greatest depression. An example consists of explaining the failure of an exam with a statement such as: "because I am stupid". A more optimistic person would produce a statement with which he or she would probably blame someone or something else, for example the difficulty of the test. In this case an optimistic explanatory style would be used and it would be external, specific and temporary. I suggest that understanding people's explanatory style is important in order to have a framework with which to interpret their answers to questions aimed at eliciting the achievability of a certain opportunity, regardless of whether it is under or beyond people's control.

Self-efficacy belief. The concept of self-efficacy refers to the personal belief in one's ability to perform a certain task (Bandura, 1986). Lack of self-efficacy can constrain people's options by making them avoid activities even when they are within

their capabilities. Self-disbelief is a cognitively based constraint that people can learn to contrast. Eliciting self-efficacy beliefs can help to understand what makes achievable or not achievable a certain opportunity in people's perception.

Social support. There are several typologies and definitions of social support in the literature (e.g. Cohen & Wills, 1985; Hupcey, 1998). Helgeson (2003) suggested that the majority of the available typologies included three main types of actual and perceived social support: 'instrumental support', 'emotional support' and 'informational support'. Instrumental support refers to people's availability of concrete help and assistance, such as help with household chores, lending money, or running errands. Emotional support refers to the availability of people who can listen, care, sympathise, provide reassurance, and make one feel valued, loved and cared for. Informational support refers to the provision of information or guidance.

Indeed, the availability and the quantity of these three types of support may well affect people's ability to engage and succeed in achieving certain opportunities.

Social capital. A substantial body of research on social capital has developed in recent years. The most prominent names in the discussion of the definition of social capital include Pierre Bourdieu (2006), James Coleman (1988), Robert D. Putnam (1993), Francis Fukuyama (1995), and Nan Lin (2001). Despite this growing body of research, there is no agreement in the literature on a single, universal definition of social capital. Major international organisations such as the Organisation for Economic Cooperation and Development (OECD) and the World Bank have adopted their own definition. For example, the definition of the OECD (2001) is:

> Networks together with shared norms, values and understandings that facilitate co-operation within or among groups. Networks relate to the objective behaviour of actors who enter into associative activity. Shared norms, values and understandings relate to the subjective dispositions and attitudes of individuals

and groups, as well as sanctions and rules governing behaviour, which are widely shared. (p. 41)

The World Bank (2010) adopts a broader definition:

Social capital refers to the institutions, relationships, and norms that shape the quality and quantity of a society's social interactions…Social capital is not just the sum of the institutions which underpin a society – it is the glue that holds them together.

Two important distinctions concerning the concept of social capital are:

- the distinction between ‘bridging’ social capital, ‘bonding’ social capital, and ‘linking’ social capital (e.g. Poortinga, 2006b; Szreter & Woolcock, 2004), and
- the distinction between the structural and cognitive aspects of social capital (e.g. Poortinga, 2006a).

‘Bridging social capital’ comprises relations across different groups in society that do not necessarily share similar social identities because of different age, ethnic group, class, etc. (Poortinga, 2006b; Szreter & Woolcock, 2004). ‘Bonding social capital’ refers to the ‘horizontal’ trusting and co-operative relations between members of a network who see themselves as being similar (Poortinga, 2006, Szreter and Woolcock, 2004). ‘Linking social capital’ is a specific form of bridging social capital that consists of norms of respect and networks of trusting relationships that connect people across explicit ‘vertical’ power or authority structures in society (Poortinga, 2006, Szreter and Woolcock, 2004). Examples are access to “public and private services that can only be delivered through on-going face-to-face interaction, such as classroom teaching, general practice medicine, and agricultural extension” (Szreter and Woolcock, 2004, p. 655).

Structural aspects of social capital refer to the extent and intensity of associational links or activity (Poortinga, 2006a). They comprise the more 'objective' organisational structures that form social capital in a social group. Cognitive aspects of social capital refer to people's perceptions of support, reciprocity, sharing and trust (Poortinga, 2006a). They refer to subjective perceptions of the available social capital.

People's bonding, bridging, and linking social capital, both in their structural and cognitive elements, can help to identify important factors that could hinder people's achievability of opportunities. For example, the nature, extent, or lack of respectful and trusting ties to representatives (i.e. linking social capital) between certain communities and formal institutions— e.g. bankers, social workers, health care providers — can have a major impact on people's capacity to engage with certain opportunities.

Health locus of control. The concept of control refers to another belief that can be referred to both opportunities externally generated and opportunities internally generated. There are different constructs in psychology that tap on different forms of people's perceived control. An example is health locus of control, which refers to people's perception of control over their health (Lefcourt, 1976). It investigates whether people believe that their health status is under their control or rather due to chance or fate. Such a construct can be relevant when the opportunity to be investigated is people's health itself. A wider concept such as 'perceived behavioural control' (Ajzen, 2002), can be more useful when referring to non health related opportunities. This latter construct refers to people's perceived control over the performance of a certain behaviour (Ajzen, 2002) and it is a component of the 'theory of planned behaviour' (Ajzen, 1988, 1991). This theory suggests that human behaviour is guided by three kinds of considerations (Ajzen, 2002):

- Behavioural beliefs; these consists of people's beliefs about the likely consequences or other attributes of the behaviour being considered. They are

deemed to produce a favourable or unfavourable attitude toward the behaviour.

- Normative beliefs; these consists of people's beliefs about the normative expectations of other people. They are deemed to result in perceived social pressure or subjective norm.
- Control beliefs; these consists of people's beliefs about the presence of factors that may further or hinder performance of the behaviour. They are deemed to give rise to perceived behavioural control, the perceived ease or difficulty of performing the behaviour.

In combination, attitude toward the behaviour, subjective norm, and perception of behavioural control lead to the formation of a behavioural intention. Given a sufficient degree of actual control over the behaviour, people are expected to carry out their intentions when the opportunity arises. Intention is thus assumed to be the immediate antecedent of behaviour (Ajzen, 2002).

Another relevant distinction is that between "contingent outcome control" and "agenda control" (Lacey, 1979). "Contingent outcome control" is control limited over imposed choices; "agenda control" is control over what, when and how outcomes have to be achieved. For example, when a thief offers to his victim a choice between life or money, he has "agenda control", while his victim has only "contingent outcome control". From this point of view, people might perceive a certain opportunity as achievable or not achievable according to whether:

5) They feel that they have control (contingent outcome control) over the procedures in which that opportunity can be achieved, in the case of opportunities which are beyond people's agency. For example, a certain subject might not perceive as achievable a certain employment position for

himself or herself because he or she does not trust the transparency and the honesty of the selection process.

6) They feel that they have control (agenda control) over the outcomes of their actions, in the case of opportunities that are under people's agency. For example, people who are affected by pain or some chronic condition might lose trust in their ability to cope with their condition.

Risk assessment. The achievability of a certain opportunity can also be determined by the assessment of the risk of pursuing it, regardless of whether it is an internally generated or an externally generated opportunity.

Research has shown that people embrace a complex and broad conception of what risk is, which cannot be reduced to the one-dimensional statistics used by experts (Slovic, 1987). Slovic (1987) pointed out that lay people's risk perception and attitude is closely related to the position of a certain event within a factor space that consists of two main factors. A horizontal factor labelled "dread risk" and a vertical factor labelled "unknown risk" (Slovic, 1987). The factor labelled "dread risk" is defined "at its high (right hand) end by perceived lack of control, dread, fatal consequences and an inequitable distribution of risks and benefits" (Slovic, 1987, p. 283). Factor 2, labelled "unknown risk", is defined "at its high end by hazards judged to be unobservable, unknown, new and delayed in their manifestation of harm" (Slovic, 1987, p 283). The most important factor appears to be the first factor, "dread risk". The more a certain action or hazard scores high on that factor the higher is the perceived risk.

Saliency. By 'saliency' I mean that the available and achievable opportunity has to be relevant for the subject. This is the third and final element to be assessed in order to have a full picture of an individual's perception of his or her opportunities. With regard to its assessment, the techniques introduced in the two previous sections could be expanded to elicit people's intentions to engage with their opportunities. For example,

in case of open-ended interview schedules, respondents could be asked to motivate their choices in relation to the employment options or the leisure activities that they mentioned as available and achievable. In case of close-ended interview schedules, respondents could be asked to sort the cards with the name of the jobs or leisure activities that they perceived as available and achievable, into positive and negative sets. The positive set of cards would entail that they see the options in question as a personal possibility, the negative set of cards would entail that they do not.

There are three main socio-psychological factors that affect the saliency of an opportunity from the individual's perspective: motivation, consistency with one's social role, and consistency with one's self typifications.

Motivation. Saliency, regardless of whether it is for an opportunity that is under or beyond peoples' control, is certainly related to people's motivation to pursue that particular opportunity.

In Schütz's theoretical framework the question of motivation is addressed within the complex concept of the private system of relevances. The concept of relevance refers to the *current interest* which is at the basis of the social actors' construction of a particular typification. As discussed, Schütz identified three types of relevances: 'topical relevances, which refer to what is at the centre of our attention at any time; 'Interpretative relevance', which refer to those aspects of people's stock of knowledge that become of interest in order to interpret, to make sense of a certain topic thanks to their *compatibility* with it; and 'motivational relevances', which refer to the goals and reasons that guide people's actions. Given this framework, in order for a social actor to have the intention to pursue a certain opportunity, this has to fit with the particular combination of topical, interpretative and motivational relevances that is generated by the main interest that is currently leading a certain individual, where the interest can consist of goals or a needs.

The psychological literature has distinguished between the concept of 'intrinsic motivation' and 'extrinsic motivation' (R. M. Ryan & Deci, 2000a). Intrinsic motivation refers to the intentional pursuit of a goal or action to fulfil personal satisfaction or "for the fun or challenge entailed" (R. M. Ryan & Deci, 2000a, p. 56). External motivation refers to the pursuit of a goal or action because of an external input or coercion. Self-determination theory is a main theoretical framework within psychology that investigates the relationships between intrinsic and extrinsic motivations as well as how social and cultural factors that undermine or facilitate people's sense of initiative, well-being, and the quality of their performance (R. M. Ryan & Deci, 2000b).

The investigation of intrinsic and extrinsic motivations can further help to understand the mechanisms that help or hinder people's engagement with different types of opportunities.

Compatibility with one's social roles. The intention to engage with a certain opportunity is also affected by the compatibility of the social role that it implies with all the other social roles with which people are involved in their everyday life. For example, in the case of an opportunity beyond the social actors' control, a person could refuse a certain job offer because it entails tasks to which that person has a conscientious objection. In the case of an opportunity under the social actors' control, a person could decide not to pursue an action, for example doing some leisure activity, because it clashes with some other commitment, such as for example the obligations associated with the role of a parent.

Perception of opportunities and the self. A final factor that can affect people's intention to engage with a certain opportunity concerns the congruency of the opportunity with the individual's self-typification. With regard to this, I suggest that it is relevant to investigate people's evaluation of their opportunities not only from the perspective of their "actual self", which reflects people's actual attributes, actions and

accomplishments (Sorrentino & Higgins, 1986), but also from the perspective of their 'ideal self' and 'ought self' (Sorrentino & Higgins, 1986). The 'ideal self' reflects the goals, hopes and desires that people hold for themselves. The 'ought self' reflects people's duties, obligations and responsibilities. In other words it represents the kind of person that an individual feels he or she should and ought to be.

A fourfold typology of experiences of opportunities

To sum up, it is suggested that people's perception of opportunities consists of three different components which all need to be explored in order to obtain a comprehensive and theoretically sound understanding of the capability set. The investigation of opportunity availability allows us to assess what options are open to the choice of social actors. The investigation of opportunity achievability allows us to investigate whether the available options are perceived as within social actors' reach. Finally, the investigation of opportunity saliency allows us to evaluate whether available and achievable options are going to be pursued or not. It is suggested that people's perception of each component can be dichotomised in 'high experience' and 'low experience'. This entails that researchers identify for the indicators of each component a relevant threshold that discriminates between what is considered to be a significant experience and what is not. So, for example, there would be situations of high opportunity availability and others of low opportunity availability, situations of high opportunity achievability and situations of low opportunity achievability, and, finally, situations of high opportunity saliency and situations of low opportunity saliency. Given these distinctions, theoretically, availability and achievability can exist in four different combinations representing four different types of experiences of opportunity, which become eight when taking into consideration their saliency (see Figure III-1 and Figure III-2). It is suggested that a situation of high opportunity availability and high

opportunity achievability implies ‘high capability’, whereas low opportunity availability and low opportunity achievability imply ‘low capability’. High opportunity availability combined with low opportunity achievability indicates a situation of ‘achievability disadvantage’, whereas low opportunity availability and high opportunity achievability indicate a situation of ‘availability disadvantage’.

Figure III-1

The model of different combinations of availability and achievability in a situation of high saliency.

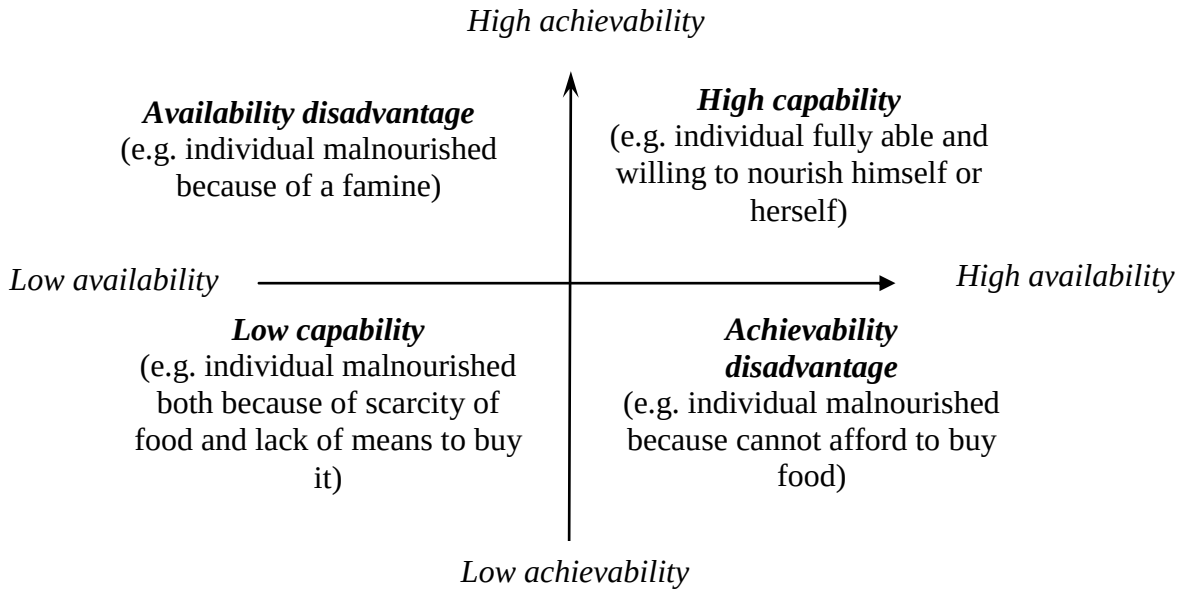
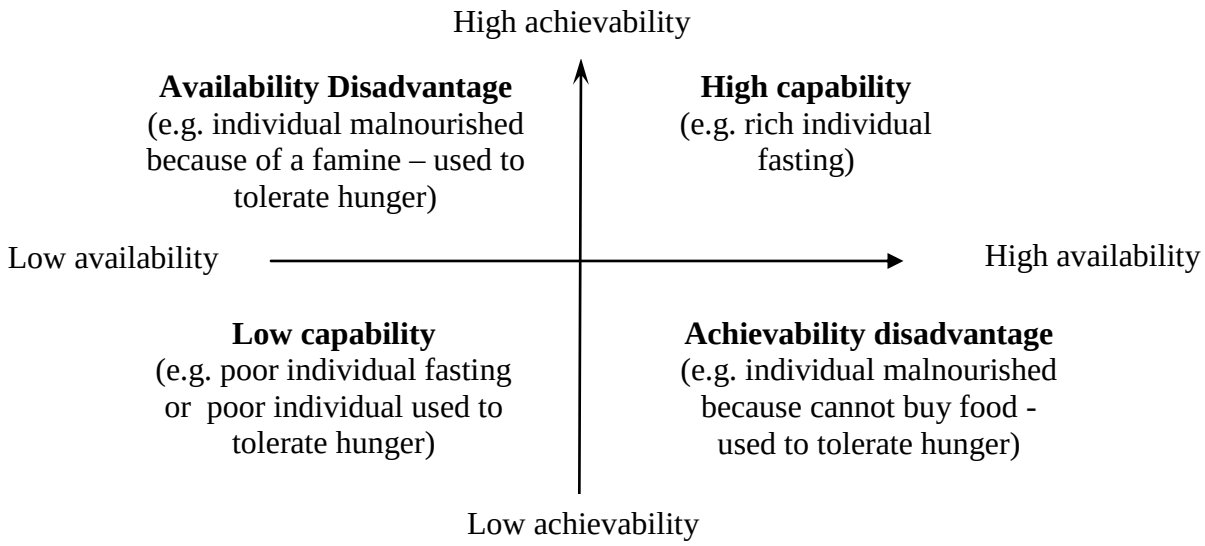


Figure III-2

The model of different combinations of availability and achievability in a situation of low saliency.



The concept of high capability refers to a situation of full capacity of engagement in relation to a certain opportunity; people with high capability are deemed to have both opportunity freedom and process freedom (see Chapter II for a definition of these concepts). The other three categories, i.e. availability disadvantage, achievability disadvantage, and low capability represent different form of disadvantage. Low capability represents the worse forms of disadvantage; individuals lack both opportunity freedom and process freedom. Availability disadvantage and achievability disadvantage are forms of disadvantage characterised respectively by lack of opportunity freedom and lack of process freedom. Whether one of these two types of disadvantage is worse than the other is an evaluation that needs to be undertaken in relation to each specific context of analysis.

It is suggested that this fourfold typology of experiences of opportunities offer a theoretical model for the operationalisation and measurement of capabilities at the individual (micro-) and community (meso-) levels of analysis. In particular, these eight types of experiences of opportunities can help to better understand people's own capability set and, therefore, to better discriminate between different experiences of quality of life. With regard to this, it is suggested that the conceptualisation and measurement of quality of life based on the proposed model can be understood as both a measure of people's advantage or disadvantage in society, and as a measure of people's well-being. In this latter case, well-being would be understood as consisting of valued functionings, as typical of the capability framework. In particular, on the basis of the suggested model, quality of life is defined as a situation of high capability. The other three categories represent lower quality of life states, with low capability indicating the worse possible state.

Referring to Veenhoven's (2007b) 3 x 3 cross tabulation of possible combinations of objective, subjective and mixed indicators of quality of life (see Chapter I and Appendix 2), it is suggested that the fourfold typology could be operationalise mixing indicators of availability, achievability, and saliency of the same type. So, either objective indicators with objective indicators, subjective indicators with subjective indicators, or mixed indicators with mixed indicators. Also, indicators of opportunity availability, opportunity achievability, and opportunity saliency should present the following characteristics in order to be able to cross tabulate them: a) they should refer to the same type of experience, for example, opportunity availability and opportunity achievability of access to public transport; b) they should elicit information related to opportunities that are experienced by the respondents at one point in time, for example, opportunity availability and opportunity achievability of their last accommodation.

Subjective opportunities as a third type of expectancies?

As discussed, an opportunity is a possibility for performing actions or achieving outcomes the meaning of which is given by sets of expectations that concern either one's behaviour or the behaviours of others. In the psychological literature the term expectation has been used in two ways (Higgins, 1992; Olson, Roese, & Zanna, 1996). Firstly, it has been used to refer to "probabilistic expectancies". Probabilistic expectancies are defined as "beliefs about a future state of affairs. They are subjective probabilities linking the future with an outcome at some level of probability ranging from merely possible to virtually certain" (Olson, et al., 1996, p. 211). Secondly, the term expectancy has been used to refer to "normative expectancies", namely "to obligations or prescriptions that individuals perceive for themselves or others (what should happen)" (Olson, et al., 1996, p. 212).

On the basis of our discussion of opportunities, we can certainly say that the concept of “normative expectancies” refers to what we called objective opportunities. However, the concept of probabilistic expectancies does not seem to include the type of expectancies that are carried by opportunities, since they are thought of in terms of possibilities, not in terms of probability. The fact that the expectancies that are carried by opportunities are thought of in terms of possibilities has a consequence both from a theoretical point of view and from a methodological point of view. From a theoretical point of view it raises the questions of whether we should contemplate a third type of expectancy, namely “possibility expectancies”, and if so, what are its main properties and how do they differ from the properties of “probabilistic expectancies” (Olson, et al., 1996). From a methodological point of view it raises the question of how to elicit and how to analyze data on expectancies that are thought of in terms of possibility.

With regard to the theoretical question, it is worth emphasizing that the concept of possibility is the focus of two branches of logic: modal logic (for an introduction see Bradley & Swartz, 1979) and possibility theory, which has first been proposed by Zadeh (1978) within the context of his theory of fuzzy sets. Despite the fact that in those two fields of study the concept of possibility has been operationalised in different ways, we can certainly say that in both cases it has been conceptualised absolutely in an independent way from the concept of probability. In both cases the concept of possibility is not considered as a subclass of the concept of probability or as a particular type of probability. In particular, it is in possibility theory that the concept of possibility is explicitly developed as a non probabilistic form of uncertainty (see Smithson, 1987, 1989). Consequently, it seems plausible to hypothesize the theoretical relevance of a third type of expectancy, namely “possibility expectancies”, as an independent and complimentary type of expectancy to the two types of expectancies, probabilistic and normative, already discussed in the literature (Olson, et al., 1996).

With regard to the methodological questions, I suggest that both the elicitation and the data analysis of opportunities require the development of original methods. In particular, for the elicitation of opportunities we need methods that address their "possibilistic", logical nature.

Concluding remarks

In this chapter I have offered a discussion of the mechanisms and processes that are relevant for the operationalisation, by means of subjective indicators, of people's perception of their opportunities. The concept of opportunities is one of the two fundamental components of the concept of capability set, together with that of freedom of choice. In the first part of the chapter I have discussed how extant research in quality of life research falls short of providing a comprehensive theoretical discussion of the concept of opportunities. In the second part of the chapter I have introduced and discussed Schütz's concepts of subjective opportunities and objective opportunities. This has allowed me to define the perception of opportunities as a possibility for performing actions or achieving outcomes the meaning of which is given by sets of expectations that concern either one's behaviour or the behaviours of others. Those expectations have a non-probabilistic nature and might represent a third type of expectancy, namely "possibility expectancies". As discussed, these findings are very important to the end of the operationalisation of the concept of opportunities.

In the next four chapters I will offer empirical applications of the suggested models with the aim of providing a more comprehensive understanding of quality of life among PLWHA.

CHAPTER IV

ASSESSING QUALITY OF LIFE THROUGH INDICATORS OF OPPORTUNITIES: A SECONDARY DATA ANALYSIS OF THE HIV FUTURE V SURVEY

In the previous chapter, the concept of opportunities was investigated and it was suggested that people's perception of opportunities consists of three main components: availability, achievability, and saliency. The investigation of these components allows us to assess what options are open to the choice of social actors (availability), whether the available options are perceived as within social actors' reach (achievability), and, finally, whether available and achievable options are relevant or not (saliency). As discussed, theoretically, availability and achievability can exist in four different combinations representing four different types of experiences of opportunity, which become eight when taking into consideration their saliency. A situation of high opportunity availability and high opportunity achievability implies high capability, whereas low opportunity availability and low opportunity achievability imply low capability. High opportunity availability combined with low opportunity achievability indicates a situation of achievability disadvantage, whereas low opportunity availability and high opportunity achievability indicate a situation of availability disadvantage (see Chapter III for a full discussion).

This and the following two chapters aim to offer an empirical application of the suggested threefold model of opportunity perception and fourfold typology of experiences of opportunities. This aim will be pursued through two objectives:

- to use the suggested models to investigate two relevant dimensions of the quality of life of people living with HIV/AIDS (PLWHA): their living arrangements and their capability to work;

- to compare the suggested models to alternative measures of the same dimensions of quality of life, so to determine whether the suggested models disclose new information regarding the housing conditions of PLWHA or can be replaced by ready available measures of quality of life and housing conditions.

These two objectives are acted on through a secondary data analysis of the HIV Futures V Survey, an Australian nationwide survey of various clinical and social aspects of the lives of PLWHA (Grierson, Thorpe, & Pitts, 2006). Despite the fact that the HIV Futures V Survey did not have as its primary aim the interrogation of the concepts and relationships discussed in this thesis, a critical evaluation of its 250 items led to identify indicators suitable for the operationalisation of two relevant opportunities: the opportunity to enjoy adequate housing and the opportunity to return to work, which therefore are chosen primarily for practical reasons. This and the following chapter will pursue the two above objectives in relationship to the opportunity to enjoy adequate housing. Chapter VI will pursue the above objectives in relationship to the opportunity to return to work.

The opportunity to enjoy adequate housing is mentioned both in Vizard's and Burchardt's (2007) list of ten core and valued functionings – particularly under the functioning 'enjoying a comfortable standard of living with independence and security' – and in Nussbaum's list of capabilities (see Appendix 3). In the Introduction, it was mentioned that referring to the capability framework helps to frame the investigation of the quality of life of PLWHA within a set of fundamental individual, social and economic right that imply a focus on PLWHA as social actors rather than as patients or clinical cases. With regard to this, adequate housing fulfils both a basic human physical need for shelter (Maslow, 1943) and many others, more complex social functionings: from social networking, to family life, to expression of one's social status and roles,

including employment (Braveman, Levin, Kielhofner, & Finlayson, 2006; Dray-Spira et al., 2006). In the literature there is an increasing interest in the relationship between housing and living with HIV/AIDS, which has also manifested in a special issue on PLWHA housing needs in the journal 'AIDS and Behaviour' (Aidala & Sumartojo, 2007). However, relatively little is known regarding the housing experiences of PLWHA in Australia. The publications in which the housing conditions of PLWHA in Australia have been addressed (e.g., Ezzy, de Visser, Grubb, & McConachy, 1998; Grierson, et al., 2006) had a limited scope of investigation on this issue, predominantly characterised by reporting descriptive data, e.g. whether respondents had changed their accommodation after being diagnosed with HIV/AIDS, with whom they lived, and whether their accommodation met their needs. A growing body of literature, predominantly American, has suggested a significant association between unstable housing or homelessness and HIV related risk-taking behaviours (e.g. Aidala, Cross, Stall, Harre, & Sumartojo, 2005; Coady et al., 2007; Corneil et al., 2006; Marshall et al., 2009; Rosenthal et al., 2007), access to health care (e.g. Aidala, et al., 2007; Buchanan, Kee, Sadowski, & Garcia, 2009; Kidder, Wolitski, Campsmith, & Nakamura, 2007), and PLWHA health outcomes (e.g. Leaver, Bargh, Dunn, & Hwang, 2007; Wolitski et al., 2010). In these studies, however, the investigation of PLWHA living arrangements is limited to the experience of housing stability, which is usually either dichotomised as homeless or housed, or thricotomised as homeless, unstably housed, or stably housed. Aidala et al. (2007) and Weir et al. (2007) point out the need to see housing as a multidimensional construct, considering that homelessness is but the most extreme among a range of unstable and inadequate living arrangements related to PLWHA health outcomes and risk taking behaviours. Particularly, Weir et al. (2007) suggest using multiple indicators to describe the variety of housing issues faced by different

individuals and different populations of PLWHA. This should allow researchers to explore PLWHA housing needs more fully.

It is suggested that both the threefold model of opportunities perception and the fourfold model of experiences of opportunity represent complementary tools for the investigation of PLWHA housing experiences. They can contribute to a richer understanding of the relationship between PLWHA living arrangements and certain social and health outcomes. In this and in the next chapter empirical applications of the two models of experiences of opportunities in relationship to housing are offered. In this chapter, the analyses will be guided by the following main and subsidiary research questions:

1. How are the opportunities to enjoy adequate housing distributed in the Futures V Survey sample of PLWHA?
    - What socioeconomic and demographic characteristics (e.g. income level, employment status, age, sex, HIV-related milestones, and geographical location) have a zero-order association with opportunity availability, opportunity achievability, and opportunity saliency among PLWHA?
    - What socioeconomic and demographic characteristics have a zero-order association with the four types of experiences of opportunities, i.e. high capability, low capability, availability disadvantage, and achievability disadvantage?
    - What demographic and socioeconomic variables best predict the four experiences of the opportunity of PLWHA to enjoy adequate housing, taking into account the relationships among these variables?

2. Is there a zero-order relationship between PLWHA health status, both mental and physical, and the four experiences of the opportunity to enjoy adequate housing?

- If so, does the zero-order relationship between health status and experiences of opportunity remain after controlling for demographic, socioeconomic, and behavioural factors (e.g. drug addictions)?

3. Do alternative, existing measures of housing experiences, such as objective housing stability, number of residence changes, and overcrowding, have different patterns of association with socio-demographic variables compared to the four experiences of the opportunity to enjoy adequate housing?

    - What socioeconomic and demographic characteristics have a zero-order association with objective housing stability, number of residence changes, and overcrowding among PLWHA? How do these differences compare with those related to the four experiences of the opportunity to enjoy adequate housing?

    - What demographic and socioeconomic variables best predict the three above mentioned measures, taking into account the relationship among such variables? Are these variables different from those relative to the four experiences of the opportunity to enjoy adequate housing?

    - Is there a zero-order relationship between PLWHA health status, both mental and physical, and the three above mentioned measures of housing experiences? If so, does the zero-order relationship between each of the three measures and health status remain controlling for demographic, socioeconomic, and behavioural factors (e.g. drug addictions)? How do

these differences compare to those of the four experiences of opportunity to enjoy adequate housing?

4. Are there zero-order relationships between the four experiences of the opportunity to enjoy adequate housing and objective housing stability, number of accommodation changes, and overcrowding conditions?
    - If so, do objective housing stability and overcrowding conditions predict the four experiences of the opportunity to enjoy adequate housing after controlling for demographic, socioeconomic, behavioural, and health status variables?
    - Do the four experiences of the opportunity to enjoy adequate housing predict number of accommodation changes after controlling for demographic, socioeconomic, behavioural, and health status variables?

These research questions include both descriptive (de Vaus, 2001) and predictive (Denscombe, 2002) questions. Descriptive research questions are exploratory; considering that it is the first time that the suggested models are empirically tested, it is first necessary to understand 'how' opportunities distribute, 'where' and 'when' (White, 2009). Answering these questions sets the ground to ask 'predictive' research questions (Denscombe, 2002). This latter type of questions are best answered after an understanding is reached of what, if any, groups of PLWHA are more likely to experience some types of experiences of opportunity rather than others.

In particular, the second research question addresses a specific implication of the capability framework. From a capability framework perspective is important to acknowledge that people's capacity to convert income and, more generally, resources into opportunities is affected by a variety of factors, including personal heterogeneities based on their health status. Hence, the second research question aims to understand

whether health status plays a role in predicting PLWHA housing experiences over and above socioeconomic and agency related (e.g. drug consumption) inequalities. If so, this would imply that health status makes an independent contribution in predicting inequalities in PLWHA experiences of housing. With regard to this, it is relevant to point out that health status has been predominantly considered as a dependent rather than as an independent variable in the literature on housing experiences. For example, the literature on the housing experiences of PLWHA has investigated the relationship between homelessness and PLWHA health status (Arno et al., 1996; Buchanan, et al., 2009; Coady, et al., 2007; Kidder, et al., 2007; Leaver, et al., 2007; M. Smith et al., 2000). Research on the Australian general population has investigated the relationship between housing tenure, i.e. renting vs. owning one's accommodation, and perceived health status (Australian Housing and Urban Research Institute, 2002). In this study, considering the fact that the population being investigated presents a chronic health condition, health status is not considered as an outcome of housing, but rather as a factor potentially affecting PLWHA housing experiences.

The third and fourth research questions compare the fourfold typology of opportunities to three alternative measures of housing experiences. In particular, the fourth research question suggests two specific causal relationships between the opportunities to enjoy adequate housing and the other measures of housing experiences.

The following research hypotheses can be derived from the literature discussed in relationship to the above research questions.

Research hypotheses

Research hypotheses will be formulated under the assumption that the study participants are going to pursue the opportunities being investigated, i.e. high saliency. The main reason for this is that, as mentioned in Chapter III, when opportunities are

investigated through subjective indicators, as it is in this work, perceptions of availability, achievability and saliency could be linked to each other in a way that may vary depending on the populations being studied and other contextual characteristics. Because of lack of research on this particular question, no specific hypotheses are formulated regarding the characteristics of the distributions of the four types of experience of opportunities (high capability, low capability, availability disadvantage, and achievability disadvantage) in case of low saliency of the opportunities being investigated.

Considering the limited focus of the extant research on PLWHA housing experiences, where relevant, research hypotheses will be formulated also referring to the literature on PLWHA quality of life undertaken in Chapter I.

Relationships between experiences of opportunities, objective measures of housing, and demographic characteristics. The majority of studies on PLWHA housing experiences included age, gender, race/ethnicity, and length of time since HIV diagnosis as demographic control factors (e.g., Aidala, et al., 2005; Aidala, et al., 2007; Weir, et al., 2007). However, four further demographic variables are investigated in this study, i.e. sexual identity, marital status, living with dependent children, and place of residence. The variables sexual identity, marital status, and living with dependent children are investigated in light of the variety of categories of individuals who live with HIV/AIDS in Australia (National Centre in HIV Epidemiology and Clinical Research, 2009). The variable place of residence is included to take into consideration the specific geographical nature of Australia, particularly in light of the lack of studies mentioned in Chapter I.

Gender, sexual identity, marital status, living with dependent children, and ethnicity. A few studies have suggested that women were more likely to experience unstable housing and homelessness compared to men (Arno, et al., 1996; Gielen et al.,

2000; Lewis, Andersen, & Gelberg, 2003), whereas others did not find a significant relationship between gender and housing experiences (Aidala, et al., 2007). A previous analysis of the HIV Futures V Survey did not find significant gender differences in relationship to the experience of poverty (Grierson, et al., 2006), a factor that could affect PLWHA experience of opportunities.

Research has shown that marital status, i.e. whether in a stable relationship or single, is related to some aspects of people's housing experiences. For example, in the general population household tenure tends to follow life-cycle stages that see renting in early adulthood, moving to home purchase and mortgages when people form relationships and raise a family, and owning the home without any mortgage in older age (Australian Bureau of Statistics, 2000). However, there are no studies that investigate such a pattern in PLWHA. Similarly, there is a lack of studies that investigate the relationship between sexual identity, i.e. whether gay/lesbian, heterosexual, or otherwise, and PLWHA housing experiences. The studies that have taken into consideration children have focused on their experiences of living with HIV/AIDS (e.g. Albano, Spagnuolo, Canani, & Guarino, 1999; L. K. Brown, Lourie, & Pao, 2000). However, there is a lack of studies that specifically look at the quality of life of PLWHA who live with dependent children.

Considering the uncertainty of evidence regarding the role of gender, marital status, living with children, and sexual identity on PLWHA housing experiences, no hypotheses are formulated on these questions. These analyses will be exploratory.

With regard to ethnic background, considering the relationship suggested in the literature between economic hardship and ethnic background (e.g., Ibrahim, Anderson, Bukutu, & Elford, 2008; Speer et al., 1999), it is hypothesised that study participants who were not born in Australia were more likely to experience low opportunity

availability and low opportunity achievability and, therefore, more likely to experience low capability, achievability disadvantage, and availability disadvantage, and less likely to experience high capability compared to Australian born study participants. Similarly, it is hypothesised that PLWHA who were born abroad were more likely to move more often, to be in an unstable housing situation, and to live in overcrowding conditions compared to those born in Australia.

Age. The literature reviewed in Chapter I showed inconsistent findings regarding the needs and psychosocial characteristics of older PLWHA, who are often identified as PLWHA aged 50 and over (Pitts, Grierson, & Misson, 2005). However, Aidala et al. (2007) found that PLWHA who were older, white, who had never used drugs, and who were men who had sex with men, were less likely to be homeless or unstably housed or to have reported a need for assistance with a housing problem. Considering that in the general population the likelihood of a household owning their home increases with age (Australian Bureau of Statistics, 2000), it is hypothesised that PLWHA aged 50 and over were more likely to experience high opportunity availability and high opportunity achievability and, therefore, more likely to experience high capability compared to PLWHA aged under 50. Similarly, it is expected that PLWHA aged 50 and over were less likely to move, and more likely to be in a stable housing situation and not to live in a situation of crowding compared to PLWHA aged under 50.

Place of residence. The vast majority of studies on PLWHA housing experiences are based on samples of PLWHA living in urban centres (e.g., Aidala, et al., 2007; Buchanan, et al., 2009; Leaver, et al., 2007). Consequently, no relevant information is available regarding the housing experiences of PLWHA living in peri-urban and rural areas. Research has shown that PLWHA living in rural areas had a higher risk of depression, lower access to health care services, and lower social support from family members and friends (Heckman, Somlai, Kalichman, Franzoi, & Kelly,

1998; Heckman et al., 1998; Schur et al., 2002; Sheth, Jensen, & Lahey, 2009).

Considering these results and the remoteness of certain Australian rural areas, it is hypothesised that PLWHA who lived in rural, regional, and peri-urban areas were more likely to experience low opportunity availability and low opportunity achievability and, therefore, more likely to experience low capability, achievability disadvantage, and availability disadvantage, and less likely to experience high capability than PLWHA who lived in urban areas.

Similarly, it is hypothesised that PLWHA who lived in rural, regional, or peri-urban environments were more likely to move more often, to be in an unstable housing situation, and to live in overcrowding conditions compared to respondents who lived in urban areas.

Length of time since diagnosis. Only a few studies have investigated the relationship between time since diagnosis and PLWHA experiences of housing. Among those, Smith et al. (2000) found that those stably housed had been living with HIV for a longer period of time. However, the literature reviewed in Chapter I some studies highlighted a negative relationship between duration of HIV infection and both PLWHA health status (Bing et al., 2000; Ezzy, de Visser, & Bartos, 1999; Jia et al., 2007; Lorenz, et al., 2006; Rai, Dutta, & Gulati, 2010) and their financial situation (Ezzy, et al., 1999). Considering the uncertainty of evidence regarding the role of time since diagnosis on PLWHA housing experiences, no hypotheses are formulated. These analyses will be exploratory.

Relationship between experiences of opportunities, objective measures of housing, and socioeconomic characteristics. Research has shown evidence of a positive association between lower socioeconomic status, i.e. income, educational attainment, and occupation status, and poor housing among PLWHA (Katz et al., 2000;

Kidder, et al., 2007; Leaver, et al., 2007; Rosenthal, et al., 2007; Wolitski, et al., 2010). Several studies have also given evidence of a positive association between socioeconomic factors and both morbidity/mortality and quality of life among PLWHA (Flannelly & Inouye, 2001; Jayasinghe et al., 2009; McFarland, Chen, Hsu, Schwarcz, & Katz, 2003; Rapiti, Porta, Forastiere, Fusco, & Perucci, 2000; Vidrine, Amick, Gritz, & Arduino, 2005; Wood et al., 2002; Worthington & Krentz, 2005). In light of these findings, it can be expected that socioeconomic conditions have a major impact on the availability and achievability of PLWHA opportunities to enjoy adequate housing and to have choice over where to live. Consequently, it can be hypothesised that PLWHA with lower socioeconomic status were more likely to experience low opportunity availability and low opportunity achievability and, therefore, more likely to experience low capability, achievability disadvantage, and availability disadvantage, and less likely to experience high capability than PLWHA with higher socioeconomic status.

With regard to the three objective measures of housing, it is also expected that respondents with lower socioeconomic background were more likely to move more often, to be in an unstable housing situation, and to live in overcrowding conditions than respondents with higher socioeconomic status.

Relationships between experiences of opportunities, objective measures of housing, and drugs addiction. Some studies have considered behavioural factors such as use of hard drugs as a predictor of PLWHA housing instability and health outcomes (e.g., Aidala, et al., 2007; Mizuno et al., 2009), whereas others have considered substance use as an outcome of housing instability (e.g., Aidala, et al., 2005; Weir, et al., 2007; Wenzel et al., 2004). In this study use of hard drugs is considered as a predictor, not as an outcome of PLWHA housing experiences. The main rationale behind this choice is that hard drug use can impact on PLWHA finance and social relationships and therefore on their capacity to secure adequate housing. Consequently,

it is hypothesised that PLWHA who injected illegal drugs were more likely to experience low opportunity availability and low opportunity achievability and, therefore, more likely to experience low capability, achievability disadvantage, and availability disadvantage, and less likely to experience high capability than PLWHA who never injected illegal drugs.

Similarly, it is hypothesised that PLWHA who injected illegal drugs were more likely to move more often, to be in an unstable housing situation, and to live in overcrowding conditions compared to respondents who did never injected illegal drugs.

Relationship between experiences of opportunities, objective measures of housing, and health status. As mentioned above, health status has been negatively associated both to homelessness (Arno, et al., 1996; Buchanan, et al., 2009; Coady, et al., 2007; Kidder, et al., 2007; Leaver, et al., 2007; M. Smith, et al., 2000) and housing tenure, i.e. renting (Australian Housing and Urban Research Institute, 2002). Considering the fact that the vast majority of the literature has considered health as an outcome of housing stability, not as a cause of housing outcomes, and that there are no previous studies that investigated the relationship between health and the wider housing experiences of PLWHA, the investigation of this question is exploratory.

Method

Measures

HIV Futures is an Australian nationwide cross-sectional survey of clinical and social aspects of the lives of PLWHA that is undertaken every two years by The Australian Research Centre on Sex, Health and Society at La Trobe University. The HIV Futures V Survey was based in large part on the HIV Futures IV Survey (Grierson, Thorpe, Saunders, & Pitts, 2004), which in turn was adapted from three previous HIV

Futures surveys (Ezzy et al., 1998; Grierson, Bartos, de Visser, & McDonald, 2000; Grierson, Misson, McDonald, Pitts, & O'Brien, 2002). Its content was developed in consultation with several organisations and individuals from the HIV/AIDS sector. It consisted of 250 items organised into eight sections: demographics; accommodation; health and treatments; services and communities; sex and relationships; employment; recreational drug use; and finances. Overall these sections explored five main domains of PLWHA life:

- socioeconomic situation (e.g. housing, finances, employment);
- social and community involvement (e.g. organisational access, disclosure);
- health status and maintenance (clinical history, treatments, health service access);
- emotional well-being (e.g. mental health, un-met needs, social support);
- socio-cultural dimensions of HIV (e.g. discrimination, attitudes to treatment, prevention issues).

It was available as both a self complete, mail back questionnaire and as an on-line survey.

Participants. The HIV Futures V Survey was completed by 974 PLWHA, a sample that represents approximately 6.4% of the HIV positive population (Grierson, et al., 2006). Respondents came from all Australian states, with the majority coming from New South Wales, Victoria and Queensland. Eighteen respondents (1.9%) indicated they were of Aboriginal/Torres Strait Island origin (ATSI). This compares to the Australian Census figure of 2.4% ATSI in the Australian population (Grierson, et al., 2006). See below the section 'Descriptive statistics' for details on the demographic characteristics of the sample.

Recruitment. Recruitment occurred from 1 October 2005 until 31 March 2006. A response rate is not available for the survey because of the multiple recruitment

strategies employed (Grierson, et al., 2006). In order to reach a diverse population of HIV positive Australians, recruitment took place using a variety of methods including direct distribution, promotion and marketing, community and clinical sites. A full list of the institutions involved in the recruitment can be found in Grierson's and colleagues' (2006) report.

Outline of variables. The different variables used for the analyses represented examples of each of the four types of variables that can be utilised to carry out secondary analysis on a case by variable matrix (Dale, Arber, & Procter, 1988):

- "Absolute variables", which "are not derived from any other variables" (p. 168) and which consisted of direct answers to the survey questions. An example are demographic characteristics such as age, sex, or place of residence: capital city/Inner suburban area, outer suburban area, regional centre (population 5,000 or more), Rural area.
- Summary variables, which summarised information from a number of existing variables by means of an arithmetic operation. An example is the equivalised crowding index (Statistics New Zealand, 2003) that was constructed for this study: Crowding Index = [(1/2 number of children under 10 years) + (number of couples) + (all other people aged 10 years and over)] / number of bedrooms.
- Constructed variables, which combined information (by using a series of logical statements) on a number of variables to represent a concept not in the original dataset. The fourfold typology of experiences of the opportunity to enjoy adequate housing is the main example of constructed variable in this study.
- Comparative variables, which used information from one variable to establish a comparative ranking on that variable for each case. The equivalised crowding index can be considered an example of both a summary and a comparative variable,

because crowding scores were used to rank respondents in terms of the liveability of their place.

Below all the variables used in the analyses are outlined. The corresponding questions asked in the HIV Futures V Survey can be found in Appendix 4.

Opportunity to enjoy adequate housing. One indicator of opportunity availability and one indicator of opportunity achievability were identified for the opportunity to enjoy adequate housing. The indicator of opportunity availability consisted of a question on the suitability of the participants' accommodation in relationship to their needs. A similar question was also used in Anand's and colleagues' survey (2009) as an indicator for the 'capability to have adequate shelter'. The indicator of opportunity achievability consisted of a question on whether the study participants experienced discrimination in relationship to accommodation. A growing body of evidence has reported discrimination as a main barrier to access adequate housing among PLWHA (Derose, Domanguez, Plimpton, & Kanouse, 2010; Page, 1999), and as a main mediator of PLWHA life satisfaction (Heckman, 2003).The original question, which had three categories – no; yes, in the last two years; yes; longer than two years ago – was dichotomised in 'yes' and 'no'. As mentioned in Chapter III, ideally, indicators of availability and achievability should present two characteristics: a) they should refer to the same type of experience, for example, opportunity availability and opportunity achievability of access to public transport; b) they should elicit information related to opportunities that are experienced by the respondents at one point in time, for example, opportunity availability and opportunity achievability of their last accommodation. The indicators of the opportunity to have adequate housing do not fully match condition b. However, both indicators elicit pertinent and relevant information for the opportunity to enjoy adequate housing, therefore it is still possible to combine them to create a typology of experiences of opportunities. Consequently, one fourfold

typology of experiences of opportunities, i.e. high capability, low capability, availability discrimination, and achievability discrimination, was created for the opportunity 'enjoyment of adequate housing'. The Futures V Survey did not have questions that could be considered as direct elicitations of the respondents' intentions to act with regard to the two opportunities being investigated. For example, there was not a question that asked the study participants whether they intended to change accommodation or not. Consequently, no indicators of opportunity saliency were identified.

A final indicator of opportunity availability was identified for the opportunity to have choice over where to live, which offered complementary information in relationship to the opportunity to enjoy adequate housing. This consisted of a question on whether the study participants had other accommodation options for the future. However, such a question was a filter question, in particular it was only answered by those participants who had indicated that their current accommodation did not meet their needs. This limits the possibility of cross tabulating this indicator with that of housing availability and achievability.

Objective housing indicators. Three objective indicators of PLWHA experiences of housing were created: objective housing stability, number of residences in the last 2 years, and an equivalised crowding index. Objective housing stability, which indicated the tenure of the respondents' dwelling, consisted of a constructed variable in which participants who owned their accommodation were categorised as stably housed, and all the others were categorised as unstably housed, although their condition was qualified by the type of accommodation in which they lived. So, for example, there were unstably housed buying their accommodation, unstably housed living in public rental, unstably housed living in private rental, and unstably housed living in other types of accommodation. This indicator was similar to that used in the

Australian Housing and Urban Research Institute (2001) investigation on the impact of housing conditions on the health of Australians.

Number of residences in the last 2 years was operationalised in three categories: no changes of accommodation, one change of accommodation, and two or more changes of accommodation in the last 2 years. This was an indicator of the 'volatility' of the respondents' accommodation.

With regard to the crowding index, there are no agreed uniform occupancy standards in Australia (Waters, 2001). In official reports, the Canadian National Occupancy Standard is often used to define households overcrowding (Australian Bureau of Statistics, 2000). This is a complex index that is sensitive to both household size and composition[1]. However, the HIV Futures V Survey did not offer all the information needed to define crowding on the basis of the Canadian National Occupancy Standard index. So, in alternative, the equivalised crowding index used by the New Zealand Statistics Office was used. This index uses the concept of adult equivalent:

> The formula weights each individual who is in a couple relationship as one half, as well as children aged under 10 years (Morrison, 1994). This gives an equivalised number of people per bedroom. Any value in excess of 1.0 represents a measure of crowding. The formula is:
>
> Crowding Index = [(1/2 number of children under 10 years) + (number of couples) + (all other people aged 10 years and over)] / number of bedrooms (Statistics New Zealand, 2003)

[1] The measure assesses the bedroom requirements of a household by specifying that:
1) there should be no more than two persons per bedroom; 2) children less than 5 years of age of different sexes may reasonably share a bedroom; 3) children 5 years of age or older of opposite sex should have separate bedrooms; 4) children less than 18 years of age and of the same sex may reasonably share a bedroom; and 5) single household members 18 years or over should have a separate bedroom, as should parents or couples (Waters, 2001).

The information contained in the HIV Futures V Survey had the following limits with regard to the requirements of the above formula. It was not possible to know whether individuals who lived together with a partner in a shared house were sharing with other couples or single individuals. Only the total number of other people with whom the house was shared was available. Also, respondents could only report the age of up to 4 children. A small number of respondents (see the Section Descriptive Data) reported having 6 children. No information was available on the fifth and sixth children, so they were not included in the formula. Despite these limits, it was still possible to gain relevant and original information from the above crowding index.

Independent variables. Four groups of independent variables were used: demographic variables, socioeconomic variables, behavioural factors, and health status variables.

Demographic variables. Eight demographic variables were used to investigate the first research question: gender, sexual identity, age, ethnicity, marital status, living with dependent children, place of residence, and length of time since HIV diagnosis. Gender was coded as males and females. Sexual identity was thricotomised in gay/lesbians, heterosexuals, and bisexuals and others. The variable age was a summary variable that resulted from subtracting the year of completion of the survey from the respondents' year of birth. Ethnicity was operationalised through an item that asked the study participants to indicate in which country they were born, which was then dichotomised in born in Australia or overseas. Although not ideal, this was the best indicator of ethnicity available in the survey. Alternative indicators, such as the respondents' official country of residence and whether of ATSI origin, did not offer a sufficient number of cases (respectively 8 and 18). Marital status consisted of an item that asked whether the respondents were married or in a regular relationship. The variable living with dependent children consisted of an item that asked the respondents

whether they lived with dependent children or not. As mentioned, place of residence consisted of an absolute variable with the categories: capital city/Inner suburban area, outer suburban area, regional centre (population 5,000 or more), rural area. Length of time since diagnosis was created by subtracting the year in which respondents tested positive from the year of completion of the survey.

Socioeconomic variables. Following the example of the main stream literature on PLWHA experiences of housing and quality of life, three main socioeconomic variables were used, i.e. personal income, educational achievement, and occupation status. However, a fourth variable, the type of accommodation the respondents lived in (e.g. own or purchasing house or flat, private rental, public rental, rent free, etc.) was also used as an indicator of their living standard (see Chapter II for a definition of this concept).

Personal income consisted of an item that asked the study participants to indicate their weekly income after tax. Educational achievement was operationalised through a question that asked the highest level of education completed, which consisted of five categories: primary school, 3 years of high school, Year 10, Year 12, Technical and Further Education (TAFE)/Trade, and University degree. The categories primary school, 3 years of high school, and Year 10 were collapsed together because of their low frequencies. Finally, occupational status was operationalised through a question that asked the respondents' employment situation, which included: student, unemployed, not working/retired, home duties, full-time work, part-time work, and other occupation. In this case too, the categories student, home duties, and other occupation were grouped together because of their low frequencies. This operation was considered legitimate on the assumption that the three groups shared the characteristics of doing activities outside the formal job market. The distinction between unemployed and not working/retired and that between full-time and part-time work were retained. The first distinction was

considered important to differentiate between those who were actively looking for a job, and those who were out of the job market. The second distinction was considered important because some studies found that PLWHA with temporary employment had worse health outcomes compared to PLWHA with stable employment (Dray-Spira et al., 2005).

The variable on the type of accommodation in which the respondents lived cannot be considered as an example of a variable on PLWHA experience of housing such as those listed in the section above. Differently from those variables, this only indicated the type of accommodation in which respondents lived, so it was an indicator of their individual and environmental resources, not of their experiences, which is why it was used as an indicator of socio-economic status.

Behavioural factors. Behavioural factors were operationalised through a question on the use of hard drugs that asked the study participants whether they had ever injected illegal drugs and, if so, if that happened in the last 12 months, or longer than 12 months ago.

Health status. Seven variables were used to operationalise the respondents' health status: perceived health, presence of co-morbidities (e.g. Hepatitis C), presence of mental health problems (e.g. depression), having an AIDS-defining condition, having an HIV-related condition, and two biological markers of disease progression, CD4 count and viral load. Perceived health consisted of an item that asked the respondents to indicate whether they would describe their state of physical health as poor, fair, good, or excellent. The variables for physical health co-morbidities, AIDS-defining conditions, HIV-related conditions, and mental health problems consisted of dichotomous items. The study participants were asked whether they had any other major physical health condition apart from HIV/AIDS, whether they ever experienced an AIDS-defining or an

HIV-related illness, and whether they had a mental health condition. The biological markers consisted of self reported outcomes of the respondents' most recent tests.

Procedure

Analytical strategies. Following the examples in the reviewed literature, the research questions were investigated using two levels of statistical analysis. First, chi-square tests of independence, for categorical variables, and *t*-tests, one-way analysis of variance (ANOVA), or Pearson correlations, for continuous variables, were computed to check the relationship between housing experiences – as operationalised through the two models of experiences of opportunities, and the three objective indicators of housing – and demographic, socio economic, and health factors. The alpha level was .05. The strength of the chi-square relationships was assessed through the Cramer's V measure, whereas Pearson *r* correlation was used to calculate the effect sizes of *t*-tests, and omega squared (ω^2) was used to calculate the effect size of ANOVAs. The usual guidelines regarding effect sizes were adopted: small effect size, $r = 0.1 - 0.23$; medium, $r = 0.24 - 0.36$; large, $r = 0.37$ or larger (Field, 2005). For cross tabulations, adjusted standardised residuals were calculated to determine what factors specifically contributed to group differences (Agresti, 1996). Adjusted standardised residuals are interpreted as a normally distributed variable, so any such residual with an absolute value that is equal to or greater than 1.96 is significant (Sheskin, 1997). For the cells that have a significant residual it can be concluded that the observed frequency differs significantly from the expected frequency. The sign of the standardised residual indicates whether the value is above (+ sign) or below (- sign) what is expected. Adjusted standardised residuals are to be preferred to standardised residuals because they have a sampling distribution closer to standard normal distribution (Bewick, Cheek, & Ball, 2004).

Then multinomial logistic regression modelling or binary logistic regression modelling were undertaken to further test these associations while controlling for potential confounding factors. Multinomial logistic regression is an extension of binary logistic regression (Tarling, 2009), it compares the odds of one type of event occurring, for example experiencing low capability, rather than a reference type of event, for example high capability. Demographic, socioeconomic, and health variable that were significantly associated with housing experiences were entered in the logistic models following a logical order: demographic variables were entered first, followed by socio economic variables and, last, health variables. In this way it was possible to ascertain the relationship of health with housing independent of the other predictors.

A forward step-by-step procedure – using a Main Effects Method, in multinomial logistic regression, and an Enter method, in binary logistic regression – was followed to choose the predictors to keep in the logistic models. When two predictors were in the model, the likelihood ratio tests were used to determine whether they had a significant ($p < 0.05$) contribution to the model. Only the predictors that maintained significance after the introduction of new ones were kept in the model. This was done to help keeping the number of empty cells and missing cases as low as possible for the final model. When two predictors were entered in the model, it was also assessed whether there was an interaction affecting them. If an interaction was found it was kept in the model. A complete model including all the relevant predictors was first created and, with regard to the multinomial logistic regression models, its goodness of fit was evaluated checking that:

1. the value of both statistics in the Goodness-of-fit table of the PASW 18 output (i.e. Pearson and Deviance) was small and their observed significance levels were large (Norusis, 2008);

2. 95% of the sample had values within ±1.96 standard deviations, and 99% of cases values within ± 2.58 standard deviations (A. Field, 2005);
3. that the number of empty cells was not excessive; a high number of empty cells reduces the reliability of the model-fitting statistics and so it needs attention.

With regard to binary logistic models, Cook's distance, leverage, standardised residuals, and DFBeta values were used to identify points for which the models fitted poorly and to identify points that exerted an undue influence on the model.

If needed, reduced models were then created checking how any changes affected the model fitting statistics, the test of parallel lines, the pseudo r-square statistics, and the number of empty cells.

It is important to recall that the recruitment of participants for the HIV Futures V survey was done using a self-selection sampling method, although using a variety of channels and means (e.g. paper and internet questionnaires) to reach as many people as possible (see the paragraph called 'Recruitment' above). From a technical point of view, inferential statistics should not be applied to non-random samples because non-probability sampling techniques are prone to sampling biases that make it unreliable extrapolating similar findings to the general population. However, it is important to point out that sampling biases refers to the method of sampling, not the sample itself. There is no guarantee that the use of probability sampling techniques results in a sample representative of the population just as there is no certainty that every sample obtained using a self-selection sampling method will be greatly non-representative of the population. Considering that the HIV Future V sample is the very best of its kind available in Australia and that a great many published research papers apply inferential statistics to non-random samples, in this and in the two following studies, it was decided

to use the mentioned inferential statistics techniques. Nevertheless, the potential biases induced by self-selection sampling on the study findings are acknowledged and discussed in the paragraph titled ‘Study limitations’ at the end of this and the two other quantitative chapters.

Results

Descriptive statistics

Demographic characteristics. The sample consisted predominantly of male (91.1%, n = 876) and gay/lesbian (80.9%, n = 767). The age of participants ranged from 19 to 78; the mean age was 45.8 years and the median was 45 years. The majority of the sample was not in a regular relationship or married (55.2%, n = 527). Among those who were married (44.8%, n = 428), three quarters lived together with their spouse/partner (73.8%, n = 316). Only 53 study participants (5.4%) lived with their dependent children. Table IV-1 shows the distribution of the demographic variables chosen for the analyses. About half of the sample had lived with HIV/AIDS for 10 years or less and half for longer than 10 years. The sample consisted predominantly of respondents who lived in inner urban settings, only about one tenth lived in rural areas.

Table IV-1

Demographic Characteristics of Participants.

Characteristics	n	%
Age at time of survey – Years (n = 961)		
19 – 50	680	70.8
51 – 78	281	29.2
Age breakdown (n = 961)		

Characteristics	n	%
19-30	43	4.5
31-40	242	25.2
41-50	395	41.1
51-60	204	21.2
61-70	68	7.1
71-78	9	0.9
Time since diagnosis (n = 960)		
0-5	270	28.1
6-10	193	19.8
11-15	201	20.9
16 and over	296	30.8
Place of residence (n = 962)		
Capital city/Inner suburban	612	63.6
Outer suburban	104	10.8
Regional centre	160	16.6
Rural	86	8.9
Place of birth		
Australia	737	76.6
Abroad	225	23.1

Objective housing stability, number of home moves, and crowding conditions. The majority of the respondents were renting, 53.5% (n = 517), only 34.7% (n = 335) of the respondents owned or were purchasing their current home (see Appendix 5). In the latest Australian Housing Survey (Australian Bureau of Statistics (ABS), 2000), it was reported that 70% of Australian households were home owners (31% with and 39% without a mortgage), whereas only 27% were renting. Table IV-2 shows the percentage and frequency of owners (with or without a mortgage) and renters across various age groups in the HIV Futures V Survey and the Australian Housing Survey (ABS, 2000). The percentage of renters who were in private rental in the HIV Futures V sample, about 73%, compares to the Australian Housing Survey figure of 74% household renting from a private landlord in the Australian population. Respondents who were in a regular relationship or married (with or without children) were more likely to own or be purchasing a house (49.4%, ASR[2] = 6.1) than those who were not in a regular relationship (see Table IV-3). An estimate 80%[3] of couples (with or without dependent children) were home owner in the Australian population. Only 26.7% of lone parents (n = 23) owned or were purchasing their home in the HIV Futures V sample, whereas 43.4% (n = 36) of couples with children owned or were purchasing their home (see Table IV-4). The Australian Housing Survey reported that 40% of one parent households owned their home (with or without a mortgage). The majority of lone parents of the HIV Futures V sample, 57%, were renting, 31.4% from a landlord and 25.6% from the public housing system (see Table IV-4). This data compares with the Australian Housing Survey (1999) data, which reports that 58.3% of lone parents were renting; of these, 36.4% from a private landlord, and 21% from a State housing authority. Among the couples with children, 43.4% (n = 36) were renting, a percentage

[2] For brevity, the expression adjusted standardised residual is shortened in ASR.

[3] Author's own elaboration of Table 1 of the 1999 Australian Housing Survey (Australian Bureau of Statistics, 2000, p. 14).

higher than the figure of 20%[3] reported in the Australian Housing Survey for couples with dependent children from 0 to 24 years of age.

Table IV-2

Percentage of Home Owners (with or without a Mortgage) and Renters across Different Age Groups.

	Owning or purchasing one's house		Renting	
	HIV Futures V	Australian Housing Survey[3]	HIV Futures V	Australian Housing Survey[3]
15-24	0.6 (2)	1.0 (52979)	0.2 (1)	13.9 (273357)
25-34	5.4 (18)	12.8 (649122)	13.6 (70)	33.1 (650945)
35-44	28.1 (93)	22.4 (1132054)	38.7 (199)	22.3 (438552)
45-54	39.9 (132)	23.1 (1170295)	33.7 (173)	13.1 (257625)
55 and over	25.9 (86)	40.6 (2051950)	13.8 (71)	17.6 (346122)

Note. Column percentage. Frequency in parenthesis under percentage. The frequencies referring to the Australian Housing Survey are estimates.

Table IV-3

Cross tabulation between Single vs. Partnered and Home Possession

	Regular relationship / Married (n = 428)	Single (n = 527)
Own or purchasing home	49.4 (6.1)	29.9 (-6.1)
Not owner	212 (-6.1)	70.1 (6.1)

Note. Column percentage.

Adjusted Standardised Residuals in parenthesis underneath the observed frequencies.

Table IV-4

Cross tabulation between Single vs. Partnered and Home Possession

	Couples with children (n = 83)	Lone parents (n = 86)
Own or purchasing home	43.4 (36)	26.7 (23)
Private rent	24.1 (20)	31.4 (27)
Public rent	19.3 (16)	25.6 (22)
Other	13.3 (11)	16.3 (14)

Note. Column percentage.

Adjusted Standardised Residuals in parenthesis underneath the observed frequencies.

With regard to crowding conditions, 5.1% of the respondents resulted to live in a condition of overcrowding as measured by the Equivalised Crowding Index described above. In the 1999 Australian Housing Survey (ABS, 2000), using the Canadian National Occupancy Standard, 5% of the 7.2 million households in Australia resulted to require one or more additional bedrooms.

Table IV-5

Crowding Conditions as Measured Through the Equivalised Crowding Index (n = 955)

Equivalised crowding index	n	%
≤ 1	906	94.9
> 1 (Overcrowding condition)	49	5.1

Opportunity to enjoy adequate housing. The vast majority of the study participants (83.7%) reported that their accommodation was suitable to their current

needs. Analysis by the Australian Institute of Health and Welfare (AIHW) of data from the Australian Bureau of Statistics 1994 housing survey indicated that around 28% of households reported some financial or non-financial problems with their housing (Australian Institute of Health and Welfare, 1997).

Similarly, 93% of the study participants reported that they did not experience any discrimination regarding accommodation (see Table IV-6). This would suggest that about four in five study participants experienced high availability and nine in ten high achievability regarding the opportunity to enjoy adequate housing. The cross tabulation of these two indicators of opportunity availability and opportunity achievability shows that, in relationship to the opportunity to enjoy adequate housing, only 3.5% of the study participants experienced low capability (see Table IV-7). The vast majority of the respondents, 80.3%, experienced high capability. Disadvantage was experienced by 16.2% of the respondents; particularly, 12.7% experienced availability disadvantage, and 3.5% achievability disadvantage. Of those who said to have a suitable accommodation only 4.2% experienced discrimination, whereas 21.6% of those who reported an unsuitable accommodation experienced discrimination.

Table IV-6

Frequencies and Percentage of Availability and Achievability for the Opportunity to Enjoy Adequate Housing (n = 974)

	n	%
Accommodation suitability		
Yes	806	83.7
No	157	16.1
Missing	11	1.1
Accommodation discrimination		
Yes	67	6.9

	n	%
No	884	90.8
Missing	23	2.4

Table IV-7

Cross tabulation of Availability and Achievability of the Opportunity to Enjoy Adequate Housing (n = 946).

	Experienced accommodation discrimination		Did not experience accommodation discrimination	
	n	%	n	%
Accommodation suitable	33	3.5	760	80.3
Accommodation not suitable	33	3.5	120	12.7

Study participants who reported an unsuitable accommodation were asked to indicate what problems they experienced. These were interpreted as availability factors, i.e. factors affecting the availability of the opportunity to enjoy adequate housing. The three main problems reported (see Table IV-8) were: accommodation too small (36.9%), lack of privacy (35.7%) and accommodation too expensive (31.2%). The majority of the participants who reported that their accommodation was not suitable indicated that they did not have accommodation options for the future (67.3%, n = 101).

Table IV-8

Reasons for Which Respondents' Current Accommodation was Unsuitable

	Cases (%)
Too small	36.9

	Cases (%)
Lack of privacy	35.7
Too expensive	31.2
Other	22.9
Confidentiality problems	22.3
Poor conditions	2.4
Too far from health services	18.5
Inadequate for health	18.5
Fear of violence	17.8
Too far from other services	15.3
Harassment	15.3
Inadequate for carers	15.3

Relationship between demographic characteristics and opportunities

Opportunity to enjoy adequate housing. The analyses of the relationships between opportunity availability, opportunity achievability and gender, sexual identity, marital status, living with dependent children, and time since diagnosis were exploratory. The chi-square tests of independence between gender, living with dependent children and both accommodation suitability and experiences of discrimination in relationship to accommodation were found to be statistically not significant (see Table IV-9 and Table IV-10 for the cross tabulation matrices). Similarly, both the *t*-test between time since diagnosis and accommodation suitability, $t(952) = -0.42$, $p = .284$, $r = 0.01$, and time since diagnosis and experience of discrimination in relationship to accommodation, $t(944) = 0.62$, $p = .538$, $r = 0.02$ were found statistically not significant. The chi-square test of independence between accommodation suitability and sexual identity was not significant too (see Table IV-9).

However, the relationship between experience of discrimination in relationship to accommodation and sexual identity was found to be statistically significant (see Table IV-10). PLWHA who identified themselves as heterosexuals, bisexuals or with other types of sexuality were more likely to have experienced discrimination in relationship to accommodation than respondents who identified themselves as gay/lesbians (see Table IV-10). The relationships between opportunity availability, opportunity achievability and marital status were significant. Respondents who were single were more likely to live in an unsuitable accommodation and to have experienced discrimination (see Table IV-9 and Table IV-10).

With regard to age, it was hypothesised that there were more PLWHA aged 50 and over who experienced high availability than PLWHA aged under 50. The result of the chi-square test of independence between accommodation suitability and age was consistent with this study's hypothesis. This relationship was significant and indicated that those aged 50 and over were 1.59 times more likely to have a suitable accommodation compared to those aged under 50, (OR = 1.594; 95% CI [1.138, 2.233]). However, the chi-square test of independence between experience of discrimination and age was not found to be statistically significant (see Table IV-10). Independent-samples *t*-tests were also performed between age and both opportunity availability and opportunity achievability to further explore these relationships; the mean ages in both variables' categories were found to be between 40 and 50 years. The *t*-test between age and accommodation suitability was $t(251.93) = 3.55$, $p < .001$, $r = 0.22$; the mean age (with standard deviations in parentheses) for those living in a suitable accommodation was 46.26 (10.05), the mean age for those living in an unsuitable accommodation was 43.61 (8.13). The *t*-test between age and experiences of discrimination in relationship to accommodation and age was $t(942) = -2.13$, $p = .033$, $r = 0.07$; the mean age and standard deviations for those who experienced discrimination

was 43.24 (8.40), the mean age for those living in an unsuitable accommodation was 45.88 (9.81).

Finally, it was hypothesised that those born abroad, and who lived in rural, regional, or peri-urban environments were more likely to experience low availability or low achievability than respondents who were born in Australia and who lived in urban areas. However, the chi-square tests of independence between place of birth, place of residence and suitability of accommodation and experience of discrimination in relationship to accommodation were all found to be statistically not significant (see Table IV-9 and Table IV-10).

Table IV-9

Cross tabulation of Suitable Accommodation vs. Not Suitable Accommodation and Age, Gender, Sexual Identity, Place of birth, Place of Residence, and Time since Diagnosis.

Independent variable	Accommodation suitable	Accommodation not suitable	χ^2	Cramer's V
Age groups			8.36**	.094
19-50	81.7 (-2.9)	18.3 (2.9)		
51-78	89.2 (2.9)	10.8 (-2.9)		
Sex (n = 957)			.12	
Male	83.8	16.2		
Female	82.4	17.6		
Sexuality (n = 941)			0.37	
Gay/Lesbian	84	16		
Heterosexual	80.2	19.8		
Bisexual/Other	86.8	13.2		
Marital status (n = 947)			6.99**	.086
In stable relationship / Married	87.1 (2.6)	12.9 (-2.6)		

Independent variable	Accommodation suitable	Accommodation not suitable	χ^2	Cramer's V
Single	80.7 (-2.6)	19.3 (2.6)		
Living with dependent children			.603	
Yes	81.1	18.9		
No	83.8	81.1		
Place of birth (n = 956)			0.006	
Australia	83.6	16.4		
Abroad	83.4	16.6		
Place of residence (n = 957)			4.31	
Capital City/Inner suburban	85.4	14.6		
Outer suburban	80.8	19.2		
Regional centre	79.2	20.8		
Rural	84.7	15.3		

Note. * $p < .05$ ** $p < .01$*** $p < .001$.

Row percentages. Frequency tables for each variable are reported in Appendix 5.

Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Table IV-10

Cross tabulation of Experiences of Discrimination in Relationship to Accommodation vs. No Experiences of Discrimination and Age, Gender, Sexual Identity, Place of birth, Place of Residence, and Time since Diagnosis.

Independent variable	Experienced discrimination	Did not experience discrimination	χ^2	*p*
Sex (n = 946)			.77	.380
Male	6.9	93.1		
Female	9.4	90.6		
Sexuality (n = 929)			13.91**	.122[a]

Independent variable	Experienced discrimination	Did not experience discrimination	χ^2	*p*
Gay/Lesbian	6 (-2.3)	94 (2.3)		
Heterosexual	8.5 (7.3)	92.7 (-0.2)		
Bisexual/Other	19.6 (3.7)	80.4 (-3.7)		
Age groups (n = 944)			.75	.385
19-50	7.5	92.5		
51-78	5.9	94.1		
Marital status (n = 936)			3.89*	.064
In stable relationship / Married	5.2 (-2.0)	94.8 (2.0)		
Single	8.5 (2.0)	91.5 (-2.0)		
Living with dependent children			.405[b]	
Yes	9.6	90.4		
No	6.9	93.1		
Place of birth (n = 946)			0.24	.621
Australia	7.3	92.7		
Abroad	6.3	93.7		
Place of residence (n = 945)			.85	.836
Capital City/Inner suburban	6.3	93.7		
Outer suburban	8	92		
Regional centre	7.6	92.4		
Rural	8.1	91.9		

Note. * $p < .05$ ** $p < .01$*** $p < .001$.

Row percentages. Frequency tables for each variable are reported in Appendix 5.

Adjusted standardised residual frequencies appear in parentheses below observed percentages. [a] Cramer's V [b] Two sided Fisher's exact test *p* value

Typology of experiences of opportunity. As for opportunity availability and opportunity achievability, the analyses of the relationships between the four experiences of the opportunity to enjoy adequate housing and gender, sexual identity, marital status, living with dependent children, and time since diagnosis were exploratory. The chi-square test of independence with gender and living with dependent children were found to be statistically not significant (see Table IV-11 for the cross tabulation matrix). Similarly, the ANOVA tests with time since diagnosis was not significant, $F(3,937) = 0.50$, $p = .677$. However, the relationship with sexual identity was significant, with PLWHA who identified themselves as bisexual or other types of sexuality who were more likely to experience achievability disadvantage (see Table IV-11).

It was hypothesised that there were more PLWHA aged 50 and over who experienced high capability compared to PLWHA aged under 50. Consistent with this study's hypothesis, the chi-square test of independence between the four types of experiences of opportunity and age indicated that this relationship was significant and that there were significantly more participants who experienced high capability among those aged 51 and over and significantly fewer among PLWHA aged under 50 (see Table IV-11).

Finally, it was hypothesised that those born abroad, who lived in rural, regional, or peri-urban environments, and who lived longer with HIV/AIDS were more likely to experience low capability, availability disadvantage, and achievability disadvantage compared to respondents born in Australia, who lived in urban areas, and who was recently diagnosed. However, the chi-square tests of independence between place of birth, place of residence and the four types of experience of the opportunity to enjoy adequate housing were found to be statistically not significant (see Table IV-11).

Table IV-11

Cross tabulation of Fourfold Typology of Opportunities and Sex, Sexual Identity, Place of birth, Place of Residence, and Time since Diagnosis.

Independent variable	High capability	Availability disadvantage	Availability disadvantage	Low capability	χ^2	Cramer's V
Age groups (n = 939)					9.59*	.101
19-50	78.1 (-2.9)	14.5 (2.8)	3.9 (1.0)	3.4 (0.1)		
51-78	86.3 (2.9)	7.7 (-2.8)	2.6 (-1.0)	3.3 (-0.1)		
Sex (n = 941)					.496[a, b]	
Male	80.7	12.5	3.3	3.5		
Female	67.5	14.3	6	3.6		
Marital status (n = 941)					7.07	
In stable relationship / Married	83.6	11.2	3.1	2.1		
Single	77.5	14.1	3.7	4.7		
Living with dependent children					.216	
Yes	73.1	17.3	7.7	1.9		
No	80.8	12.4	3.2	3.6		
Sexuality (n = 925)					0.13[a,c]	
Gay/Lesbian	81.4 (1.7)	12.6 (-0.2)	2.7 (-2.4)	3.3 (-0.8)		
Heterosexual	76.2 (-1.2)	16.4 (1.3)	4.1 (0.5)	3.3 (-0.2)		
Bisexual/Other	74.5 (-1.1)	5.9 (-1.5)	11.8 (3.4)	7.8 (1.7)		
Place of birth (n =941)					6.89*	
Australia	80.7	12	3	4.2		

Independent variable	High capability	Availability disadvantage	Availability disadvantage	Low capability	χ^2	Cramer's V
Abroad	78.5	15.1	5	1.4		
Place of residence (n = 945)					.723[a, d]	
Capital City/Inner suburban	82	11.9	3.3	2.8		
Outer suburban	76	12.8	3.5	3		
Regional centre	76.9	15.4	3.2	4.5		

Note. * $p < .05$ ** $p < .01$*** $p < .001$. Row percentages. Frequency tables for each variable are reported in Appendix 5. Adjusted standardised residual frequencies appear in parentheses below observed percentages. [a] Two sided Fisher's exact test is reported because more than 20% of cells had expected frequencies lower than 5. [b] Two sided Fisher's exact test. Monte Carlo estimate based on 10,000 sampled tables 99% CI [.483, .508]. [c] One sided Fisher's exact test. Monte Carlo estimate based on 10,000 sampled tables 99% CI [.010, .016]. [d] Two sided Fisher's exact test. Monte Carlo estimate based on 10,000 sampled tables 99% CI [.355, .367].

Objective housing stability, number of home moves, and crowding conditions. The analyses of the relationships between gender, sexual identity, marital status, living with dependent children, time since diagnosis and the three objective indicators of housing, i.e. number of moves in the last two years, objective housing stability, and crowding conditions were exploratory.

The chi-square tests of independence between gender, sexual identity, living with dependent children and both number of moves and objective housing stability were found to be statistically not significant (see Table IV-12 and Table IV-13 for the cross tabulation matrices). In order to test whether crowding conditions varied across different demographic conditions, non-parametric tests were conducted; the crowding index did not distribute normally across the categories of the demographic variables[4]. A Kruskal-Wallis test that was run to test the relationship between crowding conditions and sexual

[4] Several transformations were tried but these did not rectify the issue (see Appendix 8).

identity was not found to be significant, $\chi^2(2, N = 932) = 3.56$, $p = .168$. Similarly, the Mann-Whitney test that was undertaken to check the relationship between crowding conditions and gender was not found to be significant, $z = -1.67$, $p = .093$, $r = -.05$. However, the relationship between living with dependent children and crowding conditions was found to be significant, although the effect size was small, $z = -5.79$, $p < .001$, $r = -.19$; those with dependent children lived in higher crowding conditions than those without. The median crowding condition for those without dependent children was 0.50, whereas for those with dependent children was 1.00.

The relationships between the three indicators of objective housing and time since diagnosis were found to be significant. The relationship between number of moves and time since diagnosis was $F(2,957) = 3.63$, $p = .027$, $\omega = 0.1$. A Gabriel post-hoc test was chosen to evaluate significant differences among crowding conditions averages because of the substantial differences in the sample sizes of the three categories of the dependent variable. This test showed that the mean number of years since diagnosis for PLWHA who never changed residence in the last 2 years was significantly higher than that of those who moved 2 or more times. The mean number of years since diagnosis (with standard deviation in parenthesis) for those who never moved was 12.13 (6.80), for those who moved home 1 time 10.60 (6.19), and for those who moved 2 or more times 9.54 (7.20). The relationship between objective housing stability and time since diagnosis was $F(4,935) = 9.95$, $p < .001$, $\omega = 0.19$. A Games-Howell post-hoc test was chosen to evaluate difference in the averages of time lived with HIV because the null hypothesis of homogeneity of variance was rejected. This test showed that PLWHA who were stably housed had lived with HIV/AIDS a mean number of years significantly higher than those unstably housed who were buying their accommodation and those unstably housed in public rent. PLWHA unstably housed in private rent had a mean number of years lived with HIV/AIDS significantly higher than those unstably housed

buying, in public rent, and in any other type of accommodation. The mean number of years since diagnosis and standard deviation for PLWHA stably housed was 12.98 (6.55), for those unstably housed buying 10.78 (6.93), for those unstably housed in public rent 10.87 (6.79), for those unstably housed in private rent 14.58 (5.71), for those unstably housed in any other type of accommodation 11.70 (7.14). Time since diagnosis was negatively correlated to crowding index scores, $r(948) = -.141$, $p < .001$.

The chi-square of independence between marital status and number of residence changes in the last 2 years was not significant. However, the relationships between housing stability, crowding conditions and marital status were significant. Those stably housed and unstably housed buying were more likely to be in a stable relationship or married (see Table IV-13). A Mann-Whitney test was used to test the relationship between crowding index and marital status. The test was found to be significant, but had had a small effect size, $z = -6.47$, $p < .001$, $r = -.0.21$. Those who were not married or in a stable situation lived in higher crowding conditions (median crowding conditions 0.66) than those in a stable relationship or married (median crowding conditions 0.50).

It was hypothesised that PLWHA aged 50 and over were more likely to move less often, to be in a stable housing situation, and not to live in a situation of crowding compared to PLWHA under 50 years. Consistent with these hypotheses, the chi-square test of independence between number of residence changes, objective housing stability and age were significant. PLWHA aged 50 and over were more likely to be stably housed and to have never moved in the last two years, whereas PLWHA aged under 50 were more likely to be unstably housed in public rent, unstably housed buying and to have moved 2 or more times in the last 2 years (see Table IV-12 and Table IV-13). Similarly, the Mann-Withney test between crowding index and age was significant $z = -2.77$, p (one-tailed) = .003, $r = -0.09$; those aged 19-50 had an average rank of 490.19 whilst those aged 51-78 had an average rank of 437.96.

It was hypothesised that PLWHA who lived in rural, regional, or peri-urban environments were more likely to move more often, to be in an unstable housing situation, and to live in overcrowding conditions compared to respondents who lived in urban areas. The chi-square test of independence between place of residence and number of residence changes (see Table IV-12) was found to be statistically not significant. The relationship between objective housing stability, crowding conditions and place of residence were found to be significant. However, inspection of the adjusted standardised residuals showed that, contrary to the null hypothesis, PLWHA who were resident in rural areas were more likely to be stably housed compared to those living in urban areas (see Table IV-13 for the cross tabulation regarding objective housing stability). Nevertheless, PLWHA who were resident in outer suburban areas were more likely to be unstably housed in community housing / co-op, or other types of accommodation. On the other hand, PLWHA who were resident in urban areas were more likely to be unstably housed in public and private rental. Further analyses showed that place of residence and occupation status were significantly related, χ^2 (12, N = 935) = 52.79, $p < .001$, Cramer's V = .137; in particular, PLWHA who were retired/not working were more likely to live in rural (ASR = 3.3) or in regional areas (ASR = 3.0), similarly those who were students, on home duties or on other types of occupation were more likely to live in rural areas (ASR = 2.0). On the other hand, those working full-time were more likely to live in Capital cities or suburban areas (ASR = 5.0) and those unemployed were more likely to live in outer suburban areas (ASR = 2.5).

To investigate the relationship between crowding index and geographical location, a Kruskal-Wallis test was run and was found to be positive, χ^2(3, N = 949) = 40.22, p (one-tailed) < .001. PLWHA living in rural areas and in regional centres lived in lower crowded conditions than those living in Capital cities and inner suburban areas. The mean rank of those living in capital city/inner suburban areas was 515.75, of those

living in outer suburban areas was 414.42, of those living in regional centres 398.45, and of those living in rural areas 398.66. Six further Mann-Whitney tests were performed to test whether the crowding conditions of those living in capital cities were significantly larger than those living respectively in suburban areas, regional centres, and rural areas. Finally, it was assessed whether the crowding conditions of those living in suburban areas were significantly larger than those living in regional and rural centres. A Bonferroni correction was used to reduce the chances that the Type I error built over 0.5, so the new alpha limit was 0.0083. The tests confirmed that those living in capital cities/inner suburban areas experienced significantly more crowding conditions than those living in peri-urban areas, z = -3.68, p (one-tailed) < .001, r = -.0.14, than those living in regional areas, z = -4.98, p (one-tailed) < .001, r = -.0.18, and than those living in rural areas, z = -3.82, p (one-tailed) < .001, r = -.0.15. However, the relationship between crowding conditions and respectively regional centres, z = -0.564, p = (one-tailed) .286, r = -.0.02, and rural areas, z = -0.434, p (one-tailed) = .332, r = -.0.01, were not found to be statistically significant.

Finally, it was hypothesised that PLWHA who were born abroad were more likely to move more often, to be in an unstable housing situation, and to live in overcrowding conditions compared to those born in Australia. However, the relationships between place of birth and the three indicators of objective housing were all found to be statistically not significant (see Table IV-13). A Mann-Whitney test was performed to test whether the crowding conditions of those born abroad were significantly larger than those who were born in Australia, but was also found to be statistically not significant, z = -1.458, p (one-tailed) = .072, r = -.0.05.

Table IV-12

Cross tabulation of Number of Residence Changes in the last 2 Years and Age, Gender, Marital Status, Sexual Identity, Place of birth, Place of Residence, and Time since Diagnosis.

	No changes	1 change	2 or more changes	χ^2	Cramer's V
Sex (n = 946)				2.15	
Male	89.3	7.4	3.3		
Female	94.2	3.5	2.3		
Age groups (n = 944)				0.17*	.092
19-50	88.7 (-1.8)	7.1 (0.2)	4.3 (2.8)		
51-78	92.5 (1.8)	6.8 (-0.2)	0.7 (-2.8)		
Sexuality				.514[a]	
Gay/Lesbian	89.6	6.9	3.5		
Heterosexual	91.3	6.3	2.4		
Bisexual / Other	85.2	13	1.9		
Marital status (n = 955)				2.54	
In stable relationship / Married	6.3	2.3	91.4		
Single	7.8	3.8	88.4		
Living with dependent children				.603[b,c]	
Yes	86.8	9.4	3.8		
No	89.9	7.0	3.2		
Place of birth				4.93	
Australia	88.6	7.6	3.8		
Abroad	93.3	5.3	1.3		
Place of residence (n = 945)				4.94	

	No changes	1 change	2 or more changes	χ^2	Cramer's V
Capital City/Inner suburban	90	6.4	3.6		
Outer suburban	89.4	7.7	2.9		
Regional centre	86.9	10	3.1		
Rural	94.2	4.7	1.2		

Note. * $p < .05$ ** $p < .01$*** $p < .001$. Row percentages. Frequency tables for each variable are reported in Appendix 5. Adjusted standardised residual frequencies appear in parentheses below observed percentages. [a] Two sided Fisher's exact test *p* value. [b] Two sided Fisher's exact test is reported because more than 20% of cells had expected frequencies lower than 5. [c] Two sided Fisher's exact test. Monte Carlo estimate based on 10,000 sampled tables 99% CI [.590, .616].

Opportunity to have choice and control over where to live. The chi-square tests of independence between gender, living with dependent children, sexual identity, time since diagnosis and perceived availability of future accommodation options were found to be statistically not significant (see Table IV-14 for the cross tabulation matrix). The *t*-test with time since diagnosis was $t(147) = -1.33$, $p = .184$, $r = 0.11$. The chi-square test of independence between place of residence and future accommodation options was significant. However, contrary to the null hypothesis, there were significantly more subjects who perceived having accommodation options for the future among those living in outer suburban areas (see Table IV-14). Further analyses showed that, although PLWHA with other major health conditions were not more likely to live in suburban areas – χ^2 (3, N = 943) = 7.65, $p = 0.054$ – 63% of them lived in public rental properties, χ^2 (3, N = 943) = 34.43, $p < 0.001$, Cramer's V = .191, ASR = 5.3. Contrary to what hypothesised, the relationships with age and place of birth were found to be statistically not significant.

Relationship between socioeconomic status and opportunities

Opportunity to enjoy adequate housing. It was hypothesised that there were more respondents with lower socioeconomic status who experienced low availability and low achievability compared to respondents with higher socioeconomic status. Consistent with this study's hypothesis, the *t*-tests performed on weekly income after tax and both suitability of accommodation and perceived discrimination, as well as the chi-square tests of independence performed on occupation status, educational attainment, and accommodation type were significant (see Table IV-15 and

Table IV-16 for the cross tabulation matrices). Inspection of the adjusted standardised residuals shows that there were more respondents than expected under the null hypothesis who reported having an unsuitable accommodation or having experienced discrimination among those who were unemployed (for accommodation suitability), who were not working/retired (for discrimination), who had a lower educational attainment (for discrimination), and who lived rent free, in public rental, in community housing/coop, and other types of accommodation (for both indicators), or in private rental (for accommodation suitability). On the other hand, there were more respondents than expected under the null hypothesis with a suitable accommodation and who did not experience discrimination among those with a higher socioeconomic status: those in full time job, with higher educational attainment (i.e. university degree, for accommodation suitability, and TAFE/Trade degree for accommodation discrimination), and those who owned or were purchasing their home.

Similarly, those who lived in accommodations that did not meet their needs, and who experienced discrimination, had lower weekly income means. The relationship of income with suitability of one's accommodation was significant and the effect size was large, $t(382.152) = 9.31$, $p < .001$, $r = 0.43$; mean weekly incomes after tax (with

standard deviations in parentheses) were 357.83 (203.18) for those who lived in an accommodation that did not meet their needs, and 576.59 (417.46) for those whose accommodation met their needs. The relationship of weekly income after tax with experience of discrimination in relation to accommodation was also significant and the effect size was large, $t(95.83) = -7.05$, $p < .001$, $r = 0.58$; mean weekly incomes after tax and standard deviations for those who experienced discrimination were 340.50 (209.41) and 555.98 (398.53) for those who did not experience discrimination.

Table IV-13

Cross Tabulation of Objective Housing Stability and Age, Gender, Sexual Identity, Marital Status, Place of Birth, Place of Residence, and Time since Diagnosis.

	Stably housed	Unstably housed Buying	Unstably housed Public rental	Unstably housed Private rental	Unstably housed Other	χ^2	Cramer's V
Sex (n = 946)						2.25	
Male	19.4	16.3	38.8	14.2	11.3		
Female	17.9	19	34.5	19	9.5		
Age groups (n = 944)						127.64***	.368
19-50	10.4 (-10.8)	19.6 (3.9)	44.2 (5.7)	14.3 (-0.4)	11.5 (0.7)		
51-79	41.2 (10.8)	9.2 (-3.9)	24.3 (-5.7)	15.4 (0.4)	9.9 (-0.7)		
Sexuality						9.52	
Gay/Lesbian	19	17.5	39.4	13.2	10.8		
Heterosexual	21.4	15.1	33.3	19.8	10.3		
Bisexual/Other	19.6	11.8	31.4	19.6	17.6		
Marital status (n = 939)						42.95***	
In stable relationship / Married	24 (3.3)	22.5 (4.2)	35.3 (-1.7)	9.1 (-1.7)			

	Stably housed	Unstably housed Buying	Unstably housed Public rental	Unstably housed Private rental	Unstably housed Other	χ^2	Cramer's V
Single	15.5 (-3.3)	12.3 (-4.2)	40.6 (1.7)	19 (4.2)	12.6 (1.7)		
Living with dependent children						.671	
Yes	18.9	18.9	32.1	20.8	9.4		
No	19.4	16.5	38.7	14.2	11.2		
Place of birth						4.35	
Australia	18	16.6	39.8	14.7	10.8		
Abroad	23.5	16.7	33.9	14	11.8		
Place of residence (n = 945)						52.61***	.136
Capital City/Inner suburban	16.2 (-3.2)	16.4 (-0.3)	41.7 (2.8)	16.9 (2.7)	8.8 (-2.8)		
Outer suburban	16 (-0.9)	23 (1.8)	25 (-2.9)	14 (-0.2)	22 (3.7)		
Regional centre	24.7 (1.9)	17.1 (0.2)	35.4 (-0.8)	12 (-1.0)	10.8 (-0.1)		
Rural	35.3 (3.9)	10.6 (-1.6)	36.5 (-0.4)	3.5 (-3.0)	14.1 (0.9)		

Note: * $p < .05$ ** $p < .01$*** $p < .001$. † One-tailed α value. Row percentages. Frequency tables for each variable are reported in Appendix 5. Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Table IV-14

Cross tabulation between Accommodation Options for the Future and Age, Gender, Sexual Identity, Place of birth, Place of Residence, and Time since Diagnosis (n = 149).

Independent variable	Have future accommodation options	Does not have future accommodation options	χ^2	Cramer's V
Place of residence			9.95*	.258
Capital City/Inner suburban	26.4 (-1.8)	73.6 (1.8)		
Outer suburban	61.1 (2.8)	38.9 (-2.8)		
Regional centre	25.8 (-0.9)	74.2 (0.9)		
Rural	46.2 (1.1)	53.8 (-1.1)		
Sex			.92	
Male	34.1	65.9		
Female	21.4	78.6		
Age			.53	
18-50	71.4	28.6		
51-78	28.6	71.4		
Living with dependent children			.274[a]	
Yes	12.5	87.5		
No	33.8	66.2		
Sexuality			0.489[a]	
Gay/Lesbian	33.1	66.9		
Heterosexual	30.4	69.6		
Bisexual/Other	60	40		

Independent variable	Have future accommodation options	Does not have future accommodation options	χ^2	Cramer's V
Place of birth			0.21	
Australia	33.6	66.4		
Abroad	29.4	70.6		

Note. * $p < .05$ ** $p < .01$*** $p < .001$.

Row percentages. Frequency tables for each variable are reported in Appendix 5.

Adjusted standardised residual frequencies appear in parentheses below observed percentages.

[a] Two-sided Fisher's exact test *p* value.

Table IV-15

Cross tabulation of Suitable Accommodation vs. Not Suitable Accommodation and Occupation Status, Educational Attainment, and Accommodation Type.

	Accommodation suitable	Accommodation not suitable	χ^2	Cramer's V
Occupation status (n = 938)			52.69***	.237
Student/Home duties/Other	81.6 (-0.7)	18.4 (0.7)		
Unemployed	61.8 (-6.5)	38.2 (6.5)		
Not working/ Retired	82.7 (-0.6)	17.3 (0.6)		
Full-time work	91.6 (4.5)	8.4 (-4.5)		
Part-time work	86.5 (1.0)	13.5 (-1.0)		
Educational attainment (n = 940)			7.86*	.09
Primary school/3 years of high school / Year 10	82 (-1.1)	18 (1.1)		

	Accommodation suitable	Accommodation not suitable	χ^2	Cramer's V
Year 12	81.4 (-1.1)	18.6 (1.1)		
TAFE/Trade	82.6 (-0.9)	17.4 (0.9)		
University degree	89.3 (2.8)	10.7 (-2.8)		
Accommodation type (n = 962)			34.19***	189
Own or purchasing home	93.1 (5.7)	6.9 (-5.7)		
Private rental	80.3 (-2.3)	19.7 (2.3)		
Public rental	77.1 (-2.4)	22.9 (2.4)		
Other	76.3 (-2.3)	23.7 (2.3)		

Note. * $p < .05$ ** $p < .01$*** $p < .001$. One-tailed alpha values. Row percentages. Frequency tables for each variable are reported in Appendix 5. Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Table IV-16

Cross tabulation of Experiences of Discrimination in Relationship to Accommodation vs. No Experiences of Discrimination and Occupation Status, Educational Attainment, and Accommodation Type.

	Experienced discrimination	Did not experience discrimination	χ^2	Cramer's V
Occupation status (n = 926)			14.83**	.127
Student/Home duties/Other	9.6 (1.2)	90.4 (-1.2)		
Unemployed	10	90		

	Experienced discrimination	Did not experience discrimination	χ^2	Cramer's V
	(1.3)	(-1.3)		
Not working/ Retired	10 (2.3)	90 (-2.3)		
Full-time work	2.8 (-3.4)	97.2 (3.4)		
Part-time work	6 (-0.5)	94 (0.5)		
Educational attainment (n = 928)			9.80*	.103
Primary school/3 years of high school / Year 10	11.3 (2.8)	88.7 (-2.8)		
Year 12	7.3 (0.2)	92.7 (0.2)		
TAFE/Trade	4.2 (-2.1)	95.8 (2.1)		
University degree	6.1 (-0.7)	93.9 (0.7)		
Accommodation type (n = 949)			25.69***	.165
Own or purchasing home	1.5 (-4.8)	98.5 (4.8)		
Private rental	8.7 (1.6)	91.3 (-1.6)		
Public rental	11.9 (2.4)	88.1 (-2.4)		
Other	11.8 (2.1)	88.2 (-2.1)		

Note. * $p < .05$ ** $p < .01$*** $p < .001$.. Row percentages. Frequency tables for each variable are reported in Appendix 5. Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Typology of experiences of opportunity. It was hypothesised that respondents with lower socioeconomic were more likely to experience low capability, availability disadvantage, and achievability disadvantage compared to respondents with higher socioeconomic status. The chi-square tests of independence performed to examine the relationship between the typology of experiences of opportunities and occupation status, educational attainment, and type of housing were significant. Inspection of the adjusted standardised residuals for the chi-square relationships (see Table IV-17) shows that there more study participants than expected under the null hypothesis who experienced high capability among those in full-time employment, who had a university degree, and who owned or were purchasing their accommodation. The disadvantage and low capability cells presented small row percentages; however they showed higher percentages of experiences of disadvantage and low capability for the student, unemployed and retired, those with low education, and renters. An ANOVA test was run to test the relationship between weekly income after tax and the fourfold typology of experiences of opportunities. The assumption of homogeneity of variance was violated, therefore the Brown-Forsythe F-ratio is reported; the relationship was significant, but the effect size was small, $F(3, 147.44) = 39.36$, $p < .001$, $\omega = 0.22$. Planned contrasts were run to check whether the mean weekly income of those with high capability was higher than that of those who experienced a form of disadvantage, whether availability disadvantage, achievability disadvantage, or low capability. Finally, it was checked whether the mean weekly income of those with availability disadvantage differed from the mean weekly income of those with achievability disadvantage. The planned contrasts revealed that the difference between high capability and those who experienced a form of disadvantage was significant and the effect size was large, $t(159.21) = -9.07$, p (one-tailed) $< .001$, $r = 0.58$. However, the difference between availability disadvantage and achievability disadvantage was not significant, $t(41.04) = -0.25$, $p = .803$, $r = 0.04$.

Table IV-17

Cross Tabulation of Fourfold Typology of Opportunities and Occupation Status, Educational Attainment, and Accommodation Type.

	High capability	Availability disadvantage	Achievability disadvantage	Low capability	χ^2	Cramer's V
Occupation status (n = 922)					63.79***	.152
Student / Home duties/ Other	76.5 (-1.2)	13.7 (0.4)	4.9 (0.9)	4.9 (0.8)		
Unemployed	58 (-6.1)	32 (6.3)	5 (1.0)	5 (0.9)		
Not working/ Retired	78.2 (-1.2)	11.8 (-0.3)	4.6 (1.3)	5.5 (1.9)		
Full-time work	89.9 (5.0)	7.3 (-3.4)	1.9 (-1.8)	0.9 (-3.0)		
Part-time work	83.7 (1.1)	10.2 (-0.9)	2.4 (-0.8)	3.6 (0.1)		
Educational attainment (n = 923)					17.55*	.080
Primary school / 3 years of high school / Year 10	76 (-2.1)	13.1 (0.5)	6.3 (2.5)	4.5 (1.1)		
Year 12	77.9 (-1.0)	14.7 (1.1)	3.7 (0.1)	3.7 (0.3)		
TAFE/Trade	81.6 (0.4)	14.2 (1.1)	1.1 (-2.5)	3.1 (-0.3)		
University degree	85.6 (2.4)	8.3 (-2.4)	3.6 (0.0)	2.5 (-0.9)		
Accommodation type (n = 962)					51.66***	.135
Own or purchasing	92 (6.6)	6.4 (-4.2)	0.9 (-3.1)	0.6 (-3.5)		

	High capability	Availability disadvantage	Achievability disadvantage	Low capability	χ^2	Cramer's V
home						
Private rental	77 (-2.1)	14.5 (1.4)	3.6 (0.1)	4.9 (1.9)		
Public rental	70.6 (-3.2)	17.5 (1.9)	6.3 (2.0)	5.6 (1.5)		
Other	70 (-2.9)	18.2 (1.9)	7.3 (2.3)	4.5 (0.6)		

Note. * $p < .05$ ** $p < .01$*** $p < .001$. Row percentages. Frequency tables for each variable are reported in Appendix 5. Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Objective housing stability, number of home moves, and crowding conditions. It was hypothesised that respondents with lower socioeconomic were more likely to move more often, to be in an unstable housing situation, and to live in overcrowding conditions compared to respondents with higher socioeconomic status. Consistent with this study's hypothesis, the relationship between numbers of accommodation changes in the last 2 years, crowding conditions and socioeconomic variables showed that those with lower socioeconomic status moved more often and lived in higher crowding conditions, whereas those with higher socioeconomic status moved less often and lived in lower crowding conditions.

An ANOVA test was run to test the relationship between weekly income after tax and number of house moves in the last two years. The assumption of homogeneity of variance was violated, therefore the Brown-Forsythe *F*-ratio is reported; the relationship was significant but the effect size was small, $F(2, 101.72) = 22.41$, p (one tailed) $< .001$, $\omega = 0.13$. Planned contrasts were run to check whether the mean weekly income of those who never moved was significantly higher than that of those who moved one or two times and to check whether the mean weekly income after tax of those who moved one

time was significantly higher than that of those who moved 2 or more times. The planned contrasts revealed that the mean weekly income of those who never moved was significantly higher than that of those who moved respectively 1 time or 2 or more times; the *t*-test was significant and the effect size was large, $t(87.97) = -6.20$, p (one-tailed) < .001, $r = 0.55$. However, the difference between those who moved one time and those who moved 2 or more times was not significant, $t(51.36) = -0.58$, p (one-tailed) = .282, $r = 0.08$.

Those who moved more than 1 time were more likely to be unemployed, and to live in community housing / co-op, rent free, or other types of accommodation (see Table IV-18). On the other hand, those who did not do any move where more likely to own or purchase their accommodation and to work full time. The relationship between residence changes and educational attainment was not significant, χ^2 (6, N = 945) = 2.87, p (one tailed) = 0.412.

Crowding conditions were negatively related with weekly income after tax, $r(841) = -.090$, $p = .009$. Kruskal-Wallis tests were undertaken to test whether crowding conditions varied among PLWHA depending on their occupation status, their education attainment, and their type of accommodation. The relationships between occupations status, educational attainment and crowding conditions were not found to be statistically significant. The results of the test were respectively, $\chi^2(4, N = 929) = 6.33$, $p = .176$, for occupation status and $\chi^2(3, N = 931) = 1.87$, $p = .599$. However, the relationship between crowding conditions and type of accommodation was significant, $\chi^2(3, N = 952) = 105.47$, $p < .001$. Those living in rental properties, public or private, and in other types of accommodations had higher crowding conditions than those who owned or were purchasing their home. Seven further Mann-Whitney tests were performed to test whether the crowding conditions of those living in their own or in a purchasing home were

significantly larger than those living respectively in public rental, private rental, or other types of accommodations. Finally, it was assessed whether the crowding conditions of those living in private rental were significantly larger than those living in public rental and other types of accommodation, and whether those living in public rental had higher crowding conditions than those living in other types of accommodation. A Bonferroni correction was used to reduce the chances that the Type I error built over 0.5, so the new alpha limit was 0.0071. The tests confirmed that those living in capital cities/inner suburban areas experienced significantly more crowding conditions than those living in peri-urban areas, $z = -3.68$, $p < .001$, $r = -0.14$, than those living in regional areas, $z = -4.98$, $p < .001$, $r = -0.18$, and than those living in rural areas, $z = -3.82$, $p < .001$, $r = -0.15$. However, the relationship between living in outer suburban areas and respectively regional centres, $z = -0.564$, $p = .573$, $r = -.0.02$, and rural areas, $z = -0.434$, $p = .664$, $r = -.0.01$, were not found to be statistically significant.

An ANOVA test was run to check relationship between weekly income after tax and objective housing stability. The assumption of homogeneity of variance was violated, therefore the Brown-Forsythe F-ratio is reported; the relationship was significant and the effect size was large, $F(4, 467.89) = 40.09$, $p < .001$, $\omega = 0.39$. Three planned contrasts were run. These were: 1) to check whether the mean weekly income of those who were stably housed was significantly higher than that of those unstably housed, regardless of the type of instability; 2) to check whether the weekly income after tax of those unstably housed in private rental was significantly higher than that of those in unstably housed in public rental; and 3) to check whether the weekly income after tax of those unstably housed buying was significantly higher than that of those stably housed. The planned contrasts revealed that the mean weekly income of those stably housed was not significantly different from that of those unstably housed, $t(226.46) = -1.45$, p (one-tailed) = .073, $r = 0.10$. However, the mean weekly income differences between those

who lived in public and private rental and those stably housed and those unstably housed buying were significant. The *t*-test for the relationship between private and public rental was significant and the effect size was large, $t(435.72) = -13.12$, p (one-tailed) $< .001$, $r = 0.53$. The *t*-test for the relationship between private those stably housed and those unstably housed was significant and the effect size was medium, $t(263.25) = 4.47$, p (one-tailed) $< .001$, $r = 0.27$.

Those unstably housed who were buying their accommodation were more likely to be in full-time employment, and to have a university degree (see Table IV-19).

Table IV-18

Cross Tabulation of Number of Accommodation Changes in the Last Two Years and Occupation Status, Educational Attainment, and Accommodation Type.

	No changes	1 time	2 or more times	χ^2	Cramer's V
Occupation status (n = 945)				42.76***	.150
Student / Home duties/ Other	10.8 (-0.9)	15.9 (1.2)	10 (-0.2)		
Unemployed	8.9 (-5.9)	28.6 (4.7)	30 (3.4)		
Not working/ Retired	25.8 (-0.2)	27 (0.2)	26.7 (0.1)		
Full-time work	35.8 (3.6)	15.9 (-3.1)	20 (-1.6)		
Part-time work	18.7 (1.4)	12.7 (-1.2)	13.3 (-0.7)		
Accommodation type (n = 9)				36.75***	.138
Own or purchasing home	37.3 (5.0)	17.4 (-3.1)	0 (-4.1)		
Private rental	38	39.1	54.8		

	No changes	1 time	2 or more times	χ^2	Cramer's V
	(-1.2)	(0.1)	(1.9)		
Public rental	14.3 (-1.5)	20.3 (1.3)	19.4 (0.7)		
Other	10.4 (-4.0)	23.2 (3.0)	25.8 (2.5)		

Note. * $p < .05$ ** $p < .01$*** $p < .001$. Row percentages. Frequency tables for each variable are reported in Appendix 5. Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Table IV-19

Cross Tabulation of Objective Housing Stability and Income Quartiles, Occupation Status, Educational Attainment, and Accommodation Type.

	Stably housed	Unstably housed - Buying	Unstably housed – Public rental	Unstably housed – Private rental	Unstably housed – Other	χ^2	Cramer's V
Occupation status (n = 922)						181.16***	.221
Student / Home duties/ Other	14.3 (-1.4)	9.5 (-2.1)	37.1 (-0.2)	23.8 (2.8)	15.2 (1.5)		
Unemployed	7 (-3.3)	4 (-3.6)	40 (0.4)	29 (4.3)	20 (3.1)		
Not working/ Retired	30.9 (5.2)	7.8 (-4.4)	29.2 (-3.3)	21.8 (3.6)	10.3 (-0.3)		
Full-time work	14.3 (-2.9)	29.8 (7.6)	47.6 (4.3)	1.9 (-7.9)	6.3 (-3.2)		
Part-time work	23.8 (1.5)	17.9 (0.4)	32.1 (-1.7)	14.3 (-0.2)	11.9 (0.5)		
Educational attainment (n = 923)						54.24***	.140
Primary school / 3 years of high school / Year 10	19.2 (-0.2)	10 (-3.1)	37.4 (-0.3)	22.8 (4.2)	10.5 (-0.3)		

	Stably housed	Unstably housed - Buying	Unstably housed – Public rental	Unstably housed – Private rental	Unstably housed – Other	χ^2	Cramer's V
Year 12	13.4 (-2.2)	12.2 (-1.8)	42.1 (1.1)	17.7 (1.4)	14.6 (1.6)		
TAFE/Trade	18.6 (-0.5)	17.4 (0.3)	39.4 (0.5)	11.7 (-1.3)	12.9 (1.1)		
University degree	24.8 (2.6)	24.5 (4.0)	35.3 (-1.2)	7.6 (-3.8)	7.9 (-2.0)		

Note: * $p < .05$ ** $p < .01$*** $p < .001$.

Row percentages. Frequency tables for each variable are reported in Appendix 5.

Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Opportunity to have choice over where to live. The relationship between weekly income after tax and perceived availability of future accommodation options was significant and it had a medium effect size, $t(127) = 3.4$, p (one-tailed) $< .001$, $r = 0.29$. Consistent with this study's hypothesis, the mean weekly income of those who had a future accommodation option (with standard deviation in paranthesis), 459.76 (256.87), was higher than the income of those who did not, 313.84 (153.61). However, the relationships with occupation status, educational attainment, and accommodation type were found to be statistically not significant (see Table IV-20).

Table IV-20

Cross tabulation between Accommodation Options for the Future and Income Quartiles, Occupation Status, Educational Attainment, and Accommodation Type.

Independent variable	Have future accommodation options	Does not have future accommodation options	χ^2	Cramer's V
Occupation status (n = 143)			6.66	
Student	33.3	66.7		
Unemployed	17.1	82.9		
Not working/ Retired	33.3	66.7		
Home duties/ Other	44.4	55.6		
Full-time work	44.4	55.6		
Part-time work	33.3	66.7		
Educational attainment (n = 141)			4.49	
Primary School/3 Years of High School	11.1	88.9		
Year 10	134.5	165.5		

Independent variable	Have future accommodation options	Does not have future accommodation options	χ^2	Cramer's V
Year 12	26.7	273.3		
TAFE/Trade	139.5	260.5		
University degree	143.3	156.7		
Accommodation type (n = 149)			3.8	
Own or purchasing home	36.4	63.6		
Private rental	34.3	65.7		
Public rental	19.4	80.6		
Rent free, Community housing / co-op, Other	42.3	57.7		

Note. * $p < .05$ ** $p < .01$*** $p < .001$. One-tailed alpha values.

Row percentages. Frequency tables for each variable are reported in Appendix 5.

Relationship between drug addiction and opportunities

Opportunity to enjoy adequate housing. It was hypothesised that PLWHA who injected illegal drugs were more likely to experience low opportunity availability and low opportunity achievability. The chi-square tests of independence between suitability of accommodation, experience of discrimination in relationship to accommodation and injecting illegal drugs were significant. Consistent with this study hypothesis, PLWHA who never injected illegal drugs were more likely to report that their accommodation was suitable and that they did not experience discrimination in relationship to accommodation. On the other hand, those who injected illegal drugs, either in the last year or previously, were more likely to report that their accommodation was not suitable. Those who injected illegal drugs in the last year were also more likely

to report that they experienced discrimination in relationship to accommodation (see Table IV-21).

Typology of experiences of opportunity. It was hypothesised that PLWHA who injected illegal drugs were more likely to experience low capability, achievability disadvantage, and availability disadvantage, and less likely to experience high capability than PLWHA who never injected illegal drugs. The chi-square of independence between the fourfold typology of opportunities and injecting illegal drugs was significant. Consistent with this study hypothesis, PLWHA who never injected illegal drugs were more likely to experience high capability, whereas those who injected in the last 12 months were more likely to experience both availability disadvantage and achievability disadvantage. Those who injected longer than 12 months ago were more likely to experience availability disadvantage (see Table IV-21).

Objective housing stability, number of home moves, and crowding conditions. Similarly, it was hypothesised that PLWHA who injected illegal drugs were more likely to move more often, to be in an unstable housing situation, and to live in overcrowding conditions compared to respondents who did never injected illegal drugs. The chi-square test of independence between objective housing stability, number of accommodation changes in the last 2 years and injecting illegal drugs were significant (see Table IV-21). A Kruskal-Wallis test was carried out to check whether crowding condition varied according to whether the study participants injected illegal drugs or not. The test was significant, $\chi^2(2, N = 719) = 6.72$, p (one-tailed) = .017. PLWHA who never injected illegal drugs lived in lower crowded conditions than those who injected one year ago or longer than one year ago. The mean rank of those who never injected was 345.49, of those who injected in the last year was 373.42, and of those who injected longer than one year ago was 391.59. Three further Mann-Whitney tests were performed to check whether the crowding conditions of those who never injected

differed from those who injected, either one year ago or longer than one year ago, and whether crowding conditions varied between those who injected in the last year and those who injected longer than one year ago. A Bonferroni correction was used to reduce the chances that the Type I error built over 0.5, so the new alpha limit was 0.016. The tests showed that the difference in the crowding conditions between those who never injected illegal drugs and those who injected in the last year was not significant, $z = -1.39$, p (one-tailed) = .082, $r = -0.06$. However, the difference in the crowding conditions between those who never injected and those who injected longer than one year ago was significant, although the effect size was small, $z = -2.45$, p (one-tailed) = .007, $r = -0.10$. Those who never injected lived in lower crowding conditions (mean rank = 134.72) than those who injected longer than one year ago (mean rank = 141.68). On the other hand, the crowding conditions of those who injected one year ago did not significantly differ from the crowding conditions of those who injected longer than one year ago, $z = -0.752$, p (one-tailed) = .226, $r = -0.05$.

Table IV-21

Cross tabulation of Experiences of Injecting Illegal Drugs and Suitable Accommodation vs. Not Suitable Accommodation, Discrimination in Relationship to Accommodation vs. No Experiences of Discrimination, Typology of opportunities, Objective Housing Stability, and Number of Accommodation Changes in the Last Two Years.

	Never	In the last 12 months	More than 12 months ago	χ^2	Cramer's V
Accommodation suitable (n = 722)				27.87***	.196
Yes	88.7 (5.2)	75 (-2.6)	72.4 (-3.8)		
No	11.3 (-5.2)	25 (2.6)	27.6 (3.8)		
Experienced discrimination (n = 716)				11.26**	.125
Yes	5.5 (3.1)	14.2 (2.9)	10 (1.0)		

	Never	In the last 12 months	More than 12 months ago	χ^2	Cramer's V
No	94.5 (-3.1)	85.8 (-2.9)	90 (-1.0)		
Typology of opportunities (n = 713)				37.56***	.162
High capability	86.2 (5.8)	66.9 (-3.8)	69.3 (-3.4)		
Availability disadvantage	8.5 (-4.4)	18.9 (2.2)	20.7 (3.2)		
Achievability disadvantage	2.5 (-2.0)	7.9 (2.8)	3.3 (-0.2)		
Low capability	2.8 (-2.4)	6.3 (1.3)	6.7 (1.7)		
Objective housing stability (n = 720)				49.35***	.185
Stably housed	19.5 (3.6)	7.1 (-2.9)	11.3 (-1.6)		
Unstably housed - Buying	21.5 (4.2)	9.4 (-2.4)	9.3 (-2.8)		
Unstably housed – Public rental	39.4 (-1.6)	44.9 (0.8)	45.7 (1.1)		
Unstably housed – Private rental	10.9 (-3.5)	24.4 (3.5)	16.6 (0.8)		
Unstably housed – Other	8.8 (-2.9)	14.2 (1.0)	17.2 (2.5)		
Number of house moves (n = 728)				25.83***	.133
No changes	92.4 (4.3)	78.9 (-3.7)	84.2 (-1.8)		
1 time	5.1 (-3.4)	11.7 (1.8)	12.5 (2.4)		
2 or more times	2.5 (-2.5)	9.4 (3.6)	3.3 (-0.4)		

Note. * $p < .05$ ** $p < .01$*** $p < .001$. One-tailed alpha values.

Column percentages. The frequency table of the dependent variable is reported in Appendix 5.

Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Opportunity to have choice over where to live. The relationship between having accommodation options for the future and injecting illegal drugs was not significant, χ^2 (2, N = 119) = 1.11, *p* (one-tailed) = 0.286 (see Table IV-22 for the cross tabulation).

Table IV-22

Cross tabulation between Accommodation Options for the Future and Injecting Illegal Drugs.

Injected illegal drugs	Have future accommodation options	Does not have future accommodation options
Never	40.8 (20)	59.2 (29)
In the last year	31 (9)	69 (20)
Longer than 1 year ago	31.7 (13)	68.3 (28)

Note. * $p < .05$ ** $p < .01$*** $p < .001$.

Row percentages. Frequency in parentheses below observed percentages. Frequency tables for each variable are reported in Appendix 5.

Relationship between health status and opportunities

Opportunity to enjoy adequate housing. The investigation of the relationships between physical health, mental health and housing experiences was exploratory. The chi-square tests of independence performed to examine the relationship between self-reported physical health, having other major health issues, having a mental health condition, having being diagnosed with an AIDS-defining illness, and both suitability of accommodation and experiences of discrimination in relationship to accommodation were significant (see Table IV-23 and Table IV-24). Inspection of the adjusted

standardised residuals shows that there were significantly more respondents who reported having an unsuitable accommodation or having experienced discrimination among PLWHA with worse physical and mental health conditions. There were significantly more respondents with an unsuitable accommodation or who experienced discrimination within those who reported poor or fair health, whereas there were significantly fewer respondents with an unsuitable accommodation within those who reported good and excellent health. The odds of living in a suitable accommodation were 1.3 times higher for respondents who did not have other major health conditions (OR = 1.350; 95% CI [1.114, 1.636]) and 1.7 times higher for respondents who did not have any mental health conditions (OR = 1.719; 95% CI [1.380, 2.141]). The odds of experiencing discrimination were 1.3 times higher for respondents who had other major health (OR = 1.349; 95% CI [1.081, 1.682]) and 1.8 times higher for respondents who had mental health conditions (OR = 1.895; 95% CI [1.629, 2.204]).

The relationship between suitability of accommodation and both AIDS-defining illness and HIV-related illness were significant; the odds of living in an unsuitable accommodation were 1.6 times higher for respondents who had an AIDS-defining illness (OR = 1.631; 95% CI [1.211, 2.196]), and 1.7 higher for those who had an HIV-related illness (OR = 1.723; 95% CI [1.280, 2.318]). The relationship between experience of discrimination in relationship to accommodation and AIDS-defining illness was not significant (see Table IV-23), whereas the relationship with HIV-related illness was significant (see Table IV-24). The odds of experiencing discrimination in relationship to accommodation were 2.6 times higher for those who had an HIV-related illness compared to those who did not (OR = 2.693; 95% CI [1.679, 4.318]).

With regard to the biological markers, the *t*-tests computed to assess the relationship of suitability of accommodation, experience of discrimination in relationship to accommodation and viral load were both not significant. The first was

t(866) = -0.762, *p* = .447, *r* = 0.03, with means and standard deviation of 15464.65 (60621.52) and 20044.14 (81039.05) respectively; the second was *t*(60.01) = 0.534, *p* = .595, *r* = 0.07 with means and standard deviations of 24204.23 (1.20) and 15739.12 (58321.37). On the other hand, the relationship between suitability of accommodation and CD4 count was significant, *t*(863) = 2.46, *p* = .014, *r* = 0.08; those with a suitable accommodation had significantly higher CD4 cells count than those who reported an unsuitable accommodation, with means and standard deviations of 539.58 (334.12) and 464.87 (278.86) respectively. However, the difference in CD4 cells count for those who did not experience discrimination in relation to accommodation and those who did was not significant, *t*(856) = -1.27, *p* = .204, *r* = 0.04 with means (SD) of 545 (2.01) and 459.17 (293.86) respectively.

Table IV-23

Cross tabulation of Suitable Accommodation vs. Not Suitable Accommodation and Self-reported Physical Health, Other Major Health Conditions, Having a Mental Health Condition, AIDS-defining Illness, and HIV-related Illness.

	Accommodation suitable	Accommodation not suitable	χ^2	Cramer's V
Health Status (n = 956)			36.37***	.195
Poor	59.5 (-4.4)	40.5 (4.4)		
Fair	77.4 (-3.4)	22.6 (3.4)		
Good	87 (2.3)	13 (-2.3)		
Excellent	90.1 (2.9)	9.9 (-2.9)		
Other major health conditions (n = 945)			11.77**	.112
Yes	79.5 (-3.4)	20.5 (3.4)		

	Accommodation suitable	Accommodation not suitable	χ^2	Cramer's V
No	87.7 (3.4)	12.3 (-3.4)		
Mental health conditions (n = 955)			34.46***	.190
Yes	75.7 (-5.9)	24.3 (5.9)		
No	89.9 (5.9)	10.1 (-5.9)		
AIDS-defining illness (n = 949)			10.13**	.103
Yes	77.1 (-3.2)	22.9 (3.2)		
No	85.9 (3.2)	14.1 (-3.2)		
HIV-related illness (n = 921)			12.74***	.118
Yes	77.1 (-3.6)	22.9 (3.6)		
No	86.7 (3.6)	13.3 (-3.6)		

Note. * $p < .05$ ** $p < .01$*** $p < .001$

Row percentages. Frequency tables for each variable are reported in Appendix 5.

Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Table IV-24

Cross tabulation of Experiences of Discrimination in Relationship to Accommodation vs. No Experiences of Discrimination and Self-reported Physical Health, Having Other Major Health Conditions, Having a Mental Health Condition, AIDS-defining Illness, and HIV-related Illness.

	Experienced discrimination	Did not experience discrimination	χ^2	Cramer's V
Health Status (n = 945)			26.37***	.167
Poor	23.1 (4.1)	76.9 (-4.1)		
Fair	9.7 (2.1)	90.3 (-2.1)		
Good	6 (-1.0)	94 (1.0)		
Excellent	2.6 (-3.0)	97.4 (3.0)		
Other major health conditions (n = 935)			5.52*	.077
Yes	9.3 (2.3)	90.7 (-2.3)		
No	5.3 (-2.3)	94.7 (2.3)		
Mental health conditions (n = 946)			34.03***	.190
Yes	12.6 (5.8)	87.4 (-5.8)		
No	2.8 (-5.8)	97.2 (5.8)		
AIDS-defining illness (n = 939)			3.16	
Yes	9.6	90.4		
No	6.2	93.8		

	Experienced discrimination	Did not experience discrimination	χ^2	Cramer's V
HIV-related illness (n = 913)			17.99***	.140
Yes	12.6 (4.2)	4.7 (-4.2)		
No	87.4 (-4.2)	95.3 (4.2)		

Note. * $p < .05$ ** $p < .01$*** $p < .001$

Row percentages. Frequency tables for each variable are reported in Appendix 5. Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Typology of experiences of opportunity. As for opportunity availability and opportunity achievability, the analyses of the relationships between the four experiences of the opportunity to enjoy adequate housing and the seven variables of health status were exploratory. The chi-square tests of independence performed to examine the relationship between the typology of experiences of the opportunity to enjoy adequate housing and self-reported health status, having other major health issues, being diagnosed with a mental health condition, having an AIDS-defining illness, and having an HIV-related illness were significant (see Table IV-25). Inspection of the adjusted standardised residuals shows that there were significantly more respondents who experienced low capability, availability disadvantage, and achievability disadvantage within those who reported poor health, those who had a mental health condition, and those with an HIV-related illness. Those who had other major physical health conditions were more likely to experience low capability, and those who had an AIDS-defining illness were more likely to experience availability disadvantage. On the other hand, there were significantly more study participants who experienced high capability among

those who perceived having excellent health, did not have any other major physical health conditions, mental health problems, AIDS-defining illnesses, or HIV-related illnesses. The ANOVA test showed that those who experienced high capability had significantly higher CD4 cells counts compared to those in low capability, $F(3,849) = 2.76$, $p = .041$, with means (SD) of 539.51 (333.63) and 381.17 (212.37) respectively. A Gabriel post-hoc test was chosen to evaluate significant differences among crowding conditions averages because of the substantial differences in the sample sizes of the three categories of the dependent variable. This test showed that the mean number of CD4 cells of those experiencing high capability was higher than that of those who experienced low capability. However, the viral load among those experiencing high capability, and those experiencing low capability, availability disadvantage, and achievability disadvantage was not significant, $F(3,851) = 1.34$, $p = .259$.

Table IV-25

Cross tabulation of Fourfold Typology of Opportunities and Self-reported Physical Health, Having Other Major Health Conditions, Having a Mental Health Condition, AIDS-defining Illness, and HIV-related Illness.

	High capability	Availability disadvantage	Achievability disadvantage	Low capability	χ^2	Cramer's V
Health Status (n = 940)					49.82***	.133
Poor	50 (-4.9)	26.3 (2.6)	10.5 (2.5)	13.2 (3.4)		
Fair	72.9 (-3.7)	17.6 (2.9)	4.7 (1.3)	4.7 (1.3)		
Good	83.9 (2.2)	10.1 (-2.0)	3.1 (-0.4)	2.9 (-0.8)		
Excellent	88.7 (3.5)	8.7 (-2.0)	1.3 (-2.0)	1.3 (-2.0)		

	High capability	Availability disadvantage	Achievability disadvantage	Low capability	χ^2	Cramer's V
Other major health conditions (n = 931)					17.56**	.137
Yes	76.7 (-2.9)	14 (1.5)	3.2 (-0.4)	6.1 (3.8)		
No	84.2 (2.9)	10.7 (-1.5)	3.6 (0.4)	1.5 (-3.8)		
Mental health conditions (n = 941)					58.93***	.250
Yes	69.5 (-7.4)	18 (4.5)	6.3 (4.2)	6.1 (3.8)		
No	88.9 (7.4)	8.3 (-4.5)	1.3 (-4.2)	1.5 (-3.8)		
AIDS-defining illness (n = 949)					12.08**	.114
Yes	72.4 (-3.5)	18 (2.7)	4.8 (1.2)	4.8 (1.3)		
No	82.9 (3.5)	11 (-2.7)	3.1 (-1.2)	3 (-1.3)		
HIV-related illness (n = 921)					26.84***	.172
Yes	70.2 (-4.9)	17.5 (2.8)	6.3 (3.0)	6.0 (2.6)		
No	84.6 (4.9)	10.7 (-2.8)	2.3 (-3.0)	2.4 (-2.6)		

Note. * $p < .05$ ** $p < .01$*** $p < .001$

Row percentages. Frequency tables for each variable are reported in Appendix 5.

Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Objective housing stability, number of home moves, and crowding conditions. The analyses of the relationships between the three objective indicators of housing and the seven variables of health status were exploratory.

With regard to the variable number of house moves (see Table IV-26), those who had major health conditions or mental health problems were more likely to have moved 2 or more times. However, the relationship with AIDS-defining illness and HIV-related illness were not significant. The relationship with self-reported health, although significant, was weak; the adjusted standardised residuals show that there were no significant differences between expected and frequency counts for those who moved 2 or more times. Neither the ANOVA test between number of house moves and CD4 cells count, $F(2,867) = 0.45$, $p = .638$, nor that with viral load, $F(2,872) = 2.50$, $p = .082$, were significant.

With regard to objective housing stability (see Table IV-27), those with poor self-reported physical health, with mental health conditions, other major mental health problems, and AIDS-defining illnesses were more likely to be unstably housed in private rental, whereas those with no major health conditions, no mental health problems, excellent self-reported physical health, and AIDS-defining illness were more likely to be unstably housed buying. The relationship with HIV-related illness was not significant. The ANOVA tests of objective housing stability with CD4 cell count, $F(4,849) = .60$, $p = .661$, and viral load, $F(4,856) = 1.50$, $p = .200$, were both not significant.

With regard to the crowding index, the Kruskal-Wallis test with self-reported health status was found to be significant, $\chi^2(3, N = 948) = 8.53$, $p = .036$. The mean rank of those with poor health was 585.83, of those with fair health was 467.65, of those with good health was 476.14, and of those with excellent health was 458.76. Six further

Mann-Whitney tests were performed to check whether the crowding conditions of participants with poor health differed from those respectively of participants with fair, good, and excellent health. It was also tested whether the crowding conditions of participants with fair health differed from those of participants with good and excellent health, and, finally, whether the crowding conditions of participants with good health differed from those of participants with excellent health. A Bonferroni correction was used to reduce the chances that the Type I error built over 0.5, so the new alpha limit was 0.008. The tests showed that the difference in the crowding conditions between those with poor and fair health, $z = -2.76$, $p = .006$, $r = -0.16$, those with poor and good health, $z = -2.53$, $p = .011$, $r = -0.12$, and those with poor and excellent health, $z = -2.88$, $p = .004$, $r = -0.17$, were all statistically significant, although had small effect sizes. However, the difference in the crowding conditions between those with fair and good health, $z = -0.42$, $p = .678$, $r = -0.02$, fair and excellent health, $z = -0.41$, $p = .683$, $r = -0.02$, and good and excellent health, $z = -0.78$, $p = .434$, $r = -0.03$, were not found to be statistically significant. Similarly, the Mann-Whitney test to check the relationship between crowding conditions and mental health was significant, $z = -3.92$, $p = .001$, $r = -0.11$. In particular, PLWHA with mental health conditions lived in conditions of higher crowding (mean rank = 506.53) compared to those with no mental health conditions (mean rank = 449.69). However, the Mann-Whitney tests between crowding conditions and other major health problems, $z = -1.12$, $p = .263$, $r = -0.04$, AIDS-defining illness, $z = -0.98$, $p = .326$, $r = -0.03$, and HIV-related illness, $z = -0.96$, $p = .338$, $r = -0.03$, were not found to be statistically significant. Similarly, the correlations between crowding index and both CD4 cells count, $r(858) = .008$, $p = .809$, and viral load, $r(864) = -.017$, $p = .608$, were not significant.

Table IV-26

Cross tabulation between Number of Moves in the Last 2 Years and Self-reported Physical Health, Having Other Major Health Conditions, Having a Mental Health Condition, AIDS-defining Illness, and HIV-related Illness.

	No changes	1 change	2 or more changes	χ^2	Cramer's V
Health Status (n = 963)				15.81*	.091
Poor	86 (-0.8)	9.3 (0.6)	4.7 (0.5)		
Fair	84.7 (-3.1)	10.7 (2.7)	4.6 (1.5)		
Good	91.8 (1.9)	4.7 (-2.5)	3.5 (0.5)		
Excellent	92.3 (1.5)	6.8 (-0.2)	0.9 (-2.4)		
Other major health conditions (n = 950)				8.82*	.096
Yes	86.8 (-2.5)	8.2 (1.1)	5 (2.7)		
No	91.7 (2.5)	6.4 (-1.1)	1.9 (-2.7)		
Mental health conditions (n = 962)				23.29***	.156
Yes	84.3 (-4.7)	10.1 (3.1)	5.5 (3.5)		
No	93.6 (4.7)	4.9 (-3.1)	1.5 (-3.5)		
AIDS-defining illness (n = 954)				3.09	
Yes	89.2	6	4.7		
No	89.8	7.6	2.6		
HIV-related illness (n = 927)				3.57	
Yes	86.9	9.6	3.5		
No	91	6.3	2.7		

Note. * $p < .05$ ** $p < .01$*** $p < .001$. Row percentages. Frequency tables for each variable are reported in Appendix 5. Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Table IV-27

Cross Tabulation of Objective Housing Stability and Self-reported Physical Health, Other Major Health Conditions, Having a Mental Health Condition, AIDS-defining Illness, and HIV-related Illness.

	Stably housed	Unstably housed Buying	Unstably housed Public rental	Unstably housed Private rental	Unstably housed Other	χ^2	Cramer's V
Health Status (n = 942)						64.64***	.151
Poor	14.3 (-0.9)	7.1 (-1.7)	31 (-1.0)	38.1 (4.4)	9.5 (-0.3)		
Fair	20.5 (0.4)	11.8 (-2.4)	33.9 (-1.7)	22 (4.0)	11.8 (0.5)		
Good	20.1 (0.4)	15.8 (-0.6)	38.8 (0.4)	12 (-2.0)	13.2 (1.9)		
Excellent	18.3 (-0.5)	25.3 (4.0)	43.2 (1.8)	6.6 (-3.9)	6.6 (-2.5)		
Other major health conditions (n = 931)						54.60***	.242
Yes	21.3 (1.3)	8.6 (-6.0)	36.7 (-1.0)	20.8 (4.9)	12.7 (1.5)		
No	17.8 (-1.3)	23.4 (6.0)	39.8 (1.0)	9.4 (-4.9)	9.6 (-1.5)		
Mental health conditions (n = 941)						50.23***	.231
Yes	18.4 (-0.8)	9.6 (-5.0)	38.1 (-0.2)	22.1 (5.7)	11.8 (0.7)		

	Stably housed	Unstably housed Buying	Unstably housed Public rental	Unstably housed Private rental	Unstably housed Other	χ^2	Cramer's V
AIDS-defining illness (n = 935)						16.75**	.134
No	20.4 (0.8)	21.9 (5.0)	38.6 (0.2)	8.8 (-5.7)	10.3 (-0.7)		
Yes	19.2 (-0.2)	12.2 (-2.0)	37.6 (-0.3)	22.3 (3.8)	8.7 (-1.2)		
HIV-related illness (n = 908)						9.01	
No	19.7 (0.2)	18 (2.0)	38.7 (0.3)	12.2 (-3.8)	11.5 (1.2)		
Yes	24	13	35.8	16.5	10.6		
No	17.9	18.3	39.8	13	11		

Note. * $p < .05$ ** $p < .01$*** $p < .001$

Row percentages. Frequency tables for each variable are reported in Appendix 5.

Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Opportunity to have choice over where to live. Of the relationships between the variable accommodation options for the future and the seven indicators of health, only the chi-square tests of independence with self-reported health status and other major health conditions were significant (see Table IV-28). Although the relationship with self-reported health status was significant, no specific cells had an adjusted standardised residual greater than 2. The relationship with other major health conditions indicated that those with other major health conditions were 1.34 times more likely to have an accommodation option for the future than those with no other major health conditions (OR = 1.348; 95% CI [1.032, 1.761). The *t*-tests of independence with CD4 cells count and viral load were respectively, $t(44.02) = 1.37$, $p = .176$, $r = 0.20$, and $t(130) = -0.694$, $p = .489$, $r = 0.06$.

Table IV-28

Cross tabulation between Accommodation Options for the Future and Self-reported Physical Health, Having Other Major Health Conditions, Having a Mental Health Condition, AIDS-defining Illness, and HIV-related Illness.

Independent variable	Have future accommodation options	Does not have future accommodation options	χ^2	Cramer's V
Health Status (n = 147)			8.94*	.247
Poor	13.3 (-1.6)	86.7 (1.6)		
Fair	22.8 (-1.9)	77.2 (1.9)		
Good	40.4 (1.6)	59.6 (-1.6)		
Excellent	47.8 (1.8)	52.2 (-1.8)		
Other major health conditions (n = 143)			4.25*	.173

Independent variable	Have future accommodation options	Does not have future accommodation options	χ^2	Cramer's V
Yes	39.8 (2.1)	60.2 (-2.1)		
No	23.3 (-2.1)	76.7 (2.1)		
Mental health conditions (n = 148)			.440	
Yes	30.5	69.5		
No	35.8	64.2		
AIDS-defining illness (n = 147)			.391	
Yes	29.8	70.2		
No	35	65		
HIV-related illness (n = 141)			1.52	
Yes	28.1	38.1		
No	71.9	61.9		

Note. * $p < .05$ ** $p < .01$*** $p < .001$.

Row percentages. Frequency tables for each variable are reported in Appendix 5.

Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Relationships between measures of housing experiences

Considering the small number of cases in the low capability and achievability disadvantage categories, these were collapsed together in order to meet the chi-square test of independence minimum requirements. The fourfold typology of opportunities to enjoy adequate housing was significantly associated with both objective housing stability and number of accommodation changes. The chi-square between typology of

opportunities and objective housing stability was χ^2 (8, N = 929) = 52.35, $p < 0.001$, Cramer's V = 0.168 (see Table IV-30 for cross tabulation). PLWHA who never changed accommodation were significantly more likely to experience high capability than those who moved 2 or more times (two-sided Fisher exact test $p < .001$, see Table IV-29 for cross tabulation). Also the Kruskal-Wallis test with crowding condition was highly significant, $\chi^2(3, N = 934) = 28.78$, $p < .001$. The mean rank of those with high capability was 446.46, of those with disability disadvantage was 575.89, of those with achievability disadvantage was 487.18, and of those with low capability was 552.76. Six further Mann-Whitney tests were performed to check whether the crowding conditions of participants with high achievability differed from those respectively of participants with availability disadvantage, achievability disadvantage, and low capability. It was also tested whether the crowding conditions of participants with availability disadvantage differed from those of participants with achievability disadvantage and low capability, and, finally, whether the crowding conditions of participants with achievability disadvantage differed from those of participants with low capability. A Bonferroni correction was used to reduce the chances that the Type I error built over 0.5, so the new alpha limit was 0.008. Only the differences in crowding conditions between those with high capability and both those with availability disadvantage and low capability were significant, although their effect sizes were small; these were respectively, $z = -4.97$, $p < .001$, $r = -0.17$, and $z = -2.29$, $p = .022$, $r = -0.08$. However, the differences in crowding conditions between those with high capability and achievability disadvantage, $z = -0.89$, $p = .371$, $r = -0.03$, those with availability disadvantage and achievability disadvantage, $z = -1.78$, $p = .075$, $r = -0.15$, those with availability disadvantage and low capability, $z = -0.74$, $p = .459$, $r = -0.06$, and those with achievability disadvantage and low capability, $z = -1.04$, $p = .299$, $r = -0.13$, were all statistically not significant.

Table IV-29

Cross Tabulation of Number of Accommodation Changes and the Fourfold Typology of Opportunities of Housing Experiences (3 Categories).

	No changes	1 change	2 or more changes
High achievability	84.2 (712)	56.5 (39)	29 (9)
Availability disadvantage	11.6 (98)	21.7 (15)	22.6 (7)
Achievability disadvantage/Low capability	4.3 (36)	21.7 (15)	48.4 (15)

Note. * $p < .05$ ** $p < .01$*** $p < .001$

Column percentages. Frequency in parentheses below observed percentages. Frequency tables for each variable are reported in Appendix 5.

Table IV-30

Cross Tabulation of Objective Housing Stability and the Fourfold Typology of Opportunities of Housing Experiences (3 Categories).

	Stably housed	Unstably housed Buying	Unstably housed Public rental	Unstably housed Private rental	Unstably housed Other
High achievability	91.6 (4.2)	92.3 (4.1)	76.7 (-2.2)	70.1 (-3.3)	68.3 (-3.2)
Availability disadvantage	6.7 (-2.7)	6.4 (-2.6)	14.6 (1.4)	18.2 (2.1)	18.8 (2.0)
Achievability disadvantage / Low capability	1.7 (3.1)	1.3 (-3.1)	8.7 (1.6)	11.7 (2.3)	12.9 (2.5)

Note. * $p < .05$ ** $p < .01$*** $p < .001$

Column percentages. Frequency tables for each variable are reported in Appendix 5.

Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Predictors of the opportunity to enjoy adequate housing

The categories availability disadvantage and achievability disadvantage presented low cell frequencies (n = 33, see Table IV-7). This affected the construction of multinomial logistic models, which resulted having high numbers of empty cells (58.9%). Therefore, the decision was taken to collapse the three categories representing disadvantage together, i.e. low capability, achievability disadvantage, and achievability disadvantage, and to run binary logistic regression analysis instead. Although this choice precluded the possibility to appreciate differences across the disadvantage categories of the proposed model, analysis of Tables IV-11, Table IV-17, Table IV-21, and Table IV-25 shows that availability disadvantage and achievability disadvantage presented significant differences across the study participants. In fact, one could have cell percentages which were half or up to three times the size of the other. Consequently, the heuristic validity of the suggested discrimination between those two categories remains.

Predictors were entered in the binary logistic model in separate blocks (see Table IV-31). Given to low cell counts, the variable age was entered as a continuous variable too. The test of the full model versus a model with intercept only was statistically significant, $\chi^2(11) = 117.97$, $p < .001$. The Nagelkerke R squared was 0.268. The Hosmer–Lemeshow test showed that the model had a good fit ($p = 0.207$). There were no unusually high values of the Cook statistics, particularly none greater than 1, all cases had DFBetas less than 1, and leverage statistics were close to the calculated expected value[1] of 0.010. Table IV-32 shows a summary of the final model. Results to highlight here are that, controlling for other variables in the model, study participants who lived in private rental and other types of accommodation were less

[1] Calculated as (k + 1)/N, where K is the number of predictors and N the sample size (A. Field, 2005).

likely to experience high capability than respondents living in their own home or in a house they were buying. Similarly, those with a mental health diagnosis or with poor health were less likely to experience high capability than respectively respondents with no mental health conditions and excellent self-reported health. With regard to weekly income after tax, a 1 unit increase in income (i.e. AUS$ 100) increased by 0.2 % the odds of experiencing high capability.

Objective housing conditions and crowding conditions were added, in separate blocks, to the final model. The likelihood ratio test of both indices resulted to be statistically not significant (see Table IV-31). The Hosmer–Lemeshow tests showed that both model had a good fit (objective housing conditions $p = 0.067$, crowding conditions $p = 0.153$). When the index of crowding conditions was entered as a categorical variable with 3 categories, i.e. low crowding, medium-high crowding, and overcrowding (see the description of this variable in the section 'Predictors of crowding conditions' below), the likelihood ratio test resulted significant, however the Hosmer–Lemeshow test showed that the model did not have a good fit ($p = 0.042$). Overall, after controlling for demographic, socioeconomic, behavioural, and health status variables, objective housing condition and crowding conditions did not predict the binary version of the fourfold typology of opportunities to enjoy adequate housing.

Table IV-31

Omnibus Tests of Model Coefficients

		χ^2	df
Step 1			
	Age	10.42**	1
Step 2			
	Sexuality	1.93	2
Step 3			
	Weekly income after tax	65.44***	1

	χ^2	df
Step 4		
Employment status	4.37	4
Step 5		
Educational attainment	1.92	3
Step 6		
Accommodation type	17.17**	3
Step 7		
Injecting illegal drugs	6.37*	2
Step 8		
Self-reported health	21.99***	3
Step 9		
Other physical health conditions	0.18	1
Step 10		
Mental health	10.07**	1
Step 11		
AIDS-defining illness	0.78	1
Step 12		
HIV-related illness	2.37	1
Step 13		
CD4 cell count	1.88	1
Step 14		
Objective housing stability	0.84	4
Step 15		
Crowding conditions	2.81	1
Step 16		
Crowding conditions (3 groups)	7.22*	2

Note. * $p < .05$ ** $p < .01$*** $p < .001$

Table IV-32

Summary of Logistic Regression Analysis Predicting High Capability to Enjoy Adequate Housing (n = 646).

Predictor	*B (S.E.)*	Wald χ^2	Odds Ratio	95% C.I. for Odds Ratio	
				Lower	Upper
Constant	1.22 (0.81)	2.28	3.38		
Age	0.02 (0.01)	3.61	1.02	.99	1.02
Weekly income after tax	0.002 (0.001)	12.33***	1.002	1.001	1.003
Accommodation type (Reference category: Own or purchasing home)					

Predictor	*B (S.E.)*	Wald χ^2	Odds Ratio	95% C.I. for Odds Ratio	
				Lower	Upper
Private rental	-0.84 (0.34)	6.20*	0.42	0.22	0.83
Public rental	-0.53 (0.40)	1.70	0.59	0.26	1.30
Other	-1.06 (0.41)	6.85**	0.34	0.15	0.76
Injecting illegal drugs (Reference category: Never)					
In the last year	-0.52 (0.29)	3.23	0.59	0.33	1.04
Longer than 1 year ago	-0.44 (0.27)	2.58	0.64	0.37	1.10
Perceived health (Reference category: Excellent)					
Poor	-2.16 (0.56)	14.57***	0.11	0.038	0.034
Fair	-0.63 (0.35)	3.18	0.53	0.26	1.06
Good	-0.28 (0.33)	0.70	0.75	0.39	1.45
Mental health conditions (Reference category: None)	-0.76 (0.24)	9.80**	0.46	0.28	0.75

Note. * $p < .05$ ** $p < .01$*** $p < .001$.

Reference category: High Capability.

Predictors of the opportunity to have choice over where to live

Following the procedure suggested in the Method section, binary logistic regression analysis was employed to predict the probability of a sub-sample of the respondents to have alternative future accommodation options based on their place of residence, weekly income after tax, self-reported health status, and having other major health conditions. Each predictor was entered in separate blocks (see Table IV-33). Even though the variable ‘place of residence’ test of the full model versus a model with intercept only was not statistically significant, the Wald chi-square test was significant,

so it was retained. In small samples like the one we are using for this analysis, it can happen that the chi-square test for the odds ratio does not match with the overall chi-square test of the model (Bewick, Cheek, & Ball, 2005).

Table IV-34 shows a summary of the final model. The test of the full model versus a model with intercept only was statistically significant, $\chi^2(8) = 32.09$, $p < .001$. The Nagelkerke R squared was 0.333. The Hosmer–Lemeshow test showed that the model had a good fit ($p = 0.333$). There were no unusually high values of the Cook statistics, particularly none greater than 1, all cases had DFBetas less than 1, and leverage statistics were close to the calculated expected value of 0.1008.

Self-reported health status was not a significant predictor of having accommodation options for the future, however having other major health conditions was. Results to highlight here are that, controlling for other variables in the model, study participants who lived in outer suburban areas and those with other major health conditions were respectively 6.3 times and 3.4 times more likely to have accommodation options for the future than those living in capital cities and inner suburban areas. With regard to weekly income after tax, a 1 unit increase in income (i.e. AUS$ 100) increased by 0.4 % the odds of having accommodation options for the future.

Table IV-33

Omnibus Tests of Model Coefficients

		χ^2	df
Step 1			
	Place of residence	7.49	3
Step 2			
	Weekly income after tax	14.81***	1
Step 3			
	Self-reported health status	3.36	3
Step 4			

	χ^2	df
Other major health conditions	6.42*	1

Note. * $p < .05$ ** $p < .01$*** $p < .001$

Table IV-34

Summary of Logistic Regression Analysis Predicting Accommodation Options for the Future (n = 119).

Predictor	*B (S.E.)*	Wald χ^2	Odds Ratio	95% C.I. for Odds Ratio	
				Lower	Upper
Constant	-3.12 (0.96)	10.46**	0.04		
Place of residence(Reference category: Capital City/Inner suburban)		8.84*			
Outer suburban	1.84 (0.73)	6.36*	6.30	1.50	26.34
Regional centre	-0.14 (0.62)	0.56	0.86	0.25	2.91
Rural	1.18 (0.75)	2.48	3.27	0.74	14.33
Weekly income after tax	0.004 (0.001)	9.83*	1.004	1.001	1.007
Perceived health (Reference category: Excellent)		4.63			
Poor	-1.61 (1.01)	2.51	0.19	0.27	1.46
Fair	-0.58 (0.71)	0.65	0.56	0.13	2.28
Good	0.180 (0.67)	0.07	1.19	0.31	4.51
Other major health conditions (Reference category: No other health conditions)	1.24 (0.51)	5.85*	3.46	1.26	9.47

Note. * $p < .05$ ** $p < .01$*** $p < .001$.

Reference category: No accommodation options for the future.

Predictors of number of accommodation changes

Following the same procedure as in the previous section, demographic, socioeconomic, and health status variables were entered step by step in a multinomial

logistic model to predict the number of accommodation changes of PLWHA (see Table IV-35). Because of the low frequencies that characterised the cross tabulation between 2 or more house moves in the last two years and the categories of the variables accommodation types and age (see Table IV-12 and Table IV-18), these variables were not included in the logistic models.

The complete model was highly significant, $\chi^2(6) = 56.54$, $p < .001$, Nagelkerke R squared = 0.117; its goodness-of-fit statistics were high (Pearson chi-square 1387.44 and Deviance chi-square 574.80) although they had large *p* values (Pearson $p = .514$ and Deviance $p = 1.000$). This model had a high number of empty cells (65.9%), which resulted in an excessive number of residuals greater than ± 1.96 and ± 2.58 standard deviations given the acceptable bounds mentioned in the Method section (see a summary in Table_Appendix 7-1 in Appendix 7). In order to reduce the number of empty cells, the variable weekly income after tax was transformed in a categorical variable by breaking it into quartiles, and the variable time since diagnosis was broken into four categories: 0-5 years, 6-10 years, 11-15 years, 16 years and longer. The logistic model was then run again with these new variables. This latter model was also highly significant, $\chi^2(14) = 63.42$, $p < .001$, Nagelkerke R squared = 0.130; its goodness-of-fit statistics were smaller (Pearson chi-square 52.03 vs. 1387.44 and Deviance chi-square 54.30 vs. 574.80) and still had large *p* values (Pearson $p = .320$ and Deviance $p = .247$). This model had a smaller number of empty cells (25% vs. 65.9%), and an inspection of the Pearson residuals showed that the number of residuals greater than ± 1.96 (1 in total) and ± 2.58 standard deviations (2 in total) were well within the acceptable bounds mentioned in the Method section (see a summary in Table IV-36). Results to point out here are that PLWHA who were diagnosed 5 years ago or less were 5.7 times more likely to move 2 or more times than those who were diagnosed 16 years ago or more. Those who had been diagnosed for 15 years or less were about 3

times more likely to move 1 time compared to those who were diagnosed longer than 16 years ago. Finally, those in the first income quartile and those with mental health conditions were 3.5 times more likely to move two or more times compared respectively to those in the fourth income quartile and those with no mental health conditions.

After controlling for demographic, socioeconomic, behavioural, and health status variables, the fourfold typology of opportunities to enjoy adequate housing was entered in the logistic model. The fourfold typology made the variable mental health conditions nonsignificant (p = .179), which was taken out of the model. The new model was highly significant, $\chi^2(18) = 115.01$, $p < .001$, Nagelkerke R squared = 0.231; it had small goodness-of-fit statistics (Pearson chi-square 93.08 and Deviance chi-square 90.39) and large p values (Pearson p = .391 and Deviance p = .469). This model had a slighter higher number of empty cells (38.2%), however an inspection of its Pearson residuals showed that both the number of the residuals greater than ± 1.96 standard deviations (4 in total) and the number of the residuals greater than ± 2.58 standard deviations (1 in total) were well within the acceptable bounds mentioned in the Method section. A summary of this last model is showed in Table IV-37. Results to highlight here are that the higher probability to experience low capability for those in the first income quartile was not any longer significant. This indicates that the typology of experiences of opportunities mediates the effects of income on 2 or more home moves among PLWHA. Finally, PLWHA who experienced with low capability and achievability disadvantage were respectively 86.4 and 17.2 times more likely to move home two or more times compared to PLWHA who experienced high capability.

Table IV-35

Likelihood Ratio Tests

		χ^2	df
Step 1			
	Country of birth	5.68	2
Step 2			
	Time since diagnosis	7.32*	2
Step 3			
	Weekly income after tax	33.64***	2
Step 4			
	Employment status	14.69	8
Step 5			
	Injecting illegal drugs	9.32	4
Step 6			
	Self-reported health	12.67*	6
Step 7			
	Other physical health conditions	4.73	2
Step 8			
	Mental health conditions	10.38[a]*	2
Step 9			
	Aids defining illness	4.27	2
Step 10			
	Typology of opportunities	41.94***	6

Note. * $p < .05$ ** $p < .01$*** $p < .001$. See Appendix 6 for a full list of the interactions tested. [a] The variable self-reported health lost significance after entering the variable mental health conditions ($p = 0.123$). No interactions were found between the two so the former was removed from the model.

Table IV-36

Summary of Multinomial Logistic Regression Predicting Number of Accommodation Changes from Time Since Diagnosis, Income Quartiles, and Mental Health Conditions (n = 846).

	1 change				2 or more changes			
	B (S.E.)	Odds Ratio	95% C.I. for Odds Ratio		*B (S.E.)*	Odds Ratio	95% C.I. for Odds Ratio	
			Lower	Upper			Lower	Upper
Time since diagnosis (Reference category: 16 years and over)								
0-5 years	1.14 (0.41)	3.13*	1.40	7.00	1.74 (0.60)	5.72*	1.78	18.35
6-10 years	1.18 (0.42)	3.26*	1.42	7.46	0.70 (0.72)	2.01	0.49	8.31
11-15 years	1.14 (0.41)	3.13*	1.39	7.03	0.94 (0.66)	2.56	0.70	9.37
Income quartiles (Reference category: Fourth income quartile)								
First income quartile	1.55 (0.52)	4.70*	1.70	12.96	1.27 (0.61)	3.55*	1.07	11.75
Second income quartile	1.46 (0.52)	4.33*	1.54	12.14	0.51 (0.68)	1.66	0.44	6.31

	1 change				2 or more changes			
	B (S.E.)	Odds Ratio	95% C.I. for Odds Ratio		*B (S.E.)*	Odds Ratio	95% C.I. for Odds Ratio	
			Lower	Upper			Lower	Upper
Third income quartile	1.02 (0.54)	2.78	0.97	7.95	-0.74 (0.88)	0.48	0.08	2.70
Mental health conditions (Reference category: No)	0.69 (0.28)	1.99*	1.15	3.45	1.26 (0.47)	3.52*	1.41	8.81

Note. * $p < .05$ ** $p < .01$*** $p < .001$

Reference category: No accommodation changes.

Table IV-37

Summary of Multinomial Logistic Regression Predicting Number of Accommodation Changes from Time Since Diagnosis, Income Quartiles, and the Four Experiences of the Opportunity to Enjoy Adequate Housing (n = 835).

	1 change				2 or more changes			
	B (S.E.)	Odds Ratio	95% C.I. for Odds Ratio		*B (S.E.)*	Odds Ratio	95% C.I. for Odds Ratio	
			Lower	Upper			Lower	Upper
Time since diagnosis (Reference category: 16 and over)								
0-5 years	1.13 (0.42)	3.10*	1.37	7.01	2.02 (0.66)	7.50*	2.04	27.57
6-10 years	1.12 (0.43)	3.07*	1.32	7.10	0.55 (0.78)	1.73	0.38	7.91
11-15 years	1.14 (0.42)	3.13*	1.38	7.11	1.19 (0.72)	3.29	0.80	13.44
Income quartiles (Reference category: Fourth income quartile)								
First income quartile	1.46 (0.52)	4.30*	1.55	11.94	0.36 (0.68)	1.44	0.38	5.47

	1 change				2 or more changes			
	B (S.E.)	Odds Ratio	95% C.I. for Odds Ratio		*B (S.E.)*	Odds Ratio	95% C.I. for Odds Ratio	
			Lower	Upper			Lower	Upper
Second income quartile	1.50 (0.52)	4.50*	1.61	12.59	-0.06 (0.73)	0.94	0.22	3.97
Third income quartile	0.97 (0.54)	2.64	0.92	7.63	-1.79 (0.98)	0.17	0.02	1.15
Typology of opportunities (Reference category: High capability)								
Availability disadvantage	0.67 (0.36)	1.95	0.96	3.96	2.06 (0.60)	7.86**	2.44	25.26
Achievability disadvantage	1.66 (0.50)	5.26**	1.99	13.94	2.85 (0.80)	17.24***	3.61	82.27
Low capability	1.72 (0.53)	5.56**	1.96	15.79	4.46 (0.67)	86.41***	23.02	324.33

Note. * $p < .05$ ** $p < .01$*** $p < .001$

Reference category: No accommodation changes.

Predictors of objective housing stability

Following the same procedure as in the previous sections, relevant demographic, socioeconomic, and health status variables were entered step by step in a multinomial logistic model to predict objective housing stability. The model became overloaded with predictors, which were also characterized by many interactions. Consequently, a reduced model was created by entering first the predictors that showed a higher chi-square and then adding other predictors to check whether they significantly added to the final model. Five predictors were entered first: weekly income after tax, age groups, marital status, place of residence, and injecting illegal drugs (see Table IV-38). In order to address the question of the empty cells connected to the continuous variable weekly income after tax, this was transformed into income quartiles, a categorical variable. This variable showed to have a higher explanatory power in relation to objective housing stability compared to its continuous alternative (its Nagelkerke R squared was 0.242 vs. 0.225 of the continuous variable). The final reduced model included only four variables, income quartiles, age groups, marital status, and place of residence. Entering the variable injecting illegal drugs increased the number of empty cells from 37.1% to 56.9%, whilst it only gave a minimal contribution to the predictive power of the model, particularly in comparison to the previous predictors (see its Nagelkerke R squared value in Table IV-39). Consequently it was excluded from the model and no further predictors were added. A summary of the final model can be found in Table IV-40. This was highly significant, $\chi^2(36) = 440.90$, $p < .001$, Nagelkerke R squared = 0.430; its goodness-of-fit statistics were small (Pearson chi-square 199.11 and Deviance chi-square 181.68) and had large p values (Pearson $p = .728$ and Deviance $p = .935$). This model had 37.1% of empty cells, however an inspection of its Pearson residuals showed that both the number of residuals greater than ± 1.96 standard deviations (6 in total) and

the number of the residuals greater than ± 2.58 standard deviations (6 in total) were within the acceptable bounds mentioned in the Method section.

Results to highlight here are that, after adjusting for the other variables, PLWHA in the first income quartile were 37 times more likely to be unstably housed in private rental than stably housed compared to PLWHA in the fourth quartile. Young PLWHA were respectively 8.3 times more likely to be in public rent than stably housed and 7 times more likely to buy their property than stably housed compared to older PLWHA for those with partners[1]. PLWHA in rural areas were less likely to be renting in public or private housing than PLWHA living capital city/inner suburban. With regard to the interaction term, the odds ratio for being unstably housed in other types of accommodation (free rent, community, and coop) for single participants aged 19-50 was 8.3 times larger than for participants aged 51-78 in a stable relationship.

Table IV-38

Likelihood Ratio Tests

	χ^2	df	Sig.
Marital status	14.426	4	.006
Age	48.150	4	.000
Place of residence	.000	0	.
Time since diagnosis	.000	0	.
Interaction between marital status and time since diagnosis	11.220	4	.024

[1] The moderator approach suggested by Jaccard (2001) was used to interpret the effect of the interaction term in the logistic regression equation. This implies defining a 'focal' independent variable, which in this work is age, and a moderator variable, which here is marital status. So, in interpreting the interaction term the aim is to understand how age differences in the odds of PLWHA experiences of house stability differ as a function of marital status. In particular, the effect of each variable that is part of the interaction term is conditioned on the moderator variable being 0, in other words on the moderator variable's reference category (Jaccard, 2001).

	χ^2	df	Sig.
Weekly income after tax	57.934	4	.000
Employment status	.000	0	.
Interaction between employment status and place of residence	69.152	48	.024
Injecting illegal drugs	39.271	8	.000

Table IV-39

Likelihood Ratio Tests of Reduced Model

	χ^2	df
Step 1		
Income quartiles	221.28*** (.242)	12
Step 2		
Age groups	113.29*** (.345)	4
Step 3		
Marital status (Living with partner/spouse)	45.45*** (.382)	4
Interaction between marital status and age groups	12.60* (.392)	4
Step 4		
Place of residence	39.31*** (.430)	12
Step 6		
Injecting illegal drugs[a]	36.39*** (.443)	8

Note. * $p < .05$ ** $p < .01$*** $p < .001$

Nagelkerke R squared in parenthesis below chi-square.

See Appendix 6 for a full list of the interactions tested.

[a] Entering injecting illegal drugs increased the number of empty cells from 37.1% to 56.9%.

Table IV-40

Summary of Multinomial Logistic Regression Predicting Objective Housing Stability from Income Quartiles, Age groups (19-50 and 51-79), Marital Status, Place of Residence (n = 840).

	Unstably housed_Buying				Unstably housed_Public rent				Unstably housed_Private rent				Unstably housed_Other accommodation			
	B (S.E.)	Odds Ratio	95% C.I. for Odds Ratio		*B (S.E.)*	Odds Ratio	95% C.I. for Odds Ratio		*B (S.E.)*	Odds Ratio	95% C.I. for Odds Ratio		*B (S.E.)*	Odds Ratio	95% C.I. for Odds Ratio	
			Lower	Upper			Lower	Upper			Lower	Upper			Lower	Upper
Income quartiles (Reference category: Fourth income quartile)																
First quartile	-1.29 (0.40)	0.28**	0.13	.60	-0.10 (0.33)	0.91	0.48	1.72	3.61 (0.59)	37.02***	11.68	117.36	1.63 (0.46)	5.10***	2.08	12.52
Second quartile	-1.41 (0.41)	0.24**	0.11	0.54	0.38 (0.31)	1.47	0.79	2.71	2.10 (0.61)	8.17**	2.49	26.89	0.98 (0.47)	2.65*	1.06	6.66
Third quartile	-0.44 (0.32)	0.64	0.34	1.21	0.18 (0.30)	1.20	0.67	2.15	0.65 (0.68)	1.92	0.51	7.25	0.65 (0.47)	1.91	0.77	4.77
Age (Reference category: 50-78)	1.97 (0.43)	7.18***	3.09	16.67	2.12 (0.41)	8.36***	3.77	18.50	0.15 (0.61)	1.16	0.35	3.86	0.29 (0.53)	1.34	0.48	3.75
Marital status (Reference category: Stable relationship)	-0.17	0.84	0.32	2.20	0.74	2.10	0.95	4.64	0.36	1.43	0.49	4.19	-0.39	0.68	0.25	1.85

	Unstably housed_Buying				Unstably housed_Public rent				Unstably housed_Private rent				Unstably housed_Other accommodation			
	B (S.E.)	Odds Ratio	95% C.I. for Odds Ratio		*B (S.E.)*	Odds Ratio	95% C.I. for Odds Ratio		*B (S.E.)*	Odds Ratio	95% C.I. for Odds Ratio		*B (S.E.)*	Odds Ratio	95% C.I. for Odds Ratio	
			Lower	Upper			Lower	Upper			Lower	Upper			Lower	Upper
	(0.49)				(0.41)				(0.55)				(0.51)			
Interaction between living with partner and age																
Age 19-50 * No partner	0.12	1.13	0.36	3.57	0.10	1.11	0.42	2.94	1.79	5.99*	1.51	23.86	2.13	8.38***	2.30	30.46
	(0.59)				(0.50)				(0.70)				(0.66)			
Place of residence (Reference category: Capital city/Inner suburban)																
Outer suburban	0.44	1.56	0.67	3.64	-0.47	0.63	0.28	1.39	-0.25	0.78	0.30	2.00	0.80	2.22	0.93	5.28
	(0.43)				(0.41)				(0.48)				(0.44)			
Regional centre	0.07	1.08	0.56	2.07	-0.53	0.59	0.34	1.02	-1.06	0.35*	0.17	0.71	-0.38	0.68	0.32	1.44
	(0.33)				(0.28)				(0.37)				(0.38)			
Rural	-0.69	0.50	0.20	1.26	-0.82	0.44*	0.23	0.85	-2.81	0.06***	0.02	0.22	-0.55	0.58	0.25	1.36
	(0.47)				(0.34)				(0.66)				(0.44)			

Note. * $p < .05$ ** $p < .01$*** $p < .001$

Reference category: Stably housed.

Predictors of crowding conditions

The variable crowding conditions did not show a normal distribution (see Appendix 8), so the distribution was divided into three categories – low crowding (scores = 0.1 to 0.50), medium-high crowding (scores = 0.51 to 1.00), and overcrowding (scores > 1) – and multinomial logistic regression modelling was used to identify the relative impact of the relevant demographic, socioeconomic, behavioural, and health status variables (see Table IV-41 for the step by step procedure). The final model was highly significant, $\chi^2(18) = 226.94$, $p < .001$, Nagelkerke R squared = 0.267, its goodness-of-fit statistics were high (Pearson chi-square = 819.88 and Deviance chi-square = 669.71) although they had large *p* value (Pearson $p = .514$ and Deviance $p = 1.000$). This model had 57.6% of empty cells; an inspection of its Pearson residuals showed that the number of residuals greater than ± 1.96 and ± 2.58 standard deviations was above the acceptable limits mentioned in the Method section. In order to reduce the number of empty cells, the continuous variable time since diagnosis was transformed into a categorical variable with four categories: 0 to 5 years, 6 to 10 years, 11 to 15 years, and 16 years and over. This generated a model in which the Pearson goodness-of-fit statistics had a *p* value smaller than 0.05 ($p < 0.001$). Consequently, the variable was dichotomised in PLWHA who were diagnosed less than 10 years ago and PLWHA who were diagnosed more than 10 years ago and the model run again. This latter model was highly significant, $\chi^2(18) = 223.49$, $p < .001$, Nagelkerke R squared = 0.263, had less empty cells (40.8%), smaller goodness-of-fit measures (Pearson chi-square = 168.50 vs. = 819.88 and Deviance chi-square = 214.23 vs. 669.71) and both *p* values were large (Pearson $p = .475$ and Deviance $p = .382$); an inspection of the standardised residuals showed that the number of cells above ± 1.96 and ± 2.58 standard deviations

(respectively 4 and 3) was within the acceptable bounds stated in the Introduction section of this chapter. A summary of the final model can be found in Table IV-42.

Results to highlight here are that those who lived with dependent children were more than 72 times more likely to live in overcrowded conditions than low crowding conditions compared to those who did not live with dependent children. However, the wide confidence interval suggests that this result may be affected by the small frequencies that characterize the relevant cells and, therefore, by sampling errors. Higher odds ratios to live in overcrowding conditions than in low crowding conditions were also associated with living with HIV/AIDS for longer than 10 years compared to less than 10 years and renting, living in a private rental accommodation compared to owning or buying one's property, or living in other types of accommodation compared to owning or buying one's property.

Table IV-41

Likelihood Ratio Tests

		χ^2	df
Step 1			
	Age (19-49 and 50-72)	6.68*	2
Step 2			
	Time since diagnosis[a]	23.58***	2
Step 3			
	Marital status	35.20***	2
Step 4			
	Live with dependent children	64.59***	2
Step 5			
	Place of residence	26.05***	6
Step 6			
	Weekly income after tax	8.44*	2
Step 7			
	Accommodation types	59.60[b]***	6
Step 8			
	Injecting illegal drugs Self-reported health	3.15	4
Step 9			

	χ^2	df
Self-reported health	9.35	6
Step 10		
Mental health conditions	2.93	2

Note. * $p < .05$ ** $p < .01$*** $p < .001$

See Appendix 6 for a full list of the interactions tested.

[a] The variable time since diagnosis made the variable age become not significant ($p = .339$), so age was removed from the model.

[b] The variable accommodation types made the variable weekly income after tax become not significant ($p = .210$), so income was removed from the model.

[c] The variable accommodation types made the variable weekly income after tax become not significant, which was therefore removed from the model.

Table IV-42

Summary of Multinomial Logistic Regression Predicting Number of Accommodation Changes from Employment Status, Injective Illegal Drugs, and Fourfold Typology of Experiences of the Opportunity to Enjoy Adequate Housing (n = 922).

	Medium high crowding				Overcrowding			
	B (S.E.)	Odds Ratio	95% C.I. for Odds Ratio		*B (S.E.)*	Odds Ratio	95% C.I. for Odds Ratio	
			Lower	Upper			Lower	Upper
Marital status (Reference category: Single)	0.82	0.44***	0.32	0.60	-0.24	0.78	0.40	1.51
	(0.15)				(0.34)			
Live with dependent children (Reference category: No)	2.66	14.29***	5.52	37.01	4.29	72.86***	23.91	222.05
	(0.49)				(0.57)			
Time since diagnosis (Reference category: Longer than 10 years ago)	0.55	1.74***	1.28	2.36	1.09	2.96**	1.50	5.85
	(0.15)				(0.35)			
Place of residence (Reference category: Capital city/suburban areas)								
Outer suburban area	-0.93	0.39**	0.23	0.67	-0.32	0.72	0.28	1.88
	(0.27)				(0.49)			

	Medium high crowding				Overcrowding			
	B (S.E.)	Odds Ratio	95% C.I. for Odds Ratio		*B (S.E.)*	Odds Ratio	95% C.I. for Odds Ratio	
			Lower	Upper			Lower	Upper
Regional centre	-0.93	0.39***	0.26	0.61	-0.56	0.57	0.22	1.45
	(0.22)				(0.48)			
Rural area	-0.51	0.60	0.34	1.04	-0.18	0.84	0.25	2.77
	(0.28)				(0.61)			
Accommodation types (Reference category: Own or purchasing home)								
Private rental	1.08	2.95***	2.07	4.21	1.47	4.37**	1.88	10.18
	(0.18)				(0.43)			
Public rental	0.63	1.87**	1.17	2.99	0.74	2.09	0.66	6.59
	(0.24)				(0.59)			
Other	1.89	6.65***	3.93	11.26	2.04	7.70***	2.53	23.43
	(0.27)				(0.57)			

Note. * $p < .05$ ** $p < .01$*** $p < .001$. Reference category: Low overcrowding.

Discussion

This chapter set out to offer an empirical application of the two models suggested in Chapter III (the threefold model of opportunity perception and the fourfold typology of experiences of opportunities) by means of a secondary data analysis of the HIV Futures V Survey. The analysis aimed to answer four main research questions that intended to explore one material dimension of the quality of life of PLWHA, i.e. their experiences of housing. In this discussion section I will summarise the main findings of the analyses carried out in this chapter, discuss them in the context of the wider relevant literature, and reflect on how the models suggested in this thesis compare with alternative measures of housing experiences.

Opportunities to enjoy adequate housing. The vast majority of the study participants (83.7%) experienced high availability and high achievability (93%) with regard to the opportunity to enjoy adequate housing. These findings were higher than those reported in a study on data from the Australian Bureau of Statistics 1994 Housing Survey, which indicated that around 28% of Australian households had some financial or non-financial problems with their housing (Australian Institute of Health and Welfare, 1997). The high frequencies of opportunity achievability and opportunity availability reflected in a very high percentage of participants experiencing high capability (80.3%) and in small percentages experiencing forms of disadvantage, of which low capability represents an extreme form: 12.7% experienced availability disadvantage, 3.5% experienced achievability disadvantage, and 3.5% experienced low capability.

The bivariate analyses carried out in this chapter showed that the categories of the proposed fourfold model significantly discriminated among the study participants. In particular, among the demographic characteristics, only age, marital status and sexual

identity were related to opportunity availability and opportunity achievability. However, only age was then significantly associated with the four experiences of the opportunity to enjoy adequate housing. Consequently, the findings of the bivariate analyses supported only one of the three hypotheses originally formulated on the relationship between demographic characteristics and experiences of opportunities. In particular, PLWHA aged 51 and over were more likely to experience high opportunity availability and high capability than PLWHA aged under 50. However, the variable age did not reach statistical significance in the binary logistic model. No evidence was found to support the two other hypotheses on the negative impact that living in remote geographical areas and having a minority ethnic background could have on housing opportunities.

With regard to socioeconomic factors, the bivariate analyses confirmed this study's hypothesis that socioeconomic background, particularly the respondents' occupation status, their income and their standard of living, had a significant impact on their opportunities to enjoy adequate housing. However, only weekly income after tax and the indicator of living standard 'type of accommodation' significantly contributed in the binary logistic model. With regard to this, private renting and other types of accommodation (community housing / co-op, or other types of accommodation) were associated with lower chances to experience high capability. Public renting was also associated with lower chances to experience low capability; however, this result did not reach statistical significance, so it cannot be excluded that it was due to chance. Other studies have shown that renting is associated with worse self-reported physical health, but have left open the question regarding the direction of the causal relationship between renting, private and public, and health status (Australian Housing and Urban Research Institute, 2002). Some explain this association through the health selection hypothesis, which implies that people who are already sick or prone to become sick tend

to rent more than buying their properties; others suggest that renting can make people sick through both material and psychological mechanisms (Australian Housing and Urban Research Institute, 2002). The findings of this study contribute to this discussion by showing that private rental predicts lower chances of experiencing high capability, and higher chances to experience one form of disadvantage, including an extreme one, i.e. low capability. This would suggest that, even taking into consideration the effects of the health selection hypothesis, at least a fraction of the relationship between renting and health outcomes is causally determined by higher exposure to various forms of disadvantage.

The behavioural variable injecting illegal drugs was significantly associated with the opportunities to enjoy adequate housing of PLWHA only at the bivariate level of analysis. However, health status variables were associated with the opportunities to enjoy adequate housing both at the bivariate and at the multivariate level of analysis. In particular, having mental health conditions in addition to HIV/AIDS and reporting poor health predicted lower chances to experience high capability. Overall, these finding suggest that the main differences in the experiences of opportunities of PLWHA were not related to their ascribed status, but rather to a combination of their lifestyle and the health consequences of living with HIV/AIDS. This finding is particularly important within a capability framework, because it indicates that health characteristics generate inequalities among PLWHA that go over and beyond their socioeconomic conditions. It suggests the necessity to investigate the impact that the health needs of PLWHA have on their capacity to exercise fundamental individual, social and economic rights and their agency as social actors.

The analysis of the opportunity to enjoy adequate housing was complemented with the investigation of the availability of opportunities for future accommodation among those who experienced availability disadvantage. These analyses confirmed only

the hypothesis on the relationship between socioeconomic background and availability of future accommodation, although limitedly to weekly income after tax. No evidence was found to support the other study hypotheses. In particular, these analyses showed that PLWHA with other major health conditions were more likely to report that they had future accommodation options. This finding can be explained by the fact that PLWHA with other major health conditions were more likely to live in public rental properties, which clearly represented an element of advantage from this point of view.

Number of accommodation changes. The vast majority of the study participants did not move home in the last 2 years (89.7%). Of those who moved, only about 3% (n = 31) moved more than 2 times. At the bivariate level, number of accommodation changes was related to age, with younger participants more likely to move 2 or more times compared to older participants. However, age could not be entered in the multinomial logistic regression model just because of the small frequencies that characterised the older age group of participants. Income quartiles, time since diagnosis, and mental health conditions were all independent predictors of number of moves, with PLWHA who were diagnosed five or less years ago, who were the first income quartile, and who had mental health conditions more likely to move 2 or more times.

The fourfold typology of opportunities to enjoy adequate housing significantly predicted number of moves after controlling for those other confounding factors, mediating the relationship between mental health conditions and, partially, also poverty with number of accommodation changes.

Objective housing stability. The majority of participants in the HIV Futures V Survey were renters (53.5%), a percentage far higher than that found in the general Australian population (27%, see ABS, 2000). However, the proportion of PLWHA in private rental (73%) compared to the proportion found in the general population (see the

analysis in the section Descriptive statistics). The higher proportion of PLWHA renting can be partly explained by the fact that the vast majority of the HIV Futures V Survey (about 71%) consisted of younger people (aged 19-50). As mentioned, in the general population household tenure tends to follow life-cycle stages that see renting in early adulthood, moving to home purchase and mortgages when people form relationships and raise a family, and owning the home without any mortgage in older age (Australian Bureau of Statistics, 2000). However, Table IV-2 showed that a far higher percentage of PLWHA tend to rent in the age groups 35-44 and 45-54 compared to the general population. Although this study confirmed the hypothesis that older PLWHA (aged 51 and over) were more likely to own their home and be stably housed than younger PLWHA, it also showed that the percentage of older PLWHA (55 and over) owing or buying their property was far lower than that found in the general population. Even among PLWHA in a stable relationship, who were more likely to own or buy their house (see Table IV-13), there were less owner and home buyer (49.4%) compared to the general population (80%, see the section Descriptive statistics). It would be important to understand whether this phenomenon can be explained in terms of lifestyle reasons, therefore as a matter of free agency and choice (80% of the HIV Futures V Survey sample consisted of participants who identified themselves as gay/lesbians), or rather as a consequence of the impact that living with HIV/AIDS has on people's capacity to move from renting to buying and owning a property. With regard to this, this study has shown that unemployed PLWHA and a part of those working/retired were more likely to be in private rental then expected (see Table IV-19). This finding needs attention, especially in relation to the question of the 'volatility' of rental tenures. Private rental features as third last in the seven-dimension tenure security model of the New Zealand Office of Statistics (2004). In that model of tenure security, rental from private landlords is positioned between the state of 'transitionally and episodically

homeless' and public rental properties[1]. Although the level of security of each of the seven tenure levels is debatable, the analyses carried out in this chapter have shown that PLWHA with lower socioeconomic background were more likely to be in private rental tenures. This suggests that, at least for this population, there is a double risk, on the one hand the higher risk of experiencing some form of disadvantage, as seen in the section on the fourfold typology of opportunities, on the other hand, the risk of losing one's accommodation due to financial difficulties.

This study has also shown that those who lived in rural and regional areas were more likely to own their house compared to those living in Capital cities and suburban areas. As mentioned, PLWHA who were retired or not working and who were student or on home duties were more likely to live in rural and regional areas. These findings call for further investigations to understand whether PLWHA who lived in regional or rural areas, particularly those retired/not working, moved in those areas in order to buy affordable properties or whether they were already living there and owned their properties before becoming HIV positive. Internal migration processes would imply important questions in relation to service provision for older PLWHA in regional and rural areas.

The variable objective housing stability did not predict the four experiences of the opportunity to enjoy adequate housing. This suggests that these two measures address complimentary aspects of the housing experiences of PLWHA.

Predictors of crowding conditions. The equivalised crowding index that was constructed for this study showed that 5.1% of the HIV Futures V Sample was living in

[1] In the New Zealand Office of Statistic's (2004) seven-dimension model of tenure security, owning a home without a mortgage is considered the pinnacle of the hierarchy, while chronic homelessness is considered the least desirable tenure situation. The seven stages of tenure security in hierarchical order are: 1) Dwelling owned without a mortgage, 2) Dwelling owned with mortgage, 3) Dwelling provided rent free, 4) Dwelling rented (State), 5) Dwelling rented (Private), 6) Transitionally and episodically homeless, 7) Chronically homeless.

overcrowding conditions, a result that compared with the finding that 5% of the Australian households needed one or more bedrooms (ABS, 2000). Several factors predicted overcrowding, in particular, living with dependent children considerably increased the odds of living in overcrowding conditions. In fact, the bivariate analyses showed that 28% of those living with dependent children experienced overcrowding, a percentage far higher than that of the rest of the sample. The multinomial logistic regression model showed that those living with dependent children were more than 72 times more likely to experience overcrowding than a low-crowding condition compared to those who did not live with dependent children. PLWHA who lived in a private rental accommodation were 4.3 times more likely to experience overcrowding than a low-crowding condition compared to those who owned or were buying their home. Considering that, as discussed in the section Descriptive statistics, both lone parents and couples with children were more likely to be in private rental than owning their home, these subpopulations are potentially at risk of three main health threats: higher chances to experience a form of disadvantage, particularly low capability, high 'volatility' of their accommodation, and overcrowding conditions. In particular, living in overcrowded conditions has been consistently associated with higher risk of both mental and physical health problems (Australian Housing and Urban Research Institute, 2002) and requires attention from the policy and service provision sectors.

The index of overcrowding did not predict the four experiences of the opportunity to enjoy adequate housing. This indicates that these two constructs addressed complimentary dimensions of the housing experiences of PLWHA.

Concluding remarks. This chapter has offered an operationalisation of the threefold model of opportunity perception and of the fourfold typology of experiences of opportunity suggested in the third Chapter through a secondary data analysis of the HIV Futures V Survey. The analyses have addressed and answered four main research

questions; the first three research questions explored what are the patterns of housing experience among PLWHA in Australia, the fourth explored the relationship between the suggested measures of housing opportunity and three alternative measures of housing experiences: number of accommodation changes, objective housing stability, and crowding conditions. The analyses found that health status is an independent predictor of housing experiences and opportunities. In particular, after controlling for demographic and socioeconomic variables, those with other physical and mental health conditions tended to have worse housing opportunities/experiences. Finally, the analyses showed that the suggested fourfold opportunity model contribute original and valuable information regarding the housing experiences of PLWHA. It was an independent predictor of number of accommodation changes, but it was not predicted by the indexes of crowding conditions and objective housing stability, indicating that these measures investigated complimentary aspects of the housing experiences of PLWHA.

Limitations of the study.The HIV Futures V survey was undertaken using a self-selection sampling method, which entails that there sample is prone to a self-selection bias, that is to the risk that the sample is not representative of the population being studied, or exaggerates some particular finding from the study. Differences may exist between those who volunteered and those who refused participation in the survey which are difficult to predict and quantify. Therefore, it is important to stress that this study's findings may not be generalisable to the wider population of PLWHA in Australia.

CHAPTER V

WELL-BEING, POVERTY AND EXPERIENCES OF OPPORTUNITIES

In this chapter, a second set of analyses will be offered as an example of how the fourfold typology of opportunities to enjoy adequate housing relate to other existing measures of the quality of life of PLWHA, particularly overall well-being and poverty lines.

Overall well-being is a measure of subjective well-being (see Chapter I on this concept). The literature reviewed in Chapter I explored whether demographic and socioeconomic characteristics, social factors (e.g. social support), behavioural factors (e.g. drug addiction), and health conditions were correlates and/or predictors of subjective measures of quality of life. The findings were not univocal with regard to the role of each of the mentioned factors. Only a few studies have investigated the relationship between housing conditions and subjective measures of quality of life. In a survey aimed at investigating people's capabilities in a sample of people from England, Scotland and Wales, Anand et al. (2009) found that the variable 'adequate shelter'[1] predicted subjective well-being[2] together with 16 other variables. The literature reviewed in the previous chapter suggested that housing conditions can be a significant determinant of health outcomes and access to services among homeless and unstably housed PLWHA. However, no studies investigated the relationship between housing conditions and subjective well-being (or other measures of quality of life) among the general population of PLWHA. This chapter explores whether the fourfold typology of opportunities to enjoy adequate housing constructed in Chapter IV predicts overall well-

[1] This was operationalised through the following question: 'Is your current accommodation adequate or inadequate for your current needs? More than adequate, Adequate, Inadequate, Very inadequate' (Anand, et al., 2009, p. 132)

[2] This was operationalised through the following question: 'How dissatisfied or satisfied are you with your life overall? 1= Not satisfied at all, 2 = Completely satisfied'(Anand, et al., 2009)

being controlling for demographic, socioeconomic, health status, behavioural, and social support variables.

Poverty lines set a threshold to measure material deprivation. In the main report on the HIV Futures V Survey, Grierson et al. (2006) showed that PLWHA below the poverty line were more likely to report that paying for rent, mortgage, and housing costs was either a little difficult (46.8% versus 38.6%) or very difficult (29.2% versus 18.0%). Nevertheless, no information was given on other relevant aspects of PLWHA housing experiences, for example the relationship between poverty and accommodation suitability. The literature review carried out in the previous Chapter showed that the vast majority of the literature on PLWHA housing conditions focused on housing instability and homelessness, which are two conditions directly related to poverty. However, only a few studies investigated the relationship between poverty and the housing experiences of non-homeless PLWHA. This chapter will also investigate the relationship between the four experiences of the opportunity to enjoy adequate housing and poverty conditions among PLWHA. The aim is to explore whether poverty measures account for low capability and other forms of disadvantage. From a capability perspective, poverty measures exclude important elements of non-material deprivation, for example people's dignity. Also they do not account for the fact that the same limited resources can be exploited differently by people in different situations and with different capacities. Using data from Peru and India, Laderchi, Saith, and Stewart (2003) found that nearly half the population identified as in poverty according to monetary poverty was not poor in terms of a measure of capability poverty. So, it is important to empirically test what the relationship is between the suggested fourfold typology of experiences of opportunity and monetary measures of poverty.

Method

For an explanation of the main objectives of the HIV Futures V Survey, the characteristics of its sample, and of its recruitment procedure, I refer to the sections Measures, Participants, and Recruitment of Chapter IV, in which these topics have already been reported.

Measures

Outline of variables. All the variables used in the analyses are outlined below. The corresponding questions asked in the HIV Futures V Survey can be found in (Appendix 4). Apart from the variables 'poverty lines' and 'fourfold typology of opportunities', all the others are relevant only for the analysis on the relationship between housing experiences and overall well-being.

Overall well-being. The variable 'overall well-being' consisted of an item that asked the respondents how they would describe their overall sense of well-being, whether poor, fair, good, or excellent.

Poverty lines. Poverty lines were constructed by referring to the December quarter 2005 (the period of completion of the HIV Futures V Survey) Henderson Poverty Lines (Melbourne Institute of Applied Economic and Social Research, 2005). These referred to a range of family sizes, e.g. single person, couple, and single person or couple with dependent children, and two main circumstances, whether the household head was or was not in the workforce. The income of the study participants was determined by summing all the relevant sources of income that they reported, including housing benefits. This was because this study used the poverty lines that included housing costs (Melbourne Institute of Applied Economic and Social Research, 2005). In other studies, such as the main report on the HIV Future V Survey (Grierson, et al., 2006), although the same poverty lines were used, housing benefits were not included in

the count and so a higher proportion of participants resulted below the poverty line. The author of this work believes that it is important to include all relevant sources of income, including small amounts of money that cause some individuals to be above the poverty line of only a few tenths of dollars. This latter phenomenon, in fact, highlights the controversial nature of dichotomous measures of poverty, which inevitably tend to exclude from their count all individuals above the set threshold, no matter how little they are above it. In order to highlight the potential controversial implications of this characteristic of poverty lines, their relationships with the four experiences of opportunity to enjoy adequate housing were analysed using both poverty lines that include rental subsidies and the poverty lines that did not.

Poverty in relationship to housing was also measured through a self-reported indicator of financial hardship that asked the study participants how difficult it was in the past six months to meet the costs of rent, mortgage, and housing: not at all difficult, a little difficult, very difficult, does not apply. This latter measure was included because it allowed the researcher to distinguish between an objective measure of material deprivation and people's perception of material hardship. The different pressures and priorities that characterize people's financial situation can imply that the same amount of income, regardless of whether it is above or below the poverty line, can generate different outcomes. Therefore, this latter indicator can also contribute to the analysis of the relationship between the four experiences of the opportunities to enjoy adequate housing and poverty.

Independent variables. Six groups of independent variables plus the housing conditions variables were used as predictors for based on the literature reviewed in Chapter I and Chapter IV: demographic variables, socioeconomic variables, behavioural variables, social support variables, health status variables.

Demographic variables. Based on the literature reviewed in Chapter I, four demographic variables were used as predictors of overall well-being: gender, age, time since diagnosis, and place of residence. These were operationalised through the same questions used in Chapter IV.

Socioeconomic variables Considering the examples seen in the literature reviewed in Chapter I, three socioeconomic variables were investigated: educational attainment, employment status, and weekly income after tax. The variable accommodation type was also included as a measure of living standard. These were operationalised through the same questions used in Chapter IV.

Social support. Social support was operationalised through four questions: support received from one's partner/spouse, support received from close friends, support received from parents, and support received from family (see Appendix 4 for the actual questions). A summary variable was also constructed through a ratio of the number of no support answers to the four indicators. The advantage of this indicator was that it was a continuous variable, however it did not take into consideration the variations between the other possible answers, i.e. a little, some, and a lot of support.

Behavioural variables. One behavioural factor was used and it was operationalised through the same question on use of hard drugs that was used in Chapter IV.

Belief factors. Beliefs factors were operationalised through two questions: uncertainty regarding disease progression and uncertainty about the future. Uncertainty regarding disease progression consisted of a question that asked the study participants whether they feared that their medication would stop working in the future. Uncertainty about the future consisted of a question that asked the study participants how far ahead in time they planned in making important decisions about their lives, whether days, months, or years.

Health variables. Nine health variables were taken into consideration in the analyses: perceived health status, other major health conditions, mental health conditions, AIDS-defining illness, HIV-related illness, CD4 count, viral load – which were all operationalised through the same questions already used in Chapter IV – and physical health functionings and cognitive functionings. Physical health functionings and cognitive functionings were operationalised through two questions that asked the study participants to indicate whether, among other symptoms, they experienced respectively low energy/fatigue and confusion/memory loss in the last 12 months.

Housing conditions variables. Housing conditions variables consisted of the four variables on the experiences of housing used in Chapter IV: the fourfold typology of opportunities, objective housing stability, number of accommodation changes, and overcrowding conditions.

Procedure

Analytical strategy. First, chi-square tests of independence, for categorical variables, and *t*-tests or one-way analysis of variance (ANOVA), for continuous variables, were computed to check the relationships between the demographic, socio economic, social support, behavioural and health variables and both well-being and poverty measures. For well-being, significant associations were then further tested using ordinal logistic regression, which was chosen given the ordinal nature of the overall well-being variable. Ordinal logistic regression compares the odds of being in one category with being in others while taking the order of the categories into account. A Logit Link function was chosen because the categories of the dependent variable were evenly distributed (see Table V-5). Predictors were entered one by one in the model following a logical order: demographic variables were entered first, followed by socio economic variables, health variables, behavioural variables, social support, and beliefs

variables. Interaction effects were checked at each step. This was achieved by running models in which interaction terms between two relevant predictors were added. The statistical significance of the interaction effects was determined following a "hierarchical test procedure" (Jaccard, 2001), which consisted of two steps: first, subtracting the χ^2 of the model with the interaction term from the χ^2 of the model without it, and, second, checking on a table of critical χ^2 values whether the difference was statistically significant at the .05 level. The degrees of freedom were given by the difference in the degrees of freedom of the two models. The "hierarchical test procedure" method was preferred to an examination of the significance test of the logistic coefficient associated with the single product term because the predictor variables had more than two levels (Jaccard, 2001). Interaction terms were kept in the model if the difference between chi-squares was significant.

A complete model including all the relevant predictors was first created and its good fitting was evaluated checking that:

1. the value of both statistics in the Goodness-of-fit table of the PASW 18 output (i.e. Pearson and Deviance) was small and their observed significance levels were large (Norusis, 2008);
2. the observed and expected cell counts were similar (Norusis, 2008); the Pearson residuals were examined and it was assumed that 95% of the sample should have values that lie within ±1.96 standard deviations, and 99% of cases should have values that lie within ± 2.58 standard deviations (A. Field, 2005);
3. the null hypothesis of the test of parallel lines was not rejected (Tarling, 2009); and

4. that the number of empty cells was not excessive; a high number of empty cells reduces the reliability of the model-fitting statistics and so it needs attention.

Reduced models were then created excluding predictors whose Wald statistics were not significant at the .05 level and checking how any changes affected the model fitting statistics, the test of parallel line, the pseudo r-square statistics, and the number of empty cells.

After a final model predicting overall well-being was constructed, objective housing stability, number of accommodation changes, overcrowding conditions, and last, the four experiences of the opportunity to enjoy adequate housing were also entered. In this way it was possible to ascertain the relationship between well-being and the four experiences of opportunity independent of other relevant predictors.

As mentioned in Chapter IV, the HIV Futures V survey was done using a self-selection sampling method. The potential biases induced by self-selection sampling on the study findings are acknowledged and discussed in the paragraph titled 'Study limitations' at the end of the chapter.

Results

Descriptive data

One fifth of the study participants resulted to be below the poverty line when taking into consideration the additional income that they received through housing benefits. When housing benefits were not included in the calculations, 27.7% of the study participants resulted to be below the poverty line (see Table V-1).

Table V-1

Frequency and percentage of participants below the poverty line

	Below the poverty line	Above the poverty line
Rental subsidies included (n = 858)	20 (172)	80 (686)
Rental subsidies excluded (n = 822)	27.7 (228)	72.3 (594)

Note. Row percentages. Frequencies appear in parenthesis below percentages.

The distribution of poverty was checked across some demographic, socioeconomic, and health variables. Poverty was not significantly associated with sex and living with dependent children. However, it was significantly related to age, place of residence, sexual identity, source of income, injecting illegal drugs, living with a partner, self-reported health, and mental health conditions. Older people, heterosexuals, those who lived in rural areas, those whose main sources of income were state benefits, those who injected illegal drugs in the last year, those who did not live with a partner or spouse, those with poor or fair health, and those with mental health conditions were more likely to experience poverty (see Table V-2). In particular, those aged 51 and over were 1.4 times more likely to be below the poverty line than those aged 19-50 (OR = 1.47; 95% CI [1.16, 1.86])[3], those with mental health conditions were 1.5 times more likely to be below the poverty line than those without a mental health condition (OR = 1.58; 95% CI [1.36, 1.84])[3], and those who did not live with a partner or spouse were 1.2 times more likely to be below the poverty line than those who did (OR = 1.28; 95% CI [1.17, 1.41])[3].

[3] The odds ratio when income did not include rental subsidies were for age 1.53; 95% CI [1.22, 1.92], for mental health 1.60; 95% CI [1.37, 1.86], for living with a partner or spouse 1.39; 95% CI [1.27, 1.52].

Table V-2

Cross tabulation of participants below the poverty line vs. participants above the poverty line and Sex, Age, Sexual Identity, Place of Residence, Income Sources, Use of Illegal Drugs, Living with Partner/Spouse, Living with Dependent children, and Mental Health Conditions.

	Below the poverty line			
	Income with rental subsidies	Income without rental subsidies	χ^2	Cramer's V
Sex			2.69[a] 1.29[b]	
Males[c]	19.2 (151)	27.2 (205)		
Females[c]	27.7 (12.9)	33.9 (21)		
Age groups			9.78[a]* 12.86[b]***	.107[a] .125[b]
19-50	17.2 (-3.1)	24 (-3.6)		
51-79	26.8 (3.1)	36.7 (3.6)		
Sexual identity			9.16 [a]* 8.12[b*]	.104[a] .100[b]
Gay bisexuals	18.3 (-3.0)	25.8 (-2.8)		
Heterosexuals	30.3 (2.7)	38.3 (2.4)		
Bisexuals / Others	27.1 (1.2)	36.4 (1.3)		
Place of residence			16.66[a]** 13.47[b]*	.140 .128
Capital city / inner suburban	16.4 (-3.4)	23.3 (-3.6)		
Outer suburban	20.2 (0.1)	32.9 (1.2)		
Regional centre	25 (1.7)	34 (1.9)		
Rural	34.2 (3.3)	38.7 (2.3)		

	Below the poverty line			
	Income with rental subsidies	Income without rental subsidies	χ^2	Cramer's V
Income source			176.34[a]***	.463
			284.21[b]***	.591
Salary	2.3 (-12.1)	3.4 (-14.9)		
Super/Annuity/ Savings	6.5 (-2.4)	6.7 (-3.3)		
Benefits / Pensions / Social security	40.3 (13.1)	57.2 (16.8)		
Partner /Family / Friends / Other	23.5 (0.4)	12.5 (-1.4)		
Injected illegal drugs			18.01[a]***	.164
			25.83[b]***	.202
Never	13.4 (-4.0)	18.8 (-5.0)		
In the last year	29.2 (3.4)	39.8 (3.8)		
Longer than 1 year ago	22.9 (1.6)	33.6 (2.4)		
Living with partner / spouse			19.49[a]***	.151
			39.30[b]***	.219
Yes	11.6 (-4.4)	14.3 (-6.3)		
No	24.4 (4.4)	34.9 (6.3)		
Living with dependent children			1.74[a]	
			2.34[b]	
Yes[c]	27.9 (12)	38.5 (15)		
No[c]	19.6 (160)	27.2 (213)		
Self-reported health			28.18[a]***	.151
			42.18[b]***	.227
Poor	40.5 (3.2)	54.3 (3.6)		
Fair	26.4 (2.9)	39.0 (4.4)		
Good	19.4 (-0.4)	24.6 (-1.7)		
Excellent		15.7		

	Below the poverty line			
	Income with rental subsidies	Income without rental subsidies	χ^2	Cramer's V
	10.2 (-4.0)	(-4.3)		
Mental health conditions			28.82[a]*** 33.22[b]***	. 184 .202
Yes	28.6 (5.4)	38.2 (5.8)		
No	13.7 (-5.4)	20.0 (-5.8)		

Note. * p < .05 ** p < .01*** p < .001

Row percentages. Frequency tables for each variable are reported in Appendix 5. Adjusted standardised residual frequencies appear in parentheses below observed percentages.

[a] Chi-square for poverty lines that included rental subsidies

b Chi-square for poverty lines that did not include rental subsidies

c Frequencies appear in parentheses below observed percentages

Poverty was significantly associated with objective housing stability and number of accommodation changes (see Table V-3). There were significantly more participants below the poverty line among those living in private rental and other types of accommodation as well as among those who changed accommodation 2 or more times. On the other hand, there were significantly less participants below the poverty line among those unstably housed buying and unstably housed in public rent and those who never moved. In order to test whether crowding conditions varied between those living below and above the poverty line, Mann-Whitney tests were conducted; the crowding index did not distribute normally in the two categories of the indicators of poverty. PLWHA below the poverty line (*Mdn* = 0.50) did not seem to differ in crowding conditions from PLWHA above the poverty line (*Mdn* = 0.50) when housing benefits were included in the calculation of the poverty lines, z = -.539, *p* = .590, *r* = -.02.

However, when housing benefits were excluded from the calculation of poverty lines,

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PLWHA below the poverty line (*Mdn* = 0.58) lived in crowding conditions that were significantly higher from those of PLWHA above the poverty line (*Mdn* = 0.50), *z* = 55548.50, *p* = .001, *r* = -.12.

Table V-3

Cross tabulation of participants below the poverty line vs. participants above the poverty line and Objective Housing Stability and Number of Accommodation Changes.

	Below the poverty line		Above the poverty line			
	With rental subsidies	Without rental subsidies	With rental subsidies	Without rental subsidies	χ^2	Cramer's V
Objective housing stability					139.51[a]*** 208.84[b]***	.406 .506
Stably housed	22.8 (1.0)	23.4 (-1.4)	77.2 (-1.0)	76.6 (1.4)		
Unstable housed_Buying	5.6 (-4.8)	6.3 (-6.3)	94.4 (4.8)	93.7 (6.3)		
Unstable housed_Public rent	9.7 (-6.0)	17.2 (-5.4)	90.3 (6.0)	82.8 (5.4)		
Unstable housed_Private rent	55.5 (10.4)	78.9 (13.1)	44.5 (-10.4)	21.1 (-13.1)		
Unstable housed_Other	29.0 (2.3)	41.8 (3.1)	71.0 (-2.3)	58.2 (-3.1)		
Number of accommodation changes					16.35[a]*** 39.47[b]***	.138 .219
None	18.5 (-3.3)	24.5 (-6.1)	81.5 (3.3)	75.5 (6.1)		
1	27 (1.4)	51.7 (4.3)	73 (-1.4)	48.3 (-4.3)		
2 or more	48.1 (3.7)	65.4 (4.4)	51.9 (-3.7)	34.6 (-4.4)		

Note. * p < .05 ** p < .01*** p < .001

Row percentages. Frequencies appear in parentheses below observed percentages.

When the two measures of poverty were cross tabulated with the subjective indicator of financial hardship, they gave similar results in relation to the category ‘not difficult’, but differed in the frequencies reported in the two other categories: little difficult and very difficult (see Table V-4).

Table V-4

Cross tabulation of participants below the poverty line vs. participants above the poverty line and Perceived Difficulty to Pay for Rent, Mortgage, and Housing Costs.

	Below the poverty line		Above the poverty line			
	Income with rental subsidies	Income without rental subsidies	Income with rental subsidies	Income without rental subsidies	χ^2	Cramer’s V
Difficulty in paying rent, mortgage, and housing costs					28.45[a]*** 50.24[b]***	.199 .269
Not difficult	25.2 (31)	23.4 (41)	47.6 (285)	51.1 (265)		
Little difficult	42.3 (1.1)	44.6 (78)	36.9 (221)	35.5 (184)		
Very difficult	32.5 (40)	32 (56)	15.5 (93)	13.5 (70)		

Note. * p < .05 ** p < .01*** p < .001

Row percentages. Frequencies appear in parentheses below observed percentages.

[a] Chi-square for poverty lines that included rental subsidies

[b] Chi-square for poverty lines that did not include rental subsidies

Table V-5 shows the distribution of the variable overall well-being. Those with poor well-being were more likely to be below the poverty line and those with excellent well-being were more likely to be above the poverty line. If rental subsidies were not taken into consideration in calculating poverty lines then PLWHA who reported fair well-being also resulted to be significantly more likely to be below the poverty line (see Table V-6).

Table V-5

Frequencies and percentages of overall well-being (n = 959)

	n	%
Poor	73	7.6
Fair	306	31.9
Good	388	40.5
Excellent	192	20

Table V-6

Cross Tabulation of participants living in poverty based on income that included rental subsidies vs. income that did not include rental subsidies and Overall Well-being

	Below the poverty line		Above the poverty line			
	With rental subsidies	Without rental subsidies	With rental subsidies	Without rental subsidies	χ^2	Cramer's V
Overall well-being					22.51[a]***	.163
					33.74[b]***	.204
Poor	38.3 (23)	51.7 (31)	61.7 (37)	48.3 (29)		
Fair	23 (62)	32.8 (85)	77 (208)	67.2 (174)		
Good	18.7 (64)	24.5 (80)	81.3 (278)	75.5 (246)		
Excellent	11.4 (20)	16.1 (27)	88.6 (155)	83.9 (141)		

Note. * p < .05 ** p < .01*** p < .001.

Row percentages. Frequencies appear in parentheses below observed percentages.

[a] Chi-square for poverty lines that included rental subsidies

[b] Chi-square for poverty lines that did not include rental subsidies

Correlates of overall well-being

Overall well-being was not significantly associated with the four demographic variables; the chi-squares between well-being and sex, $\chi^2(3, N = 951) = 0.31$, $p = .959$,

age groups (19-50 and 51-79), $\chi^2(3, N = 951) = 10.60$, $p = .304$, and geographical location, $\chi^2(3, N = 951) = 0.24$, $p = .970$ were all found to be statistically not significant. The ANOVA test between time since diagnosis and well-being was also not significant, $F(3, 946) = 1.62$, $p = .182$. However, well-being was significantly associated with all of the four socioeconomic variables (see Table V-7 and the Kruskal-Wallis test for income below), with three of the four social support variables (see Table V-8) – the only exception being support from partner or spouse – with use of illegal drugs (see Table V-9), with future planning time frame and future uncertainty (see Table V-9), and with seven of the nine health status variables, the exceptions being AIDS-defining illness (see Table V-10) and viral load, $F(3, 864) = 0.50$, $p = .679$.

An ANOVA test was run to check the relationship between weekly income after tax and well-being. The assumption of homogeneity of variance was violated, therefore the Brown-Forsythe *F*-ratio is reported; the relationship was significant and the effect size was large, $F(3, 503.62) = 26.67$, $p < .001$, $\omega = 0.28$. A Games-Howell post-hoc test was chosen to evaluate difference in the averages of weekly income after tax because the null hypothesis of homogeneity of variance was rejected. This test showed that PLWHA who reported poor well-being had a weekly income after tax that was significantly lower than those with fair, good, and excellent well-being. The mean incomes (with standard deviation between parentheses) were respectively 306.07 (199.43) for those who reported poor well-being, 456.98 (319.35) for those who reported fair well-being, 565.34 (376.85) for those who reported good well-being, and 716.41 (517.59) for those who reported excellent well-being. The ANOVA test with the constructed support variable was $F(3,859) = 7.31$, $p < .001$; the average support of those who reported poor well-being was significantly lower than the average support of those who reported good, and excellent well-being. The mean incomes and standard deviation were respectively 0.84 (0.24) for those who reported poor well-being, 0.90 (0.18) for

those who reported fair well-being, 0.93 (0.16) for those who reported good well-being, and 0.95 (0.12) for those who reported excellent well-being.

An ANOVA test was run to investigate the relationship between well-being and CD4 cells count. The assumption of homogeneity of variance was violated, therefore the Brown-Forsythe *F*-ratio is reported; the relationship was significant and the effect size was large, $F(3, 263.83) = 6.97$, $p < .001$, $\omega = 0.16$. A Games-Howell post-hoc test was chosen to evaluate difference in the averages of weekly income after tax because the null hypothesis of homogeneity of variance was rejected. This test showed that the average CD4 cell count of those who reported poor well-being was significantly lower than the average support of those who reported good and excellent well-being. The average CD4 cell count of those who reported fair well-being was significantly lower only of those who reported excellent well-being. The mean CD4 cells count and standard deviation were respectively 410.72 (32.41) for those who reported poor well-being, 485.54 (16.48) for those who reported fair well-being, 527.78 (15.93) for those who reported good well-being, and 689.63 (69.23) for those who reported excellent well-being.

Table V-7

Cross tabulation of Overall Well-being with Occupation Status, Educational Attainment and Accommodation Type.

	Poor	Fair	Good	Excellent	χ^2	Cramer's V
Occupation status (n = 935)					77.47***	.166
Student / Home duties/ Other	4.9 (-1.0)	36.9 (1.2)	39.8 (-0.2)	18.4 (-0.5)		
Unemployed	17.6 (4.2)	41.2 (2.2)	28.4 (-2.6)	12.7 (-2.0)		
Not working/ Retired	13.3 (4.1)	36.5 (1.8)	35.7 (-1.8)	14.5 (-2.6)		

	Poor	Fair	Good	Excellent	χ^2	Cramer's V
Full-time work	2.5 (-4.1)	22.9 (-4.2)	47.3 (3.0)	27.3 (3.8)		
Part-time work	3.5 (-2.1)	32.9 (0.4)	42.4 (0.5)	21.2 (0.3)		
Educational attainment (n = 933)					34.84***	.112
Primary school / 3 years of high school / Year 10	10.6 (2.2)	38.8 (2.7)	34.4 (-2.2)	16.3 (-1.8)		
Year 12	10.9 (2.0)	32.7 (0.4)	40.6 (0.0)	15.8 (-1.7)		
TAFE/Trade	5.7 (-1.1)	31.3 (-0.1)	44.3 (1.4)	18.7 (-0.8)		
University degree	3.9 (-2.6)	25.1 (-2.8)	42.7 (0.8)	28.3 (3.9)		
Accommodation type (n = 954)					32.40***	.106
Own or purchasing home	3.6 (-3.4)	28.9 (-1.5)	44.9 (2.1)	22.6 (1.4)		
Private rental	8.5 (0.9)	29 (-1.6)	41.3 (0.5)	21.3 (0.7)		
Public rental	11.9 (2.1)	43.4 (3.1)	32.9 (-2.0)	11.9 (-2.7)		
Other	10.6 (1.3)	37.2 (1.2)	32.7 (-1.7)	19.5 (-0.2)		

Note. * p < .05 ** p < .01*** p < . 001

Row percentages. Frequency tables for each variable are reported in Appendix 5. Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Table V-8

Cross tabulation of Overall Well-being with Support from Close Friends, Support from Parents, and Support from Family.

	Poor	Fair	Good	Excellent	χ^2	Cramer's V
Support from close friends (n = 863)					74.05***	.169

	Poor	Fair	Good	Excellent	χ^2	Cramer's V
A lot	4.2 (-2.9)	22.5 (-5.2)	47.4 (3.2)	25.9 (3.9)		
Some	5.3 (-1.2)	35 (1.6)	43.6 (0.8)	16.2 (-2.0)		
A little	12.9 (3.1)	42.9 (3.3)	27.1 (-3.8)	17.1 (-1.0)		
None	19.2 (3.2)	48.1 (2.7)	26.9 (-2.2)	5.8 (-2.7)		
Support from parents (n = 612)					23.83*	.114
A lot	5.1 (-1.7)	26.5 (-1.6)	43.6 (0.6)	24.8 (2.2)		
Some	3.2 (-2.0)	30.2 (0.0)	46 (1.0)	20.6 (0.1)		
A little	9.4 (0.9)	36.8 (1.6)	33 (-2.1)	20.8 (0.1)		
None	13 (3.0)	31.5 (0.4)	43.2 (0.3)	12.3 (-2.7)		
Support from family (n = 635)					21.77*	.107
A lot	5.4 (-1.3)	5.1 (-1.4)	7.7 (0.0)	12.7 (2.7)		
Some	25.9 (-2.0)	31.4 (-0.2)	35.5 (1.0)	36.1 (1.2)		
A little	7.7 (0.0)	35.5 (1.0)	40.6 (0.1)	16.1 (-1.4)		
None	12.7 (2.7)	36.1 (1.2)	36.1 (-1.2)	15.2 (-1.7)		

Note. * p < .05 ** p < .01*** p < . 001

Row percentages. Frequency tables for each variable are reported in Appendix 5. Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Table V-9

Cross tabulation of Overall Well-being with Injecting Illegal Drugs, Future Planning Time Frame, and Uncertainty about one's Medication Future Efficacy.

	Poor	Fair	Good	Excellent	χ^2	Cramer's V
Injecting Illegal Drugs (n = 720)					13.66*	0.097
Never	6.1 (-2.3)	27.9 (-1.4)	45.3 (2.4)	20.7 (0.3)		
In the last year	10.9 (1.4)	38.3 (2.3)	34.4 (-1.9)	16.4 (-1.2)		
Longer than 1 year ago	10.8 (1.5)	28.4 (-0.4)	37.8 (-1.1)	23 (0.9)		
Future planning time frame (n = 932)					148.92***	.231
One day	20.1 (7.0)	44.1 (4.0)	26.3 (-4.4)	9.5 (-3.9)		
A few months	8.3 (0.5)	39.8 (3.1)	39.0 (-0.6)	12.9 (-3.2)		
One year	4.0 (-2.0)	33.9 (0.7)	42.0 (0.4)	20.1 (0.1)		
Five years	2.2 (-3.0)	26.4 (-1.7)	47.2 (1.9)	24.2 (1.6)		
Ten or more years	2.5 (-2.7)	9.4 (-6.7)	51.3 (3.0)	36.9 (5.9)		
Future uncertainty (n = 608)					54.53***	.300
Worried	9.5 (3.0)	42.8 (5.6)	34.7 (-3.1)	13.1 (-5.0)		
Not worried	2.7 (-3.0)	19.3 (-5.6)	48.1 (3.1)	29.9 (5.0)		

Note. * p < .05 ** p < .01*** p < . 001

Row percentages. Frequency tables for each variable are reported in Appendix 5. Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Table V-10

Cross tabulation of Overall Well-being with Self-reported Health, Other Major Health Conditions, Mental Health Conditions, Cognitive Functioning, Physical Functioning, AIDS defining Illness, HIV-related Illness, Future Uncertainty.

	Poor	Fair	Good	Excellent	χ^2	Cramer's V
Self-reported health (n = 958)					808.65***	.530
Poor	67.4 (15.3)	13.2 (4.0)	1.9 (-5.9)	0.4 (-4.7)		
Fair	23.3 (-1.2)	66.7 (14)	25.7 (-3.7)	6.4 (-9.6)		
Good	7 (-4.6)	20.2 (-7.8)	62.7 (12.5)	28.8 (-4.2)		
Excellent	2.3 (-3.0)	0 (-9.4)	9.7 (-7.1)	64.4 (19.4)		
Other major health conditions (n = 940)					60.38***	.253
Yes	12.9 (5.3)	38.2 (3.9)	36.3 (-2.5)	12.7 (-5.0)		
No	3.6 (-5.3)	26.3 (-3.9)	44.2 (2.5)	25.9 (5.0)		
Mental health conditions (n = 952)					111.99***	.343
Yes	13.9 (6.3)	43.3 (6.6)	32.8 (-4.2)	10.0 (-6.7)		
No	3.0 (-6.3)	23.3 (-6.6)	46.2 (4.2)	27.5 (6.7)		
Experienced confusion/memory loss in the last 1 year (n = 774)					118.89***	.392
Yes	13.9 (6.2)	43.3 (6.5)	33.8 (-3.2)	9.0 (-7.8)		
No	2.0 (-6.2)	21.4 (-6.5)	45.0 (3.2)	31.7 (7.8)		
Experienced low energy/fatigue in the last 1 year (n = 914)					129.98***	.377
Yes	9.2 (3.4)	36.8 (6.0)	41.0 (1.2)	13.0 (-10.8)		

	Poor	Fair	Good	Excellent	χ^2	Cramer's V
HIV-related illness (n = 917)					33.77***	.192
No	1.2 (-3.4)	12.4 (-6.0)	36.0 (-1.2)	50.3 (10.8)		
Yes	13.3 (4.5)	36.7 (2.2)	36.7 (-1.6)	13.3 (-3.5)		
No	4.7 (-4.5)	29.0 (-2.2)	42.7 (1.6)	23.6 (3.5)		

Note. * p < .05 ** p < .01*** p < . 001

Row percentages. Frequency tables for each variable are reported in Appendix 5. Adjusted standardised residual frequencies appear in parentheses below observed percentages.

Predictors of well-being

Following the procedure reported in the section Methods, the socioeconomic, health status, behavioural, social support, and belief variables were entered one by one in an ordinal logistic model and, at each step, it was assessed whether there was an interaction effect involving the last predictor and relevant previous ones (see Table V-11). The complete model was highly significant, χ^2 (71) = 470.81, p < .001, Nagelkerke R squared = .926, however it had 75% of empty cells, and analyzed only 249 cases, excluding 725. This implied that the findings of the complete model were not valid and so this model is not displayed. Reduced models were then constructed following two steps. First, the issue of the test of parallel lines was addressed. Following a suggestion by Tarling (2009), two categories of the dependent variable were collapsed together and two new models were tested, one in which the categories good and excellent well-being were collapsed together (from this point onward, Model 1) and one in which the categories poor and fair well-being were collapsed together (from this point onward, Model 2). Of this two models, only Model 1 did not reject the test of parallel line, consequently Model 2 was discarded (see Appendix 9 for a step by step illustration of this latter Model).

Model 1 was run both with a Logit Link function and a Complementary Log-Log function; this latter function reflected the fact that the higher values of the dependent variable were more likely, i.e. the collapsed category good and excellent well-being. Model 1 with the Complementary Log-Log Link function was highly significant, χ^2 (72) = 296.40, $p < .001$, its Nagelkerke R squared was .860, and did not violate the assumption of parallel lines ($p = .918$). A summary of the model can be found in Appendix 9 (see Table_Appendix 9-1). However, the model still had a very high number of empty cells (66.7%), many predictors that were not significant at the .05 level, and analyzed only 249 cases of the 974. In order to reduce the number of cells with 0 frequencies the variables whose Wald statistics were not significant at the .05 level were removed. These were, among the socioeconomic variables, weekly income after tax and accommodation type; among the health status variables, CD4 cell count, physical functioning and cognitive functioning; among the social support variables, support from parents; and, finally, the behavioural variable injecting illegal drugs. Model 1 without these variables was still highly significant, χ^2 (41) = 288.75, $p < .001$, its Nagelkerke R squared was .520, and did not violate the test of parallel lines ($p = 1.000$). The model analyzed 531 cases and excluded 443. A summary of this model can be found in Appendix 9 (see Table_Appendix 9-2). In this model the variables educational attainments, other major health conditions, HIV-related illnesses, support from close friends, and support constructed became not significant, so they were removed. When Model 1 was run again without these latter variables, the test of parallel lines rejected the null hypothesis that the slope coefficients were the same across the response categories ($p = .041$), so this model is not displayed. The model was run again using a Logit Link function and in this case the test of parallel line did not reject the null hypothesis ($p = 1.000$). This latter model was highly significant, χ^2 (41) = 322.70, $p < .001$, its Nagelkerke R squared was .502; it analyzed 607 cases and excluded 367 (a

summary of this latter model can be found in Appendix 9 in Table_Appendix 9-3). The variable employment lost significance, so it was removed and the model was run again (see Table V-12). The new model was highly significant, χ^2 (11) = 327.58, $p < .001$, and its Nagelkerke R squared was .501. The model analyzed 616 cases and excluded 358. The null hypothesis of the test of parallel lines was not rejected ($p = .349$). The Chi-square of the Goodness-of-fit statistics were low (Pearson χ^2 = 285.70, Deviance χ^2 = 216.27) and their p values high (Pearson χ^2 p value = .090 and Deviance χ^2 p value = .962). The model had 47.5% empty cells; an inspection of the Pearson residuals showed that there were only 8 cells that lied above ±1.96 standard deviations (the threshold of 5% mentioned in the Method section implied a maximum of 31cases), however, 8 cells had values that were greater than ± 2.58 standard deviations, of which 4 were greater than 3 standard deviations. The number of cases excluded from this model (n = 367) was also still very high. These were due to the variable support from family, which was answered only by 639 people (see Appendix 5). So, this variable was removed from the model.

The final model included three variables (see Table V-13): self-reported health status (of which the categories good and excellent were collapsed together), mental health conditions, and future planning. The model was highly significant, χ^2 (6) = 481.74, $p < .001$, its Nagelkerke R squared was .493, accounted for a far higher number of cases (n = 926) and had a smaller number of empty cells (14.5%). The Chi-square of the Goodness-of-fit statistics were lower than those of the final model (Pearson χ^2 = 50.78, Deviance χ^2 = 49.06), and the p value larger than 0.05 (Pearson χ^2 p = .080, Deviance χ^2 p value = .108). Inspection of the standardised residuals showed that there were only 4 cells with a Pearson residual above ±1.96 standard deviations, and no cells with Pearson residuals above ± 2.58 standard deviations.

The results in Table V-13 show that, holding the other variable constant, PLWHA with poor health conditions (odds ratio = 0.01), fair health conditions (odds ratio = 0.09), mental health conditions (odds ratio = 0.35), who only planned day by day (odds ratio = 0.24), who planned a few months ahead (odds ratio = 0.39), and who planned one year ahead (odds ratio = 0.56) were less likely to experience good or excellent well-being as opposed to the combined outcomes of fair well-being, and poor well-being compared to PLWHA with excellent health status, no mental health conditions, a lot of support from their family and who life plans for 10 years or longer.

Among the housing indicators, only the fourfold typology of experiences of opportunities and objective housing stability significantly predicted overall well-being controlling for the above mentioned variables (see Table V-14 and in Appendix 9 Table_Appendix 9-5). However, when entered after the fourfold typology of opportunities, none of the categories of the objective housing stability variable were significant (see Table_Appendix 9-6 in Appendix 9). Crowding conditions and number of accommodation changes in the last two years did not significantly predicted overall well-being after controlling for demographic, socioeconomic and health variables (see Table_Appendix 9-7 and Table_Appendix 9-8 in Appendix 9). The model with the fourfold typology was highly significant, χ^2 (9) = 468.77, $p < .001$ and its Nagelkerke R squared was .493. Table V-14 shows that, holding the other variable constant, PLWHA who experienced availability disadvantage were less likely (odds ratio = 0.49) to experience good or excellent well-being as opposed to the combined outcomes of fair well-being, and poor well-being compared to PLWHA who experienced high achievability.

Table V-11

Likelihood Ratio Tests and Nagelkerke Pseudo R-Square for Complete Model

		χ^2	df	Nagelkerke
Step 1				
	Occupation status (n = 935)	63.89***	4	.072
Step 2				
	Educational attainment (n = 912)	79.31***	7	.091
Step 3				
	Accommodation type (n = 910)	83.92***	10	.096
Step 4[a]				
	Weekly income after tax (n = 807)	87.54***	11	.112
Step5				
	Self-reported health (n = 806)	584.36***	14	.563
Step 6				
	Self-reported health * accommodation type (n = 806)	603.29***	23	.576
Step 7				
	Other major health conditions (n = 792)	591.79***	24	.575
Step 8				
	Other major health conditions * Employment status (n = 792)	602.21***	28	.582
Step 9				
	Mental health conditions (n = 789)	619.63***	29	.594
Step 10				
	HIV-related illness (n = 769)	600.19***	30	.592
Step 11				
	HIV-related illness * Other major health conditions (n = 769)	604.28***	31	.595
Step 12				
	CD4 count (n = 709)	566.07***	32	.602
Step 13				

	χ^2	df	Nagelkerke
Fatigue (n = 677)	555.72***	33	.613
Step 14			
Confusion/Memory loss (n = 560)	497.90***	34	.643
Step 15			
Confusion/Memory loss * Self-reported health	511.41***	37	.653
Step 16			
Injecting illegal drugs (n = 450)	417.12***	39	.659
Step 17			
Support from close friends (n = 419)	405.67***	42	.678
Step 18			
Support from close friends * Employment status (n = 419)	441.89***	54	.712
Step 19			
Support from parents (n = 307)	345.29***	56	.738
Step 20			
Support from parents * Self-reported health (n = 307)	493.75***	64	.874
Step 21			
Support from family (n = 252)	456.61***	67	.912
Step 22			
Support constructed (n = 252)	465.70***	68	.918
Step 23			
Future planning timeframe (n = 249)	470.81***	72	.926

Note. * $p < .05$ ** $p < .01$*** $p < .001$

See Appendix 6 for all the interactions that were tested.

[a] When employment status was entered the empty cells went from 25.6% to 70.4%.

[b] The test of parallel lines rejected the null hypothesis.

Table V-12

Summary of Ordinal Logistic Regression Predicting Well-Being with the Categories Good and Excellent Collapsed Together.

	B (Standard error)	Wald	95% Confidence Interval	
			Lower Bound	Upper Bound
Self-reported health (Reference category: Excellent)				
Poor health	-5.25 (0.56)	87.46***	-6.36	-4.15
Fair health	-3.29 (0.38)	76.31***	-4.03	-2.55
Good health	-1.29 (0.36)	12.89***	-2.00	-0.59
Mental health conditions (Reference category: No)[a]				
Yes	-1.14 (0.20)	32.13***	-1.54	-0.75
Support from family[b] (Reference category: A lot)				
Some	-0.61 (0.30)	4.15*	-1.19	-0.02
A little	-0.95 (0.29)	10.48**	-1.52	-0.37
None	-0.92 (0.29)	10.12**	-1.48	-0.35
A lot	0.00[a]	.	.	.
Future planning (Reference category: Ten or more years)c				
One day	-2.03 (0.41)	24.07***	-2.85	-1.22
A few months	-1.36 (0.40)	11.53**	-2.14	-0.57
One year	-1.40 (0.42)	10.83**	-2.23	-0.56

	B (Standard error)	Wald	95% Confidence Interval	
			Lower Bound	Upper Bound
Five years	-0.85 (0.43)	4.00*	-1.69	-0.02

Note. * $p < .05$ ** $p < .01$*** $p < .001$. Link function: Logit.

Reference category: Good/Excellent well-being.

[a] The interaction between self-reported health and mental health conditions was tested and was not found to be significant. [b] The interaction between support from family and self-reported health was tested and was not found to be significant. [c] The interaction between future planning and self-reported health was tested and was not found to be significant.

Table V-13

Summary of Ordinal Logistic Regression Predicting Well-Being with the Categories Good and Excellent Collapsed Together.

	B (Standard error)	Wald	95% Confidence Interval	
			Lower Bound	Upper Bound
Self-reported health (Reference category: Good/Excellent)				
Poor health	-4.63 (0.39)	137.73***	-6.27	-5.17
Fair health	-2.42 (0.18)	176.04***	-2.77	-2.06
Mental health conditions (Reference category: No)				
Yes	-1.05 (0.16)	42.59***	-1.37	-0.74
Future planning (Reference category: Five or more years)				
One day	-1.44 (0.23)	40.11***	-1.88	-0.99
A few months	-0.93 (0.21)	19.40***	-1.35	-0.52

	B (Standard error)	Wald	95% Confidence Interval	
			Lower Bound	Upper Bound
One year	-0.58 (0.24)	6.04*	-1.04	-0.12

Note. * $p < .05$ ** $p < .01$*** $p < .001$. Link function: Logit. Reference category: Good/Excellent well-being

Table V-14

Summary of Ordinal Logistic Regression Predicting Well-Being from Self-reported Health, Mental Health Conditions, Support from Family, Future Planning, and the Four Types of experiences of opportunity in relation to housing.

	B (Standard error)	Wald	95% Confidence Interval	
			Lower Bound	Upper Bound
Self-reported health (Reference category: Good/Excellent)				
Poor health	-4.32 (0.41)	111.76***	-5.12	-3.52
Fair health	-2.43 (0.18)	172.98***	-2.79	-2.07
Mental health conditions (Reference category: No)				
Yes	-1.01 (0.17)	36.25***	-1.33	-0.68
Future planning (Reference category: Five or more years)				
One day	-1.34 (0.23)	33.60***	-1.80	-0.89
A few months	-0.91 (0.27)	18.02***	-1.33	-0.49
One year	-0.55 (0.24)	5.11**	-1.02	-0.07

	B (Standard error)	Wald	95% Confidence Interval	
			Lower Bound	Upper Bound
Fourfold typology of opportunities of housing (Reference category: High achievability)				
Availability disadvantage	-0.63 (0.22)	8.12**	-1.07	-0.19
Achievability disadvantage	0.33 (0.41)	0.62	-1.14	0.49
Low capability	-0.54 (0.42)	1.65	-1.37	0.28

Note. * $p < .05$ ** $p < .01$*** $p < .001$

Link function: Logit. Reference category: Good/Excellent well-being

Relationship between poverty and opportunities of adequate housing

The cross tabulation of the four experiences of the opportunity to enjoy adequate housing and poverty lines showed different outcomes depending on whether rental subsidies were or were not included in the calculation of the poverty lines. If rental subsidies were included in the calculation of poverty lines, only 43.3% of PLWHA who experienced low capability were also experiencing poverty. If rental subsidies were not included in the calculation, then nearly 60% of those who experienced poverty also experienced low capability. Significant differences are evident also in relation to availability disadvantage and achievability disadvantage.

Table V-15

Cross tabulation of participants below the poverty line vs. participants above the poverty line and the Four Experiences of the Opportunity to Enjoy Adequate Housing.

	Below the poverty line		Above the poverty line			
	With rental subsidies	Without rental subsidies	With rental subsidies	Without rental subsidies	χ^2	Cramer's V
Four Experiences of					24.66***	.171
					47.71***	.243

	Below the poverty line		Above the poverty line			
	With rental subsidies	Without rental subsidies	With rental subsidies	Without rental subsidies	χ^2	Cramer's V
Opportunity						
High capability	17♦ (115)	22.7♦ (148)	83† (563)	77.3† (503)		
Availability disadvantage	30.4† (31)	45.5† (45)	69.6♦ (71)	54.5♦ (54)		
Achievability disadvantage	34.5† (10)	55.2† (16)	65.5♦ (19)	44.8♦ (13)		
Low capability	43.3† (13)	59.3† (16)	56.7♦ (17)	40.7♦ (11)		

Note. * p < .05 ** p < .01*** p < .001

Column percentages. Frequencies appear in parentheses below observed percentages.

[a] Chi-square for poverty lines that included rental subsidies

[b] Chi-square for poverty lines that did not include rental subsidies

† Positive adjusted standardised residual ≥ 1.96

♦Negative adjusted standardised residual ≥ 1.96

Table V-16

Cross tabulation of Fourfold Typology of Opportunities and Perceived Difficulty to Pay for Rent, Mortgage, and Housing Costs.

	High capability	Availability disadvantage	Availability disadvantage	Low capability	χ^2	Cramer's V
Difficulty in paying rent, mortgage, and housing costs					71.90***	.215
Not difficult	48.4† (302)	22.8♦ (23)	40.7 (11)	6.9♦ (2)		
Little difficult	37.8 (236)	34.7 (35)	44.4 (12)	51.7 (15)		
Very difficult	13.8♦ (86)	42.6† (43)	14.8 (4)	41.4† (12)		

Note. * p < .05 ** p < .01*** p < .001

Row percentages. Frequencies appear in parentheses below observed percentages.

† Positive adjusted standardised residual ≥ 1.96

♦Negative adjusted standardised residual ≥ 1.96

Discussion

This chapter had two objectives: to explore the relationship between well-being, on the one hand, and poverty, on the other, with the fourfold typology of opportunities to enjoy adequate housing.

The ordinal logistic model that was constructed to predict well-being included a variety of relevant indicators, however it excluded others, such as personality (optimistic vs. pessimistic), which could have been important to include. Despite this limit, the analyses carried out in this chapter showed that the typology of opportunities to enjoy adequate housing predicted well-being after controlling for socioeconomic, health status, social support, and future perspectives variables. This result is consistent with that of previous investigations on indicators of capabilities (Anand, et al., 2009; Anand, et al., 2005; Anand & van Hees, 2006). In particular, only the experiences of availability disadvantage significantly predicted well-being. This shows that the extent to which accommodations meet the needs of PLWHA is an important and independent predictor of their overall well-being. It is important to remind that whilst availability disadvantage indicated ongoing problems with the participants' accommodation, achievability disadvantage referred to episodes of discrimination in relation to housing that happened in the last two years. Nevertheless, even though these results did not reach statistical significance, PLWHA who experienced achievability disadvantage and low capability had reduced odds to experience good or excellent well-being. Overall, these results confirm the robustness of the typology of experiences of opportunities, especially in comparison to the other measures of housing experiences, and emphasise the importance of meeting the accommodation needs of PLWHA.

With regard to the analyses on the relationship between poverty and the typology of housing experiences, these were based on two poverty lines. The adjusted

standardised residuals showed that both poverty lines presented similar patterns in relation to the cells that contributed to the significance of their zero-order relationships with socioeconomic, health, and housing condition variables. However, the fact of including or not including housing benefits in the calculation of poverty lines had a significant impact on the percentage of PLWHA who experienced low capability and poverty at the same time. When housing benefits was included in the calculations, about 43% of PLWHA who experienced low capability also experienced poverty. This percentage was 59% when housing benefits were not included in the calculations. In both cases, however, between 57% and 41% of the study participants who experienced low capability did not also experience poverty. This means that low capability represents a form of disadvantage that is not fully accounted for by material deprivation. Although the study of poverty remains, clearly, a fundamental area of investigation, it does not, in itself, identify all the forms of disadvantage that can be experienced by PLWHA in relation to their accommodation and that can impact on their well-being.

Limitations of the study.The HIV Futures V survey was undertaken using a self-selection sampling method, which entails that there sample is prone to a self-selection bias, that is to the risk that the sample is not representative of the population being studied, or exaggerates some particular finding from the study. Differences may exist between those who volunteered and those who refused participation in the survey which are difficult to predict and quantify. Therefore, it is important to stress that this study's findings may not be generalisable to the wider population of PLWHA in Australia.

CHAPTER VI

OPPORTUNITY ACHIEVABILITY AND RETURN TO WORK

In this chapter, a second set of analyses will be offered as an example of how the threefold model of opportunity perception can be used to investigate a central area of research in the quality of life of PLWHA, i.e. their experiences of return to work. Particularly, the analysis will focus on the relationships between the respondents' intention to return to work and the achievability of their opportunities to return to work.

The introduction of Highly-Active Antiretroviral Therapy (HAART) in 1996 has enhanced the longevity for PLWHA (Montaner, et al., 2010), and it has consequently raised their prospect of returning to work (Brooks, Martin, Ortiz, & Veniegas, 2004; Ezzy, de Visser, Bartos, et al., 1998; Hergenrather, Rhodes, & Clark, 2006). The importance of employment in PLWHA's lives has been discussed from a variety of perspectives in the literature. Employment has been found to have a positive impact on PLWHA's needs for self-determination, relatedness, and survival (Blustein, Catraio, Coutinho, & Murphy, 2008; Maguire, McNally, Britton, Werth, & Borges, 2008; Werth, Borges, McNally, Maguire, & Britton, 2008a, 2008b), and on their self-reported quality of life (Blalock, McDaniel, & Farber, 2002; Liza M. Conyers, 2004; Escovitz & Donegan, 2005; Van Gorp et al., 2007). Several studies have reported a causal link between unemployment and PLWHA experiences of economic hardship and poverty (Arns, Martin, & Chernoff, 2004; Dray-Spira, Lert, Marimoutou, Bouhnik, & Obadia, 2003; Ezzy, et al., 1999; Ezzy, de Visser, Grubb, et al., 1998; Fogarty, Zablotska, Rawstorne, Prestage, & Kippax, 2007; Lem et al., 2005).

Nevertheless, even after the introduction of HAART, PLWHA tend to have higher unemployment rates compared to the general population, both in Australia (Ezzy, de Visser, Grubb, et al., 1998; Grierson, et al., 2006) and internationally (Dray-Spira &

Lert, 2007; Dray-Spira, et al., 2003). In the main report on the HIV Futures V Survey, Grierson, Thorpe, & Pitts (2006) showed that nearly half (46.9%) of those who described themselves as unemployed planned to start or return to work. Of these, the vast majority indicated that their main motivations to return to work were financial. Similarly high percentages of unemployed PLWHA intending to return to work have been reported in international studies (Brooks, et al., 2004). A growing body of research, which includes two special issues of scientific journals on work related questions (Braveman & Kielhofner, 2006; Liza Marie Conyers, 2005), has identified several demographic, socio-economic, and health factors associated with successful return to work for PLWHA.

With regard to PLWHA demographic characteristics, three main factors, gender, age, and time since diagnoses have been investigated in relationship to PLWHA success in returning to work. Most research has reported that males living with HIV/AIDS were more likely to retain or return to work than females living with HIV/AIDS (Dray-Spira, et al., 2006; Martin, Steckart, & Arns, 2006). In one of the reviewed studies the opposite result was found (Martin, Arns, Batterham, Afifi, & Steckart, 2006), however, considering that its sample of 126 PLWHA included only 12 females, its results should be considered with caution. Several studies have shown a greater tendency for younger workers to remain in or re-enter the workforce (Brooks, et al., 2004; Burns, Young, & Maniss, 2006; Martin, Arns, et al., 2006; Van Gorp, et al., 2007). Nevertheless, Rabkin et al. (2004) did not find that age predicted work status. Contrasting findings characterize also the studies on the role of time lived with HIV/AIDS in predicting PLWHA's return to work. Some studies have reported that time since diagnosis significantly predict PLWHA's successful return to work, with individuals who have lived longer with HIV/AIDS showing greater work limitations (Martin, Arns, et al., 2006; Martin, Steckart, et al., 2006). Other studies found little change (Rabkin, et al.,

2004) or no significant change (Burns, et al., 2006) in PLWHA employment status based on time since diagnosis.

Three main indicators of socio economic status have been identified in the literature as predictors of successful return to work: educational attainment, shorter periods of unemployment, and type of health insurance. PLWHA with a higher educational degree (Martin, Arns, et al., 2006; Martin, Steckart, et al., 2006) and with a shorter period of unemployment (Van Gorp, et al., 2007) were found to be more likely to re-enter work. In a study with a sample of 2864 PWLHA recruited from 180 clinics, hospitals and private practices in the United States, Bernell & Shinogle (2005) found that PLWHA who had private health insurance were more likely to use HAART compared to individuals with public health insurance coverage or no coverage. Indeed, PLWHA who took HAART had an increased likelihood of working.

With regard to health factors, four main groups of variables were identified in the literature as predictors of PLWHA's successful return to work: physical health functioning, mental health status, biological markers of disease progression (i.e. CD4 count, and viral load), and behavioural and beliefs factors (i.e. drug addictions and worries related to one's health condition). Research has reported consistent findings with regard to the impact of physical health functionings and behavioural and beliefs factors on PLWHA's successful return to work. PLWHA with higher perceived health (Martin, Arns, et al., 2006; Martin, Brooks, Ortiz, & Veniegas, 2003; Martin, Steckart, et al., 2006), better physical health functionings, as measured through the SF-36 Physical Health Quality of Life Summary Scale (Burns, et al., 2006; Lem, et al., 2005; Preau et al., 2004), no diagnosis of AIDS-defining illnesses (Van Gorp, et al., 2007), less uncertainty regarding their disease progression (Braveman, et al., 2006), and no history of substance abuse (Martin, Steckart, et al., 2006) were more likely to return to work. In the main report on the HIV Futures V Survey, Grierson, Thorpe, & Pitts (2006)

showed that poor health and diminished energy levels were the most common responses (48.3%) that the respondents gave to explain their most recent interruption of employment.

Mental health was also reported having a major impact on PLWHA work capabilities. Van Gorp et al. (2007) found that PLWHA with higher memory function were more likely to return to work than PLWHA with lower memory function. PLWHA with depression (Rabkin, et al., 2004) and with lower mental health functioning, as measured through the Mental Health Composite Scale (Burns, et al., 2006), were found to be less likely to be employed and to return to work. In the HIV Futures V sample, psychological health (i.e. stress, depression or anxiety) was the second most common response (47.4%) given for the causes of interruption of employment (Grierson, et al., 2006). In an analysis of a previous version of the HIV Futures survey, Ezzy, De Visser, & Bartos (1999) reported that psychological health was the primary reason reported (71%) for leaving work. From this point of view, the role of psychological health in relationship to the decision to leave work seems to have changed over time among PLWHA in Australia.

Finally, the literature on the impact on return to work of the two main biological markers of HIV/AIDS progression, CD4 count and viral load, is characterised by inconsistent findings. With regard to CD4 count, a few studies found that CD4 count below 350/ mm^3 was associated with lower chances to return to work (Burns, et al., 2006; Lem, et al., 2005; Martin, Arns, et al., 2006). However, Rabkin et al. (2004) did not find such an association. With regard to viral load, Dray-Spira et al. (2006) found that a viral load above 10,000 copies/ml predicted low return to work, whereas Rabkin et al. (2004) and Burns et al. (2006) found no association.

In this chapter, the above mentioned factors are interpreted as ‘achievability factors’, namely factors that can help to make work opportunities that are available to PLWHA within their reach. The objective of the following analyses is to explore whether the prevalence of those factors differed between: a) unemployed respondents who wanted to return to work and unemployed respondents who did not intend to return to work, and b) between those not working/retired who wanted to return to work and those not working/retired who did not intend to return to work. The aim is to understand whether the two groups who intended to return to work were in a position of advantage or disadvantage compared to respondents with a similar employment status. A position of advantage would be found if there were significantly more respondents who intended to return to work among those having the demographic, socio-economic, and health factors associated with successful return to work. On the other hand, a position of disadvantage would be found if there were significantly fewer.

Given the role of psychological factors as causes of employment interruption among PLWHA in Australia, particular attention is given to their capacity to predict return to work. The analyses will be guided by the following main research questions:

1. Were there differences in the way characteristics associated with successful return to work distributed between unemployed PLWHA who expressed the intention to return to work and unemployed PLWHA who did not?

- If so, did mental health factors predict the respondents’ intention to return to work after controlling for socio-economic factors, physical health functioning, and HIV biological markers?

2. Were there differences in the way characteristics associated with successful return to work distributed between not working/retired PLWHA who

expressed the intention to return to work and not working/retired PLWHA who did not?

- If so, did mental health factors predict the respondents' intention to return to work after controlling for socio-economic factors, physical health functioning, and HIV biological markers?

The analyses of these research questions are exploratory; no relevant literature can be used to discuss differences and similarities in the capacity to return to work between the suggested groups of PLWHA. However, based on the above review of the literature, it is hypothesised that, if the associations between the suggested comparison groups and predictors of successful return to work are significant, then psychological health will be a determinant of successful return to work as important as demographic, socio economic, and physical health factors.

Method

For an explanation of the main objectives of the HIV Futures V Survey, the characteristics of its sample, and of its recruitment procedure, I refer to the sections Measures, Participants, and Recruitment of Chapter IV, in which these topics have already been reported.

Measures

Outline of variables. All the variables used in the analyses are outlined below. The corresponding questions asked in the HIV Futures V Survey can be found in (Appendix 4).

Comparison groups. Two comparison groups were created. One included all the unemployed respondents and consisted of two groups, those who intended to return to work and those who did not. The other included all the respondents who were not

working because of being on a disability pension or were retired and was also dichotomised in those who intended to return to work and those who did not.

Independent variables. Four groups of independent variables were used based on the literature review in the Introduction section: demographic variables, socio-economic variables, health variables, and behavioural variables. In addition to these variables, overall well-being was also checked as a potential factor affecting PLWHA decision to return to work.

Demographic, socio-economic, and health related variables offered an operationalisation, through objective indicators, of PLWHA achievability of the opportunity to return to work. The achievability of the opportunity to return to work was also operationalised through a subjective indicator, which consisted of a question that asked the study participants to indicate their main motivations to return to work. The respondents could indicate a variety of motivations, financial, social, and health related. Particularly, among the health related motivations, the respondents could indicate whether they returned to work because of better psychological health or better physical health (see the section Descriptive data).

Demographic variables. Based on the literature reviewed, three demographic variables were used as correlates of return to work: gender, age, and time since diagnosis. All the demographic factors were operationalised through the same questions used in Chapter IV.

Socio-economic variables. Three socio-economic variables were investigated: educational attainment, length of unemployment, and possession of private health insurance. Educational attainment was operationalised through the same questions used in Chapter IV. Length of unemployment was operationalised through a question that asked the study participants who were not working how long ago they stopped working.

Type of health insurance was operationalised through an ad hoc question that asked the respondents whether they had a private health insurance.

Behavioural variables. Behavioural factors were operationalised through the same question on the use of hard drugs that was used in Chapter IV.

Belief factors. Beliefs factors were operationalised through a question that asked the study participants whether they feared that their medication would stop working in the future.

Health variables. Seven health variables were taken into consideration in the analyses: perceived health status, mental health conditions, AIDS-defining illness, HIV-related illness, CD4 count, viral load – which were all operationalised through the same questions already introduced in Chapter IV – and physical health functionings, and cognitive functionings, which were operationalised through the same questions already used in Chapter V.

Well-being. Well-being was operationalised through the same variable that was already illustrated in Chapter V.

Procedure

Analytical strategy. First, chi-square tests of independence, for categorical variables, and *t*-tests or one-way analysis of variance (ANOVA), for continuous variables, were computed to check the relationship between the demographic, socio economic, behavioural, health, and well-being variables and the two main comparison groups mentioned in the research questions. Significant associations were then further tested using binary logistic regression modelling. Considering that demographic and socio economic variables could have a significant impact on PLWHA's work status and on their decisions to return to work, these variables were entered first in the logistic model. Each demographic and socio economic variable was entered in separate steps

using an Enter method, so to ascertain their relationship with return to work independent of the effects of each other. When in the model there were two variables significantly predicting return to work, it was assessed whether there was an interaction affecting them. If an interaction was found it was kept in the model. After having entered all the demographic and socio economic variables, health status variables were entered in separate steps of the logistic regression. This allowed the exploration of the relationship between health variables and return to work after controlling for demographic and socio economic factors. Interaction effects among health variable and between health variables and demographic and socio economic factors were also assessed.

Residuals were examined to assess how well the regression models fit the data. Particularly, Cook's distance, leverage, standardised residuals, and DFBeta values were used to identify points for which the models fit poorly and to identify points that exert an undue influence on the model. It was expected that 95% of the sample would have values that lie within ±1.96 standard deviations, and 99% of cases would have values that lie within ± 2.58 standard deviations (A. Field, 2005).

As mentioned in Chapter IV, the HIV Futures V survey was done using a self-selection sampling method. The potential biases induced by self-selection sampling on the study findings are acknowledged and discussed in the paragraph titled 'Study limitations' at the end of the chapter.

Results

Descriptive data

About two study participants out of five (39.3%, n = 367) indicated that they were thinking to change their work arrangements. Of these, 39.7% intended to start or return to work and 14.6% intended to increase their working hours (see Table VI-1). Of

those who intended to return to work, 7.6% would reduce their worked hours, whereas 12.5% would increase their worked hours compared to a previous experience. Overall, 32.6% of those who thought to return to work indicated that they wanted to change type of work (see Table VI-2).

Table VI-1

Type of Changes to Work Arrangements

	Cases (%)
Start/return to work	39.7
Stop to work	5.2
Change type of work	47.7
Reduce hours	21.5
Increase hours	14.6
Other changes	15.7

Note. Multiple answers questions.

Table VI-2

Percentage of Individuals who Reported Multiple Changes of Work Arrangements

	Start/return to work	Stop to work	Change type of work	Reduce hours	Increase hours	Other changes
Start/return to work	--	0	32.6	7.6	12.5	4.2
Stop to work	0	--	31.6	36.8	5.3	15.8
Change type of work	27.2	3.5	--	25.4	17.3	9.2
Reduce hours	14.1	9	56.4	--	2.6	6.4
Increase hours	34	1.9	56.6	3.8	--	9.4
Other changes	10.5	5.3	28.1	8.8	8.8	--

Note. Row percentages.

Multiple answers questions.

The majority of the study participants indicated that the main reason to change their work arrangements were financial, followed by doing something worthwhile, and better psychological health (see Table VI-3). Among unemployed PLWHA and those not/working or retired, more than three quarters indicated that financial reasons were the primary motivation to return to work, followed by doing something worthwhile, have something to do, and having more social contact (see Table VI-4). Better psychological health and better physical health were respectively the fifth and sixth more often reported reasons.

Table VI-3

Reasons to Return to Work

	Cases (%)
Financial reasons	65
Do something worthwhile	49.3
Better psychological health	45.5
Reduce stress	40.8
More social contact	40.2
Better physical health	35.3
Have something to do	33.3
Part-time work	28.4
Flexible working hours	27.3
Other	17.1
Full-time work	9.9
Worse physical health	5
Worse psychological health	3.6
Less social contact	3

Note. Multiple answers questions.

Table VI-4

Cross tabulation of Motivations to Change Work Arrangements and Occupation Status

	Unemployed (n = 61)	Not working/Retired (n = 65)
Financial reasons	54 (88.5)	54 (83.1)
Reduce stress	25 (41)	19 (29.2)
Do something worthwhile	40 (65.6)	42 (64.6)
Have something to do	36 (59.0)	41 (63.1)
Better physical health	23 (37.7)	30 (46.2)
Worse physical health	0 (0.0)	2 (3.1)
Better psychological health	30 (49.2)	38 (58.5)
Worse psychological health	1 (1.6)	1 (1.5)
Flexible working hours	19 (31.1)	21 (32.3)
Part-time work	26	23

	Unemployed (n = 61)	Not working/Retired (n = 65)
	(42.6)	(35.4)
Full-time work	7 (11.5)	9 (13.8)
More social contact	34 (55.7)	41 (63.1)
Less social contact	1 (1.6)	2 (3.1)
Other	5 (8.2)	7 (10.8)

Note. Column percentages. Percentages appear in parenthesis below frequencies. Multiple answer questions.

Achievability factors among PLWHA unemployed

A series of chi-square tests of independence and *t*-tests were computed to check the relationship between the first comparison group, i.e. unemployed respondents who intended to return to work vs. unemployed respondents who did not express that intention, and demographic factors, socio-economic factors, and health related factors associated with successful return to work. None of the chi-square tests of independence with demographic, and health related factors were found to be significant (see Appendix 10). Among the socio-economic factors, only the relationship with length of unemployment in years was significant. Because this variable had a bimodal distribution and did not distribute normally within the categories of the dependent variable either, a Mann-Whitney non parametric test was conducted. This was found to be significant, $z = -2.27$, $p = .023$, $r = -.29$. Those unemployed that did not want to return to work tended

to be unemployed for longer time; the median for the group unemployed who did not want to work was *Mdn* = 6.00, the median for the group of unemployed who wanted to go back to work was *Mdn* = 3.00.

The relationships with self-reported psychological and physical health reasons for returning to work, as well as overall well-being were also statistically not significant (see Table VI-5).

Table VI-5

Cross Tabulation of Unemployed who Intended to Return to Work vs. Unemployed who Did not Intend to Return to Work and Better Psychological Health, Better Physical Health, and Overall Well-being.

	Unemployed Do not return to work	Unemployed Return to work	χ^2	*p*
Better Psychological health[b]			0.15	0.694
Yes	6 (20)	24 (80)		
No	5 (16.1)	26 (83.9)		
Better Physical Health[b]				.733[a]
Yes	5 (21.7)	18 (78.3)		
No	6 (15.8)	32 (84.2)		
Well-being			4.33	.227
Poor	7 (38.9)	11 (61.1)		
Fair	21 (50.0)	21 (50.0)		
Good	19 (65.5)	10 (34.5)		

	Unemployed Do not return to work	Unemployed Return to work	χ^2	*p*
Excellent	5 (38.5)	8 (61.5)		

Note. Row percentages. Percentages appear in parenthesis below frequencies. [a] Two-sided Fisher's Exact Test is reported because 1 cell (25%) had expected count less than 5. [b] Multiple response question.

Achievability factors among PLWHA not working and retired

Chi-square tests of independence and ANOVA tests were also computed to check the relationship between demographic factors, socio-economic factors, and health related factors associated with successful return to work, and the second comparison group, i.e. not working or retired respondents who intended to return to work vs. not working/retired respondents who did not intend to return to work. Among the demographic factors, only age was significantly associated with being retired/not working and intending to return to work, $t(240) = 3.73$, $p < .001$, $r = 0.23$. Mean ages (with standard deviations in parentheses) were 53.23 (9.65) for those retired who did not intend to return to work, and 47.59 (8.54) for those retired who intended to return to work. Among the socio-economic factors, only the relationship with length of unemployment in years was significant, $t(196) = 2.50$, $p = .013$, $r = 0.18$. The variable length of unemployment had 637 missing cases, whereas age only 13. Mean length of unemployment in years and standard deviations were 8.85 (5.16) for those retired who did not intend to return to work, and 6.59 (3.78) for those retired who intended to return to work. Among the health factors, only the relationship with perceived health and use of illegal drugs were significant (see Table VI-6). However, the relationship with perceived health status was determined only by the under representation of respondents with poor health status among not working or retired respondents who intended to

return to work. With regard to use of illegal drugs, contrary to what suggested in the literature (Martin, Steckart, et al., 2006), PLWHA who injected illegal drugs in the last year were more likely to want to return to work (see Table VI-6).

Table VI-6

Cross Tabulation of Retired or Not Working who Intended to Return to Work vs. Retired or Not Working who Did not Intend to Return to Work and Perceived Health and Injecting Illegal Drugs.

	Not working/Retired Do not return to work	Not working/Retired Return to work	χ^2	*p*
Perceived health			9.39	0.24
Poor	100 (2.3)	0.0 (-2.3)		
Fair	84.1 (1.4)	15.9 (-1.4)		
Good	73.5 (-1.8)	26.5 (1.8)		
Excellent	71.8 (-1.2)	28.2 (1.2)		
Use of illegal drugs			10.17	.006
Never injected	83.1 (3.1)	16.9 (-3.1)		
Injected in the last year	57.1 (-2.2)	42.9 (2.2)		
Injected > 1 year ago	62.9 (-1.7)	37.1 (1.7)		

Note. Row percentages.

Adjusted standardised residual frequencies appear in parentheses below observed percentages.

The relationships with self-reported psychological and physical health reasons for returning to work, as well as overall well-being were found to be statistically not significant (see Table VI-7 and Table VI-5).

Table VI-7

Cross Tabulation of Retired or Not Working who Intended to Return to Work vs. Retired or Not Working who Did not Intend to Return to Work and Better Psychological Health, Better Physical Health, and Overall Well-being.

	Not working/Retired Do not return to work	Not working/Retired Return to work	χ^2	*p*
Better Psychological health			0.01	0.910
Yes	8 (21.1)	30 (78.9)		
No	6 (22.2)	21 (77.8)		
Better Physical Health			0.10	0.745
Yes	7 (23.3)	23 (76.7)		
No	7 (20.0)	28 (80.0)		
Well-being			6.19	0.103
Poor	26 (81.3)	6 (18.8)		
Fair	71 (79.8)	18 (20.2)		
Good	73 (84.9)	13 (15.1)		
Excellent	22 (64.7)	12 (35.3)		

Note. Row percentages. Percentages appear in parenthesis below frequencies.

Following the procedure suggested in the Method section, binary logistic regression analysis was employed to predict the probability that unemployed participants intended to return to work based on their age, length of unemployment, perceived health, and use of illegal drugs. Each predictor was entered in separate blocks (see Table VI-8). A summary of the final model can be found in Table V-9. The test of the full model versus a model with intercept only was statistically significant, $\chi^2(4)$ =

16.77, p = .002. The Nagelkerke R squared was 0.192. The Hosmer–Lemeshow test showed that the model had a good fit (p = 0.159). There were no unusually high values of the Cook statistics, particularly none greater than 1, all cases had DFBetas less than 1, and leverage statistics were close to the calculated expected value of 0.033.

The model suggests that those with poor or fair health and who injected drugs were less likely to belong to the group of those who intended to return to work.

Table VI-8

Omnibus Tests of Model Coefficients

		χ^2	df
Step 1			
	Length of unemployment	4.73*	1
Step 3			
	Self-reported health	7.42*	2
Step 4			
	Injecting illegal drugs	4.62*	1

Note. * p < .05 ** p < .01*** p < .001

Table VI-9

Summary of Logistic Regression Analysis Predicting Return to Work among Retired Participants Who Intended to Return to Work (n = 121).

Predictor	*B (S.E.)*	Wald χ^2	Odds Ratio	95% C.I. for Odds Ratio	
				Lower	Upper
Constant	0.89 (0.64)	1.95	2.44		
Length of unemployment (years)	-0.09 (0.05)	3.68	0.91	0.83	1.01
Perceived health (Reference category: Excellent)					
Poor/Fair	-1.71 (0.67)	6.52*	0.18	0.05	0.67
Good	-0.40 (0.55)	0.55	0.67	0.23	0.67
Use of illegal drugs (Reference category: Never used)	-0.98	4.53*	0.38	0.15	0.93

Predictor	*B (S.E.)*	Wald χ^2	Odds Ratio	95% C.I. for Odds Ratio	
				Lower	Upper
	(0.46)				

Note. * $p < .05$ ** $p < .01$*** $p < .001$

Reference category: Retired does not return to work.

Discussion

This chapter set out to explore whether two subgroups of PLWHA who intended to return to work – those unemployed and those retired or not working – showed characteristics of advantage or disadvantage compared to respondents with similar employment status but who did not intend to return to work. The analyses aimed to understand whether there was a contrast between the need to return to work, for example because of financial reasons, and the capability to return to work based on health and other converting factors.

No specific advantage or disadvantage was identified among unemployed individuals in relation to health characteristics, beliefs, use of illegal drugs, and demographic characteristics. Among the socioeconomic characteristics, unemployed PLWHA who intended to return to work showed to be unemployed for a shorter period of time compared to those who did not intend to return to work. Among retired participants, two elements of advantage emerged among those who intended to return to work compared to those who did not intend to return to work. These were the fact of reporting better health status and not injecting illegal drugs. These results confirm the findings of previous literature that showed that PLWHA who were unemployed for a shorter period of time and who did not inject illegal drugs were more likely to return to work.

Limitations of the study. The HIV Futures V survey was undertaken using a self-selection sampling method, which entails that there sample is prone to a self-selection bias, that is to the risk that the sample is not representative of the population being studied, or exaggerates some particular finding from the study. Differences may exist between those who volunteered and those who refused participation in the survey which are difficult to predict and quantify. Therefore, it is important to stress that this study's findings may not be generalisable to the wider population of PLWHA in Australia.

CHAPTER VII

EXPLORING THE PERCEPTION OF OPPORTUNITIES IN PEOPLE LIVING WITH HIV

Differently from the three previous quantitative chapters, this does not attempt to empirically apply the fourfold typology of experiences of opportunities. It reports the findings of a qualitative study aimed at checking whether the information collected through semi-structured interviews with a sample of people living with HIV/AIDS (PLWHA) suggested topics and questions that could not be accounted for using the threefold model of opportunity perception suggested in Chapter III. In such a case, the threefold model would need to be expanded or adjusted. This aim was pursued by exploring the cognitive and social factors that hindered or facilitated the study participants' perceptions of opportunities in their everyday life.

The analyses are based on a series of 29 semi-structured interviews that were conducted with PLWHA who resided in the inner suburbs of Sydney, the outer suburbs of Sydney and regional areas in New South Wales, Australia (Wollongong, Byron Bay, Blue Mountains).

Method

Sample's characteristics and sampling strategy

The participants in the research included 29 people living with HIV of which 26 were men and 3 were women. They were all Caucasians. Four interviewees were between 29 and 35 years old, nineteen were between 35 and 59, and 6 were over 60. The time in which they had been diagnosed with HIV varied from the early eighties to the year 2002. Seventeen respondents were diagnosed between 1983 and 1990. All contracted HIV from having sex with a man.

Participants were recruited from three different geographical locations: urban, suburban and regional areas. Those areas are rated respectively as highly accessible (inner and outer suburbs of Sydney) and accessible (what I have called regional areas) in the Accessibility and Remoteness Index of Australia (ARIA, 2001), which is a geographic measure of remoteness from service centres of populated Australian localities. This choice had a double goal. On the one hand, it was a strategy to implement maximum variation sampling, which implies looking for participants who have a common experience (in this case living with HIV/AIDS), but who vary on as wide a variety of demographic characteristics as possible (Crabtree & Miller, 1999). This strategy is particularly relevant when researchers intend to "obtain the broadest range of information and perspectives on the subject of study" (p. 39) to challenge their own preconceived views and to develop understanding of the studied phenomenon. On the other hand, it allowed me to investigate whether respondents living in different geographical locations reported different experiences in terms of hindrances and facilitators of opportunities in their everyday life. Considering the scarcity of research on different experiences of PLWHA residing in different geographical locations in Australia (see Chapter I), this seemed an important question to explore.

Ethics approval and recruitment

The research received ethics approval from both the Australian National University's and the La Trobe University's ethics committees. Participants were recruited following a purposive sampling strategy through the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University in Melbourne. The ARCSHS has a list of PLWHA who gave them permission to be contacted in order to check their availability to volunteer as respondents for new social research projects. Therefore, a letter detailing the nature of the study (see Appendix 11) and one

introducing myself (see Appendix 12) were firstly sent by the staff of ARCSHS to thirty people who were living in the inner suburbs of Sydney, thirty people who were living in the outer suburbs of Sydney and thirty people who were living in regional areas. After that first turn of letters staff of ARCSHS contacted by phone those potential interviewees in order to answer any question and invite participation. Eventually, 10 people from every geographical area agreed to take part in the study. The refusal rate was about 66%. Consequently, I was passed the contact details of those who agreed to take part in the study in order to contact them personally and organize the interviews.

I was able to carry out all of the interviews exception for one. An interviewee of the inner suburbs of Sydney, in fact, was not able to attend his interview. After that he withdrew from the study. The eventual sample consisted of twenty nine people.

The interviews were all tape-recorded and they were carried out between March and June 2005. All the interviews, except for three, were conducted in institutional settings. Considering that the sample was taken from three subpopulations, this choice allowed me to reduce the quantity of travel involved in conducting the interviews.

I carried out most of the interviews with people living in the inner and outer suburbs of Sydney in the premises of the AIDS Council of New South Wales (ACON). I used the ACON premises also for the interviews in Wollongong. I used the premises of the “Clinic 145” at Tweed Heads and of the Community & Cultural Centre at Byron Bay for the interviews in the Byron Bay area. Finally, I used the premises of the Blue Mountains Sexual Health Clinic in Katoomba for my interviews in the Blue Mountains. The three interviews that were not carried out in institutional premises were carried out at the house of the interviewees due to the lack of alternatives.

At the beginning of each interview the topic of the interview and the content of the ethics form were explained. A copy of the informed consent form (see Appendix 13)

was signed and returned to me and a copy was kept by each respondent for his or her personal record (see Appendix 14). Each interview took on average one hour.

Interview schedule

The data were collected by interviewing respondents using a semi-structured interview schedule. This made possible the adaptation of the interview schedule to the particular set of experiences of opportunities of each interviewee. The interview schedule, as presented below, may appear a bit rigid. However, the discussion below only aims at showing the way in which questions were constructed and linked to the topics being investigated. During the interviews the questions were not necessarily asked following the order presented below (see Appendix 15 for the full list), but rather following the natural development of the conversation.

The interview questions were constructed following the algorithm "research questions → theory-questions → interview-questions" suggested by Wengraf (Wengraf, 2001). This approach addresses the question of the operationalisation of concepts in qualitative research (Wengraf, 2001). It points out the necessity of clearly linking the informant questions to the concepts and research questions that they try to answer. In a nutshell, this approach suggests firstly defining the main research questions behind the study. Second, it suggests spelling out the research questions in several 'theory questions' which the researcher wants the interviewees to help answer. Theory questions may sometime coincide with the research questions. The difference between these two expressions is that theory-questions should be expressed using concepts and relationships typical of the research community, so in 'theory-language'. Research questions can also be expressed in theory-language; however, sometime they set wider goals, which need then to be broken down into more specific theory-questions. The most important distinction in Wengraf's (2001) model is the distinction between theory-

questions and interview-questions. These latter ones must be written in the language of the interviewees. For each theory-question researchers need to develop suitable sets of interview-questions.

The main and subsidiary research questions behind this qualitative investigation were:

1) Can the proposed threefold model of people's perception of opportunities account for all of the factors that the study participants reported as affecting their opportunities?
2) Were there differences in the factors that helped or hindered opportunities among PLWHA living in different geographical locations?

I spelled out these three research questions in the following two theory questions:

1) What are the most valued functionings in the respondents' everyday life?
2) What social, cognitive and emotional factors helped and what hindered the study participants' perception of valued opportunities?

Finally, I wrote a few informant questions through which I aimed at collecting interview material relevant to answering both research and theory questions.

First theory question. The first theory question aimed at eliciting the respondents' most important daily activities and goals. This was done in order to create a common benchmark for the elicitation of the respondents' perception of opportunities. In Chapter II, I mentioned that an open question in the debate around the operationalisation of the capability approach concerns the identification of valued capabilities. From a methodological point of view, relevant information on capabilities should be assessed in a way that is relatively complete and sensitive to diversity (Alkire,

2002). In order to address these questions, I referred to the concept of ‘personal strivings’ (Emmons, 1986, 1999; Emmons & King, 1988), namely the goals that people typically try to achieve in their everyday life. The interviewees’ personal strivings were elicited through the following set of informant questions (see Appendix 15 for the full list).

The first and second informant questions (1: Can you tell me about the time that you first found out that you were HIV+? both in terms of when and the circumstances around it? 2: What thoughts stood out for you at that time? What was it like to discover that you were HIV+?) asked the respondents to tell me about their experience of finding out they were HIV+. Those questions aimed at collecting information on the particular circumstances of each interviewee at the time they were diagnosed. They were also intended to provide a bit of background information on which to start the interview.

The third and fourth informant questions (3: Can you tell me what you have been spending your time doing in the past week and what you plan to do this weekend. [How did you spend last Monday, Tuesday, Wednesday….] 4: Was this a typical week for you?) asked the interviewees to detail their daily activities in a typical week. The aim of those questions was to collect information on the routine activities of the interviewees and, therefore, to introduce the questions on personal strivings.

The fifth, sixth and seventh informant questions (5: Can you tell me what are the objectives, the goals that you characteristically try or hope to achieve in your daily behaviour? 6: Can you give me any examples of things that you find yourself thinking a great deal about? 7: What are the most important things for you at the moment?) were all prompts that Emmons (1999) suggests lead to the elicitation of personal strivings. They aimed at eliciting people’s most valued everyday functionings.

Second theory question. The second theory question aimed at identifying the factors that made the respondents perceive the opportunities to pursue their personal strivings as non reachable or desirable. The following group of informant questions were developed to this end.

The eight informant question (8: Can you tell me about your experiences of pursuing your goals in your everyday life?) explicitly asked interviewees to express their experiences with regard to the pursuit of their personal strivings.

The ninth, tenth and eleventh informant questions (9: Can you give me any example of an occasion when you found yourself thinking that you could not pursue a certain goal or plan? 10: What were the issues at the time that made you think that? 11: Is there anything that you find yourself thinking a great deal about and that you would like to do or achieve, but must do without because you think that you cannot do it?) all aimed at collecting information on people's negative experiences associated with the pursuit of their goals. If the respondents did not mention HIV, then I explicitly asked them to tell me about an episode where a certain goal was not reachable because of the implications of being HIV+. These questions were intended to elicit episodes of failed opportunities.

The twelfth and thirteenth informant questions (12: Can you give any example of a situation where, on the contrary, you felt that you had a chance to achieve a certain goal? 13: What were the issues at the time that made you think that?) aimed at collecting information on people's successful experiences with pursuing their goals. If the respondents did not mention HIV, then I explicitly asked them to tell me about an episode where a certain goal was not reachable because of the implications of being HIV+. These questions were intended to elicit episodes of successful opportunities.

The fourteenth informant question (14: Sometimes after people find out that they are HIV positive they change the goals that they try to pursue with their everyday behaviours, sometimes they don't. What is the case with you?) aimed at assessing whether respondents experienced a change in their most valued functionings after they found out to be HIV+.

The fifteenth informant question (15: Can you give me example of any aspect of your life in which you felt that being HIV + worked to your advantage?) aimed at assessing whether a change that people valued positively occurred in people's capability set after they found out to be HIV+.

The sixteenth and seventeenth informant questions (16: How do you think things could be at this stage if you were not HIV+? 17: How do you think they could have been worse?) were two counterfactual questions aimed at exploring the perception of losses and gains in the respondents' capability set.

Finally, three more questions were asked to further explore and prompt the investigation of the factors affecting people's perception of opportunities: What incidents related to your experience of being HIV+ stands out for you? Do you feel that you have shared with me everything that is significant with regard to the way you experience opportunities in your daily life? Is there any other question that you would have liked me to ask you to better understand the way you perceive your opportunities in your daily life?

Analytical strategies

The full text of each interview was transcribed by professional transcribers. The data analysis was carried out using thematic analysis (Braun & Clarke, 2006), which is "a method for identifying, analysing and reporting patterns (themes) within data" (p. 79). This method is not tied to any specific theoretical and epistemological position

(Braun & Clarke, 2006). In fact, identifying and analysing themes in qualitative data is a process performed within the vast majority of qualitative methods (G. W. Ryan & Bernard, 2000). Alternative analytical methods, in particular grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990), interpretative phenomenological analysis (e.g. J. A. Smith, Flowers, & Larkin, 2009), Schütz's phenomenological sociology (e.g. Schütz, 1962a, 1962d), and discourse analysis (Gee, 2005) were taken into consideration, but rejected on the ground that they added a layer of complexity to the exploration of the data without any evident advantage in relation to answering the research questions. I now briefly discuss the main reasons that led me to decide not to engage with these methods.

Grounded theory was developed in the 1960s by two sociologists, Anselm Strauss and Barney Glaser (1967); it is a method that is used to generate theories through the analysis of qualitative data. One of the major methodological assumptions of grounded theory is that the data collection and the data analysis phases proceed simultaneously in the research process (Glaser & Strauss, 1967). Consequently, the analytical work begins very early during the data collection phase, so that the developing theory can guide further data collection by both 'theoretical sampling' and theoretical questions in interviews. Theoretical sampling is the sampling technique adopted in grounded theory (Glaser & Strauss, 1967). It consists of various stages; it starts with 'open sampling', which resembles 'maximum variation sampling', however it pretty quickly moves to other phases, for example 'relational and variational sampling', which are guided by the coding of the data (Crabtree & Miller, 1999). These further phases imply that researchers analyse their data and decide what data to collect next. This emphasis on early coding, theoretical development, and sampling could have caused the development of too narrow a theoretical focus too early in this study and also the development of a theory which applied to a very specific sub sample of PLWHA.

The aim of this study is to identify factors that helped or hindered the perception of everyday life opportunities across PLWHA, not to develop a theory of opportunity perception that applied to a specific group of PLWHA. Consequently, grounded theory was excluded.

Interpretative phenomenological analysis was first proposed by Smith (1996) and it then rapidly grew in popularity within psychology (Landridge, 2007; J. A. Smith, et al., 2009). As a phenomenological approach, it focuses on the investigation of the life world of the study participants. However, it is characterised by the fact of sharing with cognitive psychology an interest in the investigation of mental processes (J. A. Smith, et al., 2009). This attempt to bridge a cognitive interest on mental processes and the exploration of the life-world has been criticised as theoretically untenable (Landridge, 2007). From a methodological point of view, it uses 'purposive sampling', which entails recruiting a small number of participants who share common characteristics (J. A. Smith, et al., 2009). The theoretical contradictory nature of this approach and its sampling technique discouraged me to use it to address the research questions of this study.

With regard to Schütz's phenomenological sociology, it has hardly ever being applied empirically in qualitative studies (Muzzetto, 1997). Although the investigation of its consequences at the level of data collection and data analysis is indeed an area ripe for both theoretical and methodological development, it did not seem appropriate to engage with such a specific task in this context, because it goes beyond the focus of this study.

Finally, discourse analysis, which developed from linguistic studies (e.g. Austin, 1962), is the study of language-in-use (Gee, 2005). There are different approaches to discourse analysis, for example some focus on the content of the issues discussed in a

conversation or a newspaper article (Gee, 2005), others focus on the structure of language (its grammar) and how it functions to make meanings in specific contexts. However, overall, the main aim of discourse analysis is to explore how certain categories are constructed through people's language, rather than on underlying cognitive or meaning-making processes (Verkuyten, 2005). The focus of this study was not on how opportunities were constructed in the respondents' language or on how hindrances and facilitators to opportunities were represented in their answers, so discourse analysis did not seem a relevant method to answer this study's research questions.

In order to keep the data analysis as open as possible to all of the information contained in the interviewees' answers, the following procedure was followed; the data was coded and analysed using the software for qualitative research NVIVO version 2.0:

1) The transcripts of the interviews were read in full in order to obtain an overall picture of the contents;

2) Statements that expressed ideas related to the phenomena being studied were coded, namely highlighted and stored as retrievable text in a code (i.e. category) created in NVIVO. Each code expressed a distinct idea related to the research questions. Some of the codes were created on the basis of the categories suggested in Chapter 3. Examples are the codes 'self efficacy belief', 'social support', and 'motivation'.

3) An analyses of the extracted statements contained in each code was carried out. The meaning of the statements was determined by referring to the original words used by the interviewees and the further descriptions they provided of the same questions;

4) Repeated ideas, namely ideas expressed by one or more research participants, were identified and listed in new codes.

5) Groups of repeated ideas that expressed a common topic were identified and themes were formulated on the basis of those common topics. In this study five themes were identified;

6) Finally, it was checked whether the experiences reported by the study participants regarding the hindering or facilitating factors could be accounted for by the categories of the threefold model of opportunity perceptions. Alternative explanations were sought and evaluated.

Results

The interviews proceeded as expected and all of the respondents were able to answers all of the interview questions. The counterfactual questions helped with the elicitation of the perceived availability of opportunities of people own making. The respondents primarily engaged in upward counterfactual thinking, namely about how things could be better. By doing so they revealed some opportunities that they do not perceive as any longer available to them because of their HIV status. When prompted to generate downward counterfactual thoughts, namely to think of how things could be worse compared to their current situation, most of the interviewees simply answered: “I could be dead”.

A couple of respondents expressed surprise at question: “15: Can you give me an example of any aspect of your life in which you felt that being HIV+ worked to your advantage?”. In both cases the reason for the surprise was due to the fact that the interviewees never thought of their condition from that point of view before, since they

could not think at any advantage connected to their illness. This did not disrupt or alter the course of the interview. Consequently, the questions were kept.

The analysis of the interviews led to the identification of five main themes that arose directly as a consequence of contracting HIV/AIDS. Each theme represents a factor that affected the interviewees' perceptions of the availability, achievability or saliency of opportunities:

- HIV/AIDS status;
- Contracted time perspectives;
- Personal resources;
- Financial constraints;
- Empowerment.

These themes concerned all of the respondents, regardless of their age, gender and geographical location. They indicated factors that had a very comprehensive effect on the respondents' perception of opportunities. In particular, the areas of people's experiences and perceptions that were affected by these factors could be accounted for by the three categories, availability, achievability, and saliency, suggested in Chapter III.

Before I turn to the discussion of each single theme, I want to specify the way in which I will introduce the interviewees' quotations. I will match each quotation with the pseudonym of the respondent who did it, which will be followed, within parentheses, by some relevant information such as age, gender, year of diagnosis and geographical location. In particular, the information on geographical location will have the following shorthand: IS stands for "inner suburb of Sydney", OS stands for "outer suburb of Sydney", and RA stands for "regional area". So for example, the shorthand "Oscar (47-

m-1989-OS)" denotes Oscar, a 47 year-old male who was diagnosed in 1989 and lives in the outer suburbs of Sydney.

HIV status and opportunity perception

As pointed out in Chapter III, it is important to distinguish between opportunities generated by the social system and opportunities that are of people's own making.

Opportunities created by the social system. Respondents considered their HIV status as a crucial factor affecting the availability of opportunities only in limited cases. The interview questions through which I was able to assess the role of HIV with regard to the perception of the availability of opportunities were those worded as counterfactuals, such as: "How do you think things could be at this stage if you were not HIV+?" When answering this question people engaged in upward counterfactual thinking, about how things could be better. Consequently, I also prompted them to engage in downward counterfactuals by asking: "How do you think things could be worse?" The answer to that question was often: "I could be dead".

Regardless of their current state of health, respondents mentioned some opportunities generated by the social system that they perceived as no longer available to them:

1) Pursuing job opportunities in case of disclosure (15 interviewees mentioned it);
2) Travelling abroad to the USA (7 interviewees mentioned it);and
3) Pursuing certain professions, such as registered nurse (3 interviewees mentioned it);

The first opportunity was mentioned by more study participants. The law of most western countries protects the right of the worker not to disclose his or her HIV

status. However, 15 interviewees mentioned that they feared that the disclosure of their HIV status would immediately affect their availability of job opportunities. For example, Jaime (29-m-2002-RA) expressed that fear in the following way:

> Employers would be reticent to employ somebody like me […] because people with HIV would be seen as a liability, sick leave, if something happens and they want to sack you, you could turn around and say discrimination and that sort of stuff so…

Evidently, Jaime thought that the disclosure of his HIV status would immediately decrease the availability of his employment opportunities. This was a typical example of the stigma that the study participants felt attached to be HIV+. It is relevant to distinguish here between the concept of 'enacted stigma' and 'felt stigma' (Scambler, 2004). The concept of enacted stigma refers to episodes of discrimination experienced by the study participants on the grounds of the negative stereotypical views of being HIV+. The concept of felt stigma can refer to both the shame associated with being HIV+ and the fear of encountering enacted stigma, as in Jaime's interview extract. Whilst some study participants reported episodes of enacted stigma, the vast majority talked of their felt stigma. Felt stigma and enacted stigma are both powerful hindrances that can affect the availability of opportunities in PLWHA.

The second mentioned opportunity was an example of a not normatively available opportunity to the interviewees. In fact, people living with HIV cannot legally enter the USA unless they obtain special permission from the US embassy. However, interviewees were aware that the vast majority of countries do not put any restrictions on the entrance of PLWHA. In these cases, even though the opportunity to travel abroad was perceived as available, very often the respondents experienced problems with regards to either its achievability or saliency. Financial constraints, for example, were a factor that affected the achievability of a holiday abroad for three of the 7 interviewees

that mentioned this question. For those interviewees the opportunity to travel abroad was available, but not achievable.

Another factor affecting the achievability of travels abroad were the worries and fears that they raised in some of the respondents. In this case, respondents did not think that travelling abroad was something they could achieve because of either low self-efficacy belief or health problems. For example, Luke (59-1985-OS) summarised these worries and fears in the following way:

> You know, there is a possibility that I suppose I could get stuck in another country, having medical treatment there. And then there's complications with life insurance and stuff like that.

With regard to the third opportunity, namely pursuing certain professions, it is important to discriminate the fear of the respondents of disclosure, which affected the saliency of opportunities, from cases in which job opportunities were normatively not available to them because of the current legislation. In the first case, job opportunities were normatively available to them, because, for example, being HIV negative was not considered as a health requirement for it. However, the fear of disclosure led some study participants to renounce available opportunities. For example, Amanda (46-f-1990-OS), while talking of her job hunting for assistant nurse positions, commented:

> One of them [of her colleagues] was telling me that they do a blood test, and that's when - I actually didn't go for the job then because of the medical test, 'cause I don't know actually what's involved, and that sort of pulls me away because I'm terrified of someone finding out.

Amanda did not know whether the blood test was for testing HIV and whether being HIV negative was a requirement for that particular position. However, her fear of disclosure and felt stigma led her to not pursue that job opportunity.

In summary, the analysis revealed that the interviewees reported a limited number of opportunities generated by the social system that they perceived as not any longer available to them. Some of those opportunities were not any longer available because of specific legislation on the rights and duties of PLWHA, some because of the interviewees' perception. I will now proceed to analyse the impact of living with HIV on the opportunities of people's own making.

Opportunities of people's own making. In Chapter III, it was mentioned that, in relation to opportunities of people's own making, the concept of availability referred to the thinkability of the projects being considered. Taboos were given as an example. The interviewees quoted a number of opportunities of their own making which they perceived as no longer available to them explicitly because of their HIV status. The most recurrent ones were:

- finding a partner;
- creating a family, either gay or heterosexual, and having children (continuing the bloodline).

With regard to the first opportunity, it was the belief that no one would be willing to engage in a long term relationship with an HIV positive person that determined its unavailability. In this case too, the strength of the felt stigma was evident. For example, Larry (m[1]-1983-IS) expressed that belief in the following way:

> Most of my partners have been HIV negative and I'd come to the realisation that nobody is ever going to enter a relationship with somebody who's HIV positive with any kind of long term plans, so…

William (53-m-1998-RA) with regard to this said:

[1] The age of this participant was a missing data.

> I don't think anyone would be taking me on at this late stage of my life, in terms of just stability or future stability for a family, for example.

With regard to the second opportunity, namely that of creating a family, Dylan (38-m-1993-IS) said:

> My health status has been fortunately very good so apart from the pills and the routine of that and dealing with side effects and so on and so forth, I don't think it's made [referring to his HIV status] any major decisions in the way I conduct my life, other than that I can't have children.

Similarly, William (53-m-1998-RA) commented:

> I would have loved to have had a family, kids, you know, like a lot of people think gay guys are not interested in having children, but I think that's a goal for everybody and as you get older you start thinking about that more often and then start to realise it's not going to happen … I think I would be a good parent, but I could not be a parent in the traditional sense on bloodlines and that was something that I remember thinking; because of HIV I will never be able to do that.

To sum up, the analysis of the interviews showed that HIV status affected the availability of a limited number of both opportunities generated by the social system and of people's own making. However, although the respondents mentioned only two opportunities of their own making as affected by their HIV status, these represented important and valued functionings.

The availability of the vast majority of the opportunities in the respondents' everyday life was considered unaffected by their HIV status. It was the achievability of some of these everyday life opportunities that was a problem for a substantial group of respondents. Opportunity achievability could be affected by several factors. For example, the level of hindrance that HIV generated to people's physical and cognitive

functioning varied in gravity depending on the stage of illness and on whether the interviewees were telling about episodes or phases of their life in which they were physically sick. From this point of view, a research focus on people's physical, cognitive and emotional functioning can be of relevance for the study of opportunities when the interviewees experience an acute phase of the illness. In those cases, impaired health can drastically affect the achievability of many opportunities.

However, the analysis also revealed many other factors that heavily affected the participants' perception of their opportunities regardless of their current state of health and impairment. I will now turn to a discussion of those factors.

Contracted time perspective

After knowing they were HIV positive, all of the respondents initially experienced a substantial change in time perspective. Such a change consisted of a constriction of their life expectancy. That belief changed because the thought of death, which usually remains untopical and is not a factor which adults generally account for in planning their goals, suddenly became a topical, crucial issue in their life. The analysis revealed that interviewees who were diagnosed as HIV positive in the 1980s, and anyhow before the introduction in 1996 of Highly Active Antiretroviral Therapy, experienced a major time contraction of their expected life span. For example, Jackson (59-m-1985-RA) said:

> You know, I thought, everybody thought, well, two years is about as much as, you'd be lucky live, two years".

Omar (47-m-1989-OS) told:

> I just didn't see that I was going to live any more than 12 months or 18 months.

Especially for people who were diagnosed at the beginning of the epidemic, that belief did not have its origin in the medical knowledge about the illness, but it

developed in the particular context of fear that surrounded HIV in those early years. For example, when asked about the source of his belief that his death was imminent, Omar-(47-m-1989-OS) said:

> I1: And that temporal framework was set by the doctor or by you?
>
> R: Just by what I - no, not by doctors. Ah - but from what you hear in papers and that, and just the - the Grim Reaper[2] was around and all those ads, and anybody who got it would ultimately die.

When prompted on the same topic, Andrew (43-m-1989-RA) said:

> I1: You told me before that you consider it a sort of death sentence, was that because the doctor told you that or was just your knowledge or - - -
>
> R: My know… from what was around me at that time; Sydney was quite like a lot of people around that were really sick and dying, people were dying, would find out and they would die within a month. I mean I know that's from the mind and the way that they thought about stuff, but it was just people were just seeming to be, you know, dropping off like flies. Yep.

The experience of a contracted life span perspective, however, did not last forever, it only characterised some years of the interviewees' life after they found out they were HIV positive. That perception, in fact, mutated with time and generated a different theme, which I discuss below.

Opportunity untopicality. The time frame contraction affected people's perception of both availability and saliency of opportunities. Time frame contraction led the respondents to a loss of interest in opportunities that implied a commitment to long term goals. From this point of view, opportunities were perceived as unavailable if their outcomes could only be appreciated in the long term. However, time frame contraction also affected the saliency of the opportunities to pursue. In the most extreme cases, they

[2] Referring to death.

thought: “what’s the point of starting to do anything?”, which made less relevant not only long term goals and opportunities, but also short term ones. For example, Omar (47-m-1989-OS) said:

> Yeah, when I was ah - up until I got diagnosed, I always had plans. I used to set ten year plans, five year plans, two year plans, and always achieved them. But when I got diagnosed, I stopped planning because I wasn't gonna be around, I'll be dead, so why worry about it? You know, just live every day as it comes”.

Likewise, Timothy (33-m-2000-IS) responded to this question:

> I1: Do you find that the way in which you set your goals and priorities now is different compared to when you were not HIV positive?
>
> R: Yeah, yeah I don’t it is nothing subconsciously, I don’t... there the sort of great career dreams and stuff like that and that’s now more just getting... its more short term.

The effects of the time frame contraction fell into the coding category knowledge/ignorance taken from the model suggested in Chapter III. There it was pointed out that the perception of the availability of opportunities raised the question of people’s knowledge or ignorance of opportunities. With regard to this, it was mentioned that the investigation of different types of ignorance could help to identify the reasons for which some opportunities might not be perceived as available, achievable or important. To this end, a distinction was suggested between the action of ignoring something, which is an active concept, and being ignorant of something, which is a passive concept (Smithson, 1989). The act of ignoring something consists of stating the irrelevance of some information, event or experience and consists of three phenomena: untopicality, taboo and undecidability (Smithson, 1989). The time frame contraction effects consist of the untopicality of opportunities. Opportunities become untopical

either because they are too far away in time, or because the respondents are focused on the short term, day to day living only.

Opportunity undecidability. Once the respondents overcame the first, most critical phase of the contracted life span perspective experience, they started gaining a new interest in the future and in planning ahead. Alex (49-m-2000- OS) worded his experience with the two phases, the contraction of time perspective and his overcoming of it in the following way:

> I found out in 2000, and I just - my life has just been unchanged for four years. I get up and I socialise, and I do things. But I haven't started anything new; any long term projects. If you like, I consider for the last four years I was like the government. All I'm interested in doing is something that I can do while I'm in government. I couldn't be bothered doing any infrastructure or anything that lasts a long time. You know what I mean? Let's not build a new dam, because I might not be in government. I was like that. Now I'm over that, and that's why I've moved into this house project [he had started re-developing his own house], 'cause it will be a long project. It will be two or three years before it's all done.

However, the respondents' newly acquired interest in the future was constantly threatened by the uncertainties related to their health situation. Luke (59-m-1985-OS) expressed this uncertainty in the following way:

> R: I find it difficult to make decisions a lot of the time.
>
> I: About [buying] a new car or in general?
>
> R: In general, particularly, what causes some of the difficulties is the concept of future, knowing how long I might need something for or whether it be my money or my car or… you know, it's just a strange foggy future that might go one way or another.

Patrick (38-m-1988-RA) said of the same issue:

> Well, I know I'm fine for 12 months but I can't say I'm going to be fine in five years. It's that sort of thing. I can't make a five or a 10 year plan because I don't know.

This kind of uncertainty was not probabilistic. It rather had a semantic nature; it concerned the fact that things could go one way or the other. The interviewees' health situation could stay stable for yet another long time or they could suddenly experience some new symptoms or develop resistance to their current treatment. This fundamental ambiguity made every decision about commitment towards long term opportunities very difficult to take for the interviewees, since the state of those opportunities, namely whether they were available, achievable or salient, was indeterminate.

Personal resources

The theme of personal resources referred to a broad series of factors, from psychological, e.g. self efficacy believes, to social, e.g. social support and social capital (see Chapter III for a definition of these concepts).

Self efficacy belief acted primarily on the perception of the achievability of opportunities. The most interesting finding with regard to this was the interaction between the theme of the undecidability of opportunities and self efficacy belief. In fact, the fundamental ambiguity that characterised the future of most study participants determined a loss of self efficacy belief regarding their ability to cope with new situations. As Isabelle (32-f-1993-IS) expressed it:

> I think that if I make any changes, is it going to destabilise me. I feel safe and comfortable where I am, so that [HIV status] definitely does impact, yeah, I don't know if I can actually identify exactly what it is, it's just a feeling, you

know you feel safe in the status quo, you know everything is balanced and okay…

With regard to social support, this was experienced mainly from friends, partners or parents. Social support affected primarily the achievability of the respondents' opportunities. It did so in different ways, depending on its kind. For example, it was thanks to the material social support from his network of friends that Nathan (40-m[3]-IS) was able to live in an apartment rent free, go out for dinner, or on holiday more often than he could have afforded. Peter (43-m-1989-RA) was able to buy new clothes thanks to the financial help he received from his godmother.

Practical support did not come only from friends or loved ones, but often also from the network of public services. For example, respondents who lived in the regional area around Byron Bay, who did not own a car and were unable to travel long distances because of their health condition, were able to pick up their treatment drugs from the local chemist instead of the hospital pharmacy, which was far away. After they ordered their treatment drugs in advance by phone from the hospital pharmacy of the city of Lismore, the drugs were delivered to a local chemist close to where they lived in Byron Bay, which was of great help to them. As an another example, both the interviewees who lived in the outskirts of Sydney and the respondents who lived in regional areas used an individual transport service provided by ACON (AIDS Council of New South Wales). This consisted of a driver who could be booked in advance and who could drive the respondents to attend their businesses. The service operated from door to door.

Finally, social support could affect the saliency of opportunities by acting on people's motivations. This was the case, for example, for Oliver (45-m-1986-OS). He started a course at TAFE (Technical and Further Education Institute) thanks to the support he received from a friend. This support acted both on his motivation, therefore

[3] The year of diagnosis was a missing data for this participant.

on the saliency of that opportunity, and also on his self efficacy belief, therefore on his perception of achievability of that goal.

Financial constraints

Financial constraints strongly characterised 17 study participants who lived on a disability pension, particularly those who did not have any other complementary source of income. Financial constraints caused a number of deprivations in the life of these respondents. Two were particularly discussed in their answers: limitations to their social life and its consequences on access to therapies and health care. The impact of financial constraints on the respondents' social life manifested as the inability to socialise with friends, for example by inviting them for a meal or a drink. The impact on their access to health care services manifested in the need to change one's specialist or general practitioner because they started charging patients[4]. For the respondents who were on a disability pension, the cost of treatment drugs had a significant impact on their budget. The cost of the HIV-related drugs is subsidised in Australia and most of the interviewees did not find paying for the drugs an insurmountable obstacle. However, the cost of the drugs was quite high in cases such as that of Peter (34-m-1991-RA):

> During the year, the first part of the year mum has to use her money as well to make up my share of the rent, the bills that I can't afford to pay because I'm paying $50, $60 a pension cheque on medication. When I reach my safety net I try and put in a bit more to help her out. I mean, she's had to do it so many times. She knows how much money I have to go through, you know, to get my drugs and she's quite understanding.

[4] In Australia doctors can either charge the patient for the visit or charge the State. In the first instance it is the patient that will have to apply for a partial refund of the cost of the visit. In the second case, doctors will have to wait the processing of their bills by the competent office. More and more doctors are abandoning the system of charging the State, known as 'bulk billing', and ask their patients to pay for their visits.

So, social support and financial support were fundamental in this case in order to be able to afford the medicines. Social support and financial support were mentioned also by other respondents as important factors in order to overcome the financial difficulties associated with living on the very limited income of the disability pension. Most of the interviewees who had the pension as the only source of income received help from charity foundations such as the Bobby Goldsmith Foundation or other institutions such as the Community Support Network. These institutions paid half of some bills, for example the power and the gas bills, as well as the cost of the telephone rental. Reliance on support from charities did not appear to differ among urban, regional and rural respondents.

Empowerment

A definition of empowerment was given in Chapter II. In this context it is intended as the possibility to have an active role and control in the management of one's treatment. This theme synthesised the non pragmatic issues related to the respondents' experiences of accessibility of health care services. Pragmatic issues were mostly related to the respondents' lifestyle characteristics. For example, whether respondents worked or were retired (usually on a disability pension). All those respondents who were in a full time job find the opening hours of the hospital pharmacy very inconvenient. For example, with regard to this Edward (50-m-1985-IS) said:

> getting access to my drugs, even now, is difficult because I have to take time off work to go to a Hospital Pharmacy, you can't get my drugs through a normal Pharmacy ....

Alex (49-m-2000-OS) similarly said:

R: There's certainly no problem getting the prescriptions from the doctor. The trouble is getting the drugs. You have to get the drugs from the pharmacy at the hospital; the hospital has very restricted hours.

I: Which day of the week and what time?

R: Well, you can only get them Monday to Friday, and you can only pick them up between 8.30 and five.

I: Which are your working hours?

R: Which are my working hours, and it's a pain

Amanda (46-f-1990-OS) pointed out the same problem:

'Cause that stupid time schedule again at the pharmacy. It could be the day where I can't go there on Thursday because I've booked a shift, but I can't cancel a shift because it's not the right thing to do at work. You just can't cancel shifts, it's not polite to do that. But my health's more important too, but stupid me not realizing.

None of the respondents who lived in regional areas reported this problem. The reason why is that none of them were working full time at the time I carried out my interviews.

However, access to health care was not conditioned only by pragmatic issues raised thus far. Two other groups of factors were identified. The first group concerned the relationship between the interviewees and the health clinic. The second group concerned the relationship between the respondents and third parties.

The first group consists of two components:

1) People’s trust in the doctors at the centre;

2) People’s perception of their own involvement in the treatment or therapy.

Respondents seemed to prefer clinics in which there were doctors who they felt they could trust and with whom they felt they could “work together”. For example, Max (57-m-1983-RA) had to drive about 35 minutes to reach the health centre from where he picked up his treatment drugs and where he carried out his regular health check-ups. It is worth quoting in full the following passage of his interview, where he expressed his point of view on the question of the balance between distance to travel and his sense of trust and relationship with the doctors of the health centre that he was attending.

> R: It's a fair way to go, there are alternatives. I could come here which is a lot closer [referring to the clinic where the interview took place], but I'm just happy with the treatment I'm getting there and the people that I'm seeing there, so, I'm quite happy with that.
>
> I: So what are the aspects of the service that you value most when you choose one health clinic rather than another?
>
> R: Ah, the quality and the personality of the doctor.
>
> I: Can you expand a bit on what you mean by quality please?
>
> R: Ah, well, the amount of faith or trust that I have in the doctor's knowledge and his ability to use the knowledge and the way that he imparts that knowledge.
>
> I: So when you told about your doctor’s ability to apply his knowledge, can you give me an example of what you mean?
>
> R: Yeah, his ability to explain to me why he would recommend a course of treatment and his willingness to explain rather than to just say, this is what you will do. I'd like to be able to consult rather than be told.

Similarly, Oscar-47-m-1989-OS, said:

> I could go to […] which is a lot closer. But, because of the people that I know at […] and the time that I've been dealing with them, and the shortcuts that I can get around, it's so much nicer to go to people that you know and you've got a

> rapport with, and try to develop those things again. And all the notes are there. The other reason is that when I had the back problems with the spinal fusion, they were able to pull up all my notes from that. If I go to any hospital now, because of all this stuff that's in me electronically for my back on legs - people have never seen it. They have only been four or five people in Australia that's had that operation done to them…

William (53-m-1998-RA) travelled to Sydney from a regional area of the New South Wales. It was more than one hour drive. He said about this:

> There's a local STD clinic which is run by the local hospital at […] Hospital. I would go there but again I don't particularly like the doctors. There's a younger doctor there now who isn't as experienced. I don't particularly like the nurses and I don't particularly like the clinical counsellors that they've got there either.

In all the above cases the interviewees do not choose the closest health clinics to them. They stuck to their current ones because they had a good relationship with their doctors. A relationship based on trust and on good communication was clearly important to them.

The second group of factors that I mentioned did not concern the relationship of the respondents with the staff and doctors of the medical centre, but with third parties who were relevant to them. The prospect of involuntary disclosure and socially awkward encounters was a criterion that influenced the participants' choice of which clinic to attend. For example, Isabelle (32-f-1993-OS) expressed this point in the following way:

> Well I still have the fact that I've got to travel in the city to get my drugs, to see my Doctor, when ideally I would be going to the public hospital that's closer to home, but because I work along with my health services etc. and I have

> colleagues, by virtue of the fact that I have interdisciplinary meetings etc. with clients, that I could actually run into someone, that's why I've chosen at this point in time to separate the two, so it's not the most ideal or the most convenient way of having the services but at the moment I feel, I guess it's important to me.

In this case, despite the fact that from a pragmatic point of view the public hospital is evidently closer, therefore more accessible, Isabelle did not consider that clinic as an accessible option for her. The reason for this was that she feared that going to that hospital might expose her to the risk of involuntary disclosure of her HIV status. Similarly, Patrick (38-m-1988-RA), in the context of telling me about his problems for having his denture fixed, said:

> They were going to send me to […] for the specialist dentist to deal with the HIV. I said, "No, I can't go to […] ". They said, "Why?" I said, "I have five family members work at […] , three of them surgical", and I said, "They don't know my status and I'm not going to have it them find out that (a) I'm in hospital and (b) I'm positive".

The fear of involuntary and unwanted disclosure leads Patrick too to reject a first, geographically closer clinic for his denture needs.

How shall we word questions about opportunities?

As part of the interview process, I asked the interviewees to answer the following question in writing: "To what extent do you have the opportunity for leisure activities?", which I took from the WHOQOL-HIV BREF questionnaire (WHO). This is a closed-ended question with the following scale: 1– Not at all; 2 – A little; 3 – Moderately; 4 – Mostly; 5 – Completely. The analysis of the respondents' answers to my question: "what did you think of when you answered this question?", led to a

significant finding. Because of its generality, the WHOQOL-HIV BREF question does not discriminate between whether a respondent's answer refers to the availability or the achievability of opportunities. In fact, most participants answered by referring to the availability of their opportunities, since they thought of the time they had on their hands or the place where they lived. However, their answers did not include the achievability of those opportunities. For example, Harry (47-m-1984-OS) answered the question with a 5 (completely). However, when prompted to comment on the question he said:

> I do (have the opportunity) all the time, but I choose not to, because I am too …, I am too tired.

Similarly, Lucas (39-m-1988-RA), who answers 4, therefore mostly, said:

> Well, I have a lot of time on my hands, so that's what I thought of. I've got plenty of time. 'Cause people I know who work, they're always stressed and they're always anxious and they're always saying, "Oh, I can't do this, can't go there, I've gotta work, I'm really busy, I can't talk now" and hang up. They haven't got a lot of time to do anything. When they do have some time off, you know, they have to clean and wash and shop and cook, and do all those things. So I've got all this time on my hands for leisure activities, but the leisure activities are limited to what's free and doesn't cost any money; you know. I can't get on a plane and go on a holiday and I can't just hire a boat or I can't, you know, decide to go to a concert, or things like that 'cause it all costs money. So I can do things that are free, inexpensive.

When the participants did not provide a very high score on the scale it was often because they factored the achievability of the opportunities into their answers. However, the questionnaire item does not give any clue to understand whether people's score is low because opportunities are unavailable, or because they cannot achieve them. For example, Oscar (47-m-1989-OS) answered 2 (very little), and he commented:

> […] Very little, and I thought that was mainly physical limitations rather than leisure activities, going to pictures or something like that. Yes, I can do it, but it hurts to sit in a movie theatre for a full length of a movie. So, I have the opportunity - I suppose that's probably wrong, 'cause I do have the opportunity. Physically I can't do it. So, it depends on the interpretation of opportunity.

The question of the generality of the WHOQOL-HIV BREF is also related to the fact that it does not provide any anchoring benchmark against which people can make their judgments. Every question that asks people “how much” with regard to any concept, including the concept of opportunity, should explicitly provide the respondents with an anchoring benchmark. If not, people intuitively supply their anchoring benchmarks. As the above reported quotations show, those anchoring benchmarks can be extremely varied.

This finding is important because it shows that one only survey question cannot measure opportunities in a comprehensive way. In the third chapter a few techniques to elicit the availability, the achievability, and the saliency of opportunities were suggested. One common characteristic of those techniques was that the measurement of the availability of opportunities was carried out only at the nominal level. Respondent were asked to list, divide, and order certain relevant opportunities. Other techniques should be investigated that elicit these constructs on a continuum.

Concluding remarks

The analysis of the interviews showed that the threefold model of opportunities perceptions introduced in Chapter III offers a heuristically valid coding scheme for interpreting people’s perception of opportunities. All of the identified factors (in the form of themes) that affected some relevant everyday life opportunities of the study

participants could be traced back to one or more of the three components of the model: availability, achievability, and saliency.

With regard to the specific findings of the study, some of these confirmed previous qualitative research. For example the theme restricted time perspective, which greatly affected the study participants' perception of opportunities (Ezzy, 2000). As pointed out in Chapter three, opportunities, as courses of actions, are experienced in the future past tense. Therefore, they imply the ability to position oneself in the future and look at one's actions as if they were already accomplished. When this ability to think our actions back and forward in time is threatened, then the process of meaning making of opportunities is affected in one of its most fundamental constitutive elements.

The analyses also pointed out that an exclusive focus on the impact of the HIV virus on the physical and cognitive functioning of PLWHA, typical of health-related quality of life research, does not provide a full picture of the impact that living with HIV/AIDS has on people's lives. Other important phenomena, such as the untopicality and undecidability of opportunities, which are linked to the decreased life expectancy or PLWHA, should be taken into consideration.

Finally, these analyses showed the importance of social support, social capital, and empowering factors for the availability, achievability, and saliency of opportunities.

Limitations of the study. In this study I interviewed people who regularly accessed community and health services. In fact, the list of people living with HIV from which the respondents were selected consists of individuals who were involved in many activities related to the research and the social life of PLWHA. Consequently, I did not interview people who were not involved in institutional or social life activities and who might not have had, for this reason, a similar awareness of their rights and duties. This characteristic of the sample – its lack of representation of the entire population of PLWHA – limits the generalisability of the findings. However, the use of the maximum

variance sampling strategy helped to strengthen the confidence that the findings regarding the factors that influenced people's experiences of opportunities can be referred to individuals with different backgrounds.

CHAPTER VIII

CONCLUSIONS

This thesis set out to identify a more inclusive approach to the investigation of quality of life among people living with HIV/AIDS (PLWHA). Such an approach was identified in the capability framework suggested by Amartya Sen (1985a). To this end, the thesis first reviewed the literature on the origin of the concept of quality of life, both in the social and in the medical sciences. Three main characteristics of the concept of quality of life were identified. First, there are two types of definitions of quality of life; one considers this construct as a specific aspect of people's well-being, the other defines it as a measure of advantage. Both types of definitions usually use a gap method to evaluate people's quality of life; this entails measuring the difference between people's current state and an ideal situation. This can be either normatively determined, as in the advantage approach, or defined by people's desires or needs, as in the well-being approach. Second, quality of life has been and can be investigated both by means of subjective and objective indicators, although some approaches in the literature suggest that it only concerns subjective perceptions. Third, the investigation of quality of life in PLWHA consists primarily of health-related quality of life studies, which over-emphasise the role of health as the most important determinant of quality of life. As a consequence, health-related quality of life implies a focus on PLWHA primarily as patients or clinical cases, rather than as social actors with individual, social and economic rights experiencing freedoms and constraints to fulfil valued social roles and achieve desired social statuses.

The above findings were used to introduce and discuss the way in which quality of life was conceptualised in the capability framework, and its core concept, capabilities. With regard to the first point mentioned above, these analyses showed that

in the capability framework quality of life can be conceptualised as representing either a measure of advantage or of well-being. An original definition of quality of life was proposed for each of the two conceptualizations. With regard to the question of whether quality of life should be assessed through subjective or objective indicators, the crucial role of Sen's (1993b, 1994, 2002a) epistemological perspective, 'positional objectivity', was highlighted. This was interpreted as an interpretive approach, which entails that social action has an intentional content that says the kind of action it is and that to understand such an intentional content it is necessary to refer to the system of meanings that generates it (Schwandt, 2000). Consequently, it was proposed that Sen's concept of positional objectivity could be expanded and strengthened by placing it in the more inclusive and developed interpretative framework represented by the phenomenological sociology of Alfred Schütz (1962a, 1972). Such a philosophical approach presented two strengths. First, it offered a well-developed, although not complete, philosophical and theoretical exploration of the main structures and of the mechanisms that govern people's perceptions in their 'world of daily life', i.e. 'life-world' (Schütz, 1962a, 1972; Schütz & Luckmann, 1973). Second, at the epistemological and methodological level, it required exploring and making explicit the model of social actor that underpinned the operationalisation and measurement of the concept of capabilities. In particular, two dimensions were identified in the concept of capabilities: capabilities as opportunities and capabilities as freedoms. The focus of this study was fixed on the first dimension, i.e. capabilities as opportunities. Therefore, the psychological and sociological literature that investigated the mechanisms and meaning-making processes that characterise social actors' perceptions of opportunities in the life-world were explored. These analyses led to the development of a threefold model of opportunity perception – i.e. opportunity availability, opportunity achievability, and opportunity saliency – and a fourfold

typology of experiences of opportunities, i.e. high capability, low capability, availability disadvantage , and achievability disadvantage.

On the basis of the two suggested models, quality of life was defined as a situation of ‘high capability’, with states of lower quality of life represented by three forms of disadvantage: low capability, which is the worse quality of life condition, availability disadvantage, and achievability disadvantage. Through a mixed method concurrent nested design, the two models were applied empirically in three quantitative and one qualitative studies. The quantitative studies consisted of three secondary data analyses undertaken on the HIV Futures V Survey, an Australian national survey on social and clinical aspects of the life PLWHA. The first study evaluated the experiences of the opportunity to enjoy adequate housing among PLWHA; it checked how these experiences distributed in the HIV Futures V sample and compared them to existing, alternative measures of housing conditions. The second study evaluated the relationship between the four experiences of the opportunity to enjoy adequate housing and respectively a measure of material deprivation, poverty, and a measure of subjective well-being. The third study explored whether PLWHA who intended to return to work were in a situation of advantage or disadvantage compared to those who did not intend to return to work. The aim was to explore the relationship between need to return to work and disadvantage. The qualitative study investigated the factors that hindered and facilitated the perception of opportunities in a sample of 29 PLWHA, with a focus on checking the heuristic validity of the threefold model of opportunity perceptions.

This chapter will offer a brief discussion of the quantitative and qualitative findings and summarise the theoretical and methodological implications of the overall study.

Study findings

Comparing the results of the secondary data analysis with the findings of the interviews reveals several similarities, but also some differences. The negative impact of perceived or enacted discrimination on the achievability of opportunities emerged clearly in both analyses. Similarly, the impact of financial deprivation on achievability and availability of opportunities resulted in both studies. The relevance of people's future time perspective was another factor that similarly characterised the qualitative and quantitative analyses. However, the individual interviews revealed some specific cognitive mechanisms, e.g. opportunity untopicality and opportunity undecidability, which were not explored in the quantitative analyses. In the secondary data analysis, physical and mental health were significant predictors of people's experiences of opportunities. In the interviews, health was also reported as an issue significantly affecting people's opportunities, specifically in acute phases or in the late stages of the illness. However, the impact of mental health on people's opportunities was not explored in the individual interviews. Similarly, age, which was a significant predictor in the quantitative analysis, was not explored in the qualitative analyses. The importance of social support both for the achievability and saliency of opportunities was strong in the interviews. However, this variable did not significantly predict people's experiences of the opportunity to enjoy adequate housing.

On the methodological and theoretical level, the qualitative analysis did not produce findings that challenged the three categories of the model of opportunity perceptions: opportunity availability, opportunity achievability, and opportunity saliency. At the same time, the quantitative analyses showed that, compared to complimentary measures, the fourfold model of experiences of opportunity and the

threefold model of opportunity perceptions offered original insights on the housing and job searching experiences of PLWHA.

In the last analysis, triangulating the results from both studies leads us, on the one hand, to confirm that the threefold model of perceived opportunities, which is the basis of the fourfold model, is heuristically valid. On the other hand, it offers a wider perspective on the plurality of factors that can affect people's perception of opportunities. However, there seems to be a set of core factors, in particular socio-economic conditions, health status, and future perspectives that need to be addressed in any studies aimed at investigating opportunities among PLWHA. The relevance of any other factors will have to be decided each time according to the aims and the context being studied.

The theoretical and methodological contributions of these findings will be discussed both in relation to the capability framework and the literature on PLWHA.

Theoretical contributions

From a theoretical point of view, two main contributions can be ascribed to this research project in relation to the capability framework and two in relation to the literature on PLWHA.

With regard to the contribution in relation to the capability framework, first, this study pointed out the need to strengthen the epistemological basis of the capability framework, positional objectivity, which was interpreted as an interpretivist approach. Consequently, the more developed interpretivist framework of Schütz's phenomenological sociology was proposed and used to develop an original operationalisation of the concept of capabilities: a fourfold typology of people's experiences of opportunities. This showed to give an original contribution to the understanding of the housing experiences of PLWHA, both in relation to alternative

measures of housing experiences, i.e. measures of volatility, crowding conditions, and stability, and in relation to measures of subjective well-being and poverty. Second, two original conceptualisations of quality of life were proposed based on the capability framework. One in which quality of life figured as the most comprehensive investigation of people's well-being (see Table II-2), the other which was based on the newly proposed operationalisation of capabilities through the fourfold model of opportunity experiences.

With regard to the literature on PLWHA, this study contributed to the debate on the causal relationship between living in rental properties and lower quality of life and self-reported health outcomes. In particular, it showed that people living in private rental had higher chances to experience a form of disadvantage than high capability compared to people living in their own home or in a purchasing home. Consequently, it suggested that disadvantage could be the relevant mediating factor in the causal relationship between renting and both poor quality of life and self-reported health. Second, the threefold model of opportunity perceptions offered a theoretical framework to undertake investigations on the opportunities of PLWHA to return to work. These types of studies are currently characterised by the fact of stressing the relevance of psycho–social factors in determining the work experiences of PLWHA; however, such factor are empirically identified and no specific theoretical framework is used to explain their occurrence or distribution. The threefold model of opportunity perceptions contributed to that literature by offering a reading of the experiences to return to work of PLWHA in terms of advantage and disadvantage. Therefore, it offered a theoretical framework that allowed identifying social and health inequalities among PLWHA who work and those who don't, but would like to.

Methodological contributions

As for the theoretical aspects of this study, two main methodological contributions can be ascribed to this research project in relation to the capability framework and two in relation to the literature on PLWHA.

With regard to the contribution in relation to the capability framework, first, this study suggested referring to the structural elements of the life-world identified by Schütz to guide the exploration of people's perception of opportunities. Such structures represent frames and concepts that scholars can use in order to clarify the mechanisms and structures that they assume govern the perceptions of social actors in the life-world, with a particular reference to the phenomena being investigated. Second, it discussed direct and indirect methods for the elicitation of the components of the proposed threefold model of opportunity perceptions; both through subjective and objective indicators. The literature on counterfactual thinking was discussed and practical methods to elicit opportunity availability, opportunity achievability, and opportunity saliency were suggested.

With regard to the literature on PLWHA, this study offered an application of the capability framework to the population of PLWHA, which provided an innovative way to evaluate housing experiences in this population. In particular, it conceptualised housing experiences as a complex phenomenon that needs to be investigated through a variety of indicators. Consequently, it offered an in-depth analysis of the housing experiences of PLWHA in Australia which included measures that had not been previously used in studies on housing experiences of PLWHA. For example, apart from the fourfold model of opportunity experiences, an index of crowding conditions.

Future directions

The study of quality of life by means of the elicitation of people's capabilities is a relatively new and promising area of investigation. As I have argued in the thesis, capabilities can and should be assessed through the full range of indicators. In particular, in this work I operationalised capabilities focusing on its meaning as opportunities. A similar investigation would be needed to understand the main components of people's perception of freedom, which is the other way to conceptualise capabilities.

The proposed fourfold model of opportunities should be operationalised using both ad hoc questionnaire items (so subjective measures), and social indicators (so objective statistics). For a systematic test of the proposed models, questionnaires should be developed and then tested for validity and reliability. Once valid and reliable measures of the three components of the perception of opportunities are generated for each relevant life domain, two further goals become important. First, it would be important to study systematically the factors that affect people's perception of opportunities. Second, it would be important to investigate the relationships between people's perception of opportunities and both subjective well-being and psychological well-being. Research has shown that these two cognitive components of people's well-being represent related but distinct constructs (Keyes, Shmotkin, & Ryff, 2002). Large cross cultural studies of perceived opportunities would allow the comparison of groups and countries using a measure that could offer original and valuable information for the understanding of quality of life.

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Appendix 1

The literature review followed a purposive review methodology. It did not intend to systematically retrieve all the research produced on quality of life, its conceptualisation, and measurement, but rather to offer a comprehensive panorama of different perspectives on these topics.

The review used two main techniques to identify relevant material:

- Electronic searching from 2000 to 2010 of the following five databases: PsycINFO, Web of Science, and Pubmed.
- Tracking references and authors names from the retrieved papers, which led to relevant literature published before 2000.

The electronic searches were performed using combinations of terms referring to:

- The expression ‘quality of life’, which was searched as a heading using the relevant function in each database;
- Definitions and conceptualisation of quality of life (e.g. definition, concept/conceptualisation, taxonomy, classification, typology – with the use of appropriate wild cards for each database to maximize the retrievement of relevant material);
- People living with HIV/AIDS (e.g. HIV and AIDS).

Appendix 2

Figure_Appendix 2-1

Differences between subjective, objective, and mixed indicators (Source: Veenhoven, 2007b, p. 21)

Substance	**Assessment**		
	Objective	*Mixed*	*Subjective*
Objective	**1**	**2**	**3**
Mixed	**4**	**5**	**6**
Subjective	**7**	**8**	**9**

The following indicators of health can exemplify this classification.

Type 1: Illness revealed by symptoms such as weight loss or biochemical tests

Type 2: Illness diagnosed by a doctor on the basis of a patient's complaints.

Type 3: Perception of being ill by one-self (possibly without feeling sick)

Type 4: Being and feeling ill as apparent in sickness behaviors such as absenteeism and doctor visits

Type 5: Being and feeling ill measured by a health questionnaire that involves both perceptions of functional health and health complaints

Type 6: Being and feeling ill as reported directly by a person

Type 7: Feeling ill as apparent in consumption of relief drugs, such as painkillers or tranquilizers

Type 8: Feeling ill measured by a sickness complaint inventory

Type 9: Feeling ill measured by response to a single question on how fit or sick one feels

Appendix 3

NUSSBAUM'S (2000) AND VIZARD'S AND BURCHARDT'S (2007) LISTS OF CAPABILITIES

Nussbaum's (2000) list of ten capabilities	**Vizard's and Burchardt's (2007) list of 10 capabilities**
Life Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living. **Bodily Health** Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.	**The capability to be alive** Including, for example, being able to: • avoid premature mortality through disease, neglect, injury or suicide • be protected from arbitrary denial of life **The capability to be healthy** Including, for example, being able to: • attain the highest possible standard of physical and mental health, including sexual and reproductive health • access to timely and impartial information about health and healthcare options • access healthcare, including non-discrimination in access to healthcare • be treated medically, or subject to experiment, only with informed consent • maintain a healthy lifestyle including exercise and nutrition • live in a healthy and safe environment including clean air, clean water, and freedom from pollution and other hazards **The capability to enjoy a comfortable standard of living, with independence and security** Including, for example, being able to: • enjoy an adequate and secure standard of living including nutrition, clothing, housing, warmth, social security, social services and utilities • have personal mobility, and access to transport and public places • live with independence, dignity

Bodily Integrity Being able to move freely from place to place; to be secure against violent assault, including sexual assault; having opportunities for sexual satisfaction and for choice in matters of reproduction. **Senses, Imagination, and Thought** Being able to use the senses, to imagine, think, and reason — and to do these things in a 'truly human' way, a way informed and cultivated by an adequate education, including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing works and events of one's own choice, religious, literary, musical, and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid non-beneficial pain. **Emotions** Being able to have attachments to things	and self-respect • have choice and control over where and how you live • enjoy your home in peace and security • access green spaces and the natural world • share in the benefits of scientific progress including information and technology **The capability to live in physical security** Including, for example, being able to: • be free from violence including sexual, domestic and identity-based violence • be free from cruel, inhuman or degrading treatment or punishment • be protected from physical or sexual abuse • go out and to use public spaces safely and securely without fear **The capability to be knowledgeable, to understand and reason, and to have the skills to participate in society** Including, for example, being able to: • attain the highest possible standard of knowledge, understanding and reasoning • be creative • be fulfilled intellectually • develop the skills for participation in productive and valued activities, including parenting • learn about a range of cultures and beliefs and acquire the skills to participate in a multicultural society • access education, training and lifelong learning that meets individual needs • access information and technology necessary to participate in society

and people outside ourselves; to love those who love and care for us; to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development.) **Affiliation** Being able to live with and toward others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another. Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, and national origin.	**The capability to engage in productive and valued activities** Including, for example, being able to: • undertake paid work • care for others • have rest, leisure and respite, including holidays • choose a balance between paid work, care and leisure on an equal basis with others • work in just and favourable conditions, including health and safety, fair treatment during pregnancy and maternity, and fair remuneration • not be forced to work in a particular occupation or without pay • not be prevented from working in a particular occupation without good reason **The capability to enjoy individual, family and social life** Including, for example, being able to: • develop as a person • develop your moral outlook and other beliefs • formulate and pursue goals and objectives for yourself • hope for the future • develop and maintain self-respect, self-esteem and self-confidence • have a private life, including protection of personal data • access emotional support • form intimate relationships, friendships and a family • celebrate on special occasions • be confident that your primary relationships will be treated with dignity and respect • spend time with, and care for, others • enjoy independence and equality in primary relationships including marriage • be free in matters of reproduction

Control Over One's Environment Political — being able to participate effectively in political choices that govern one's life; having the right of political participation, protection of free speech and association. Material — being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others, having the freedom from unwarranted search and seizure. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers. **Practical Reason** Being able to form a conception of the good; and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience and religious observance.) **Other Species** Being able to live with concern for and in relationship to animals, plants, and the world of nature. **Play** Being able to laugh, to play, to enjoy recreational activities	• enjoy special support during pregnancy and maternity, and during childhood **The capability to participate in decision-making, have a voice and influence** Including, for example, being able to: • participate in decision-making • participate in the formulation of government policy, locally and nationally • participate in non-governmental organisations concerned with public and political life • participate in democratic free and fair elections • assemble peacefully with others • participate in the local community form and join civil organisations and solidarity groups, including trade unions **The capability of being and expressing yourself, and having self-respect** Including, for example, being able to: • have freedom of conscience, belief and religion • have freedom of cultural identity • have freedom of expression (so long as it doesn't cause significant harm to others) • communicate, including using ICTs, and use your own language • engage in cultural practices, in community with other members of your chosen group or groups (so long as it doesn't cause significant harm to others) • have self-respect • live without fear of humiliation, harassment, or identity-based abuse • be confident that you will be treated with dignity and respect • access and use public spaces freely

	The capability of knowing you will be protected and treated fairly by the law Including, for example, being able to: • know you will be treated with equality and non-discrimination before the law • be secure that the law will protect you from intolerant behaviour • be free from arbitrary arrest and detention • have fair conditions of detention • have the right to a fair trial • access information and advocacy as necessary • have freedom of movement, and be free to choose where you live • have the right to name and nationality • own property and financial products including insurance, social security, and pensions in your own right • know your privacy will be respected and personal data protected

Appendix 4

Questions and variables (reported between brackets) chosen to represent the opportunity components of the valued functionings 'enjoyment of a comfortable standard of living, with independence and security'.

Type of indicator	Opportunities	
	To enjoy adequate housing	To have personal mobility and access to transport and public places
Opportunity - Availability	**B2)** Is this accommodation suitable for your current needs? *Yes (go to B4) No* (ac_ok) **B3a)** Do you have other accommodation options for the future? Yes No	**B12**) Do you own, or have access to a car? *Yes No* (car)
Opportunity - Achievability	**B10)** Have you received less favourable treatment than other people in relationship to accommodation as a result of having HIV/AIDS? *Yes, in the last 2 years (please specify)Yes, more than 2 years ago (please specify) No* (ac_disc)	**B13)** How easy is it for you to get public transport to and from your home? *Very difficult Difficult Easy Very easy* (pt)
Opportunity – Saliency	Not available	Not available

Demographic variables

A1) In what year were you born?

A5a) What gender do you identify with? Male Female None

A6) Which of the following best describes the area in which you live? (tick one box only)

Capital City - Inner suburban / Regional centre (population 5,000 or more) / Outer suburban / Rural

C1) In what year did you first test positive for HIV?

Socioeconomic variables.

A8) What is the highest level of education you have completed? (tick one box only)

Primary school only / Up to 3 years High School / 4th form/Year 10 / Leaving certificate- HSC- Year 12 / Tertiary diploma - Trade certificate – TAFE / University degree

B1) Where do you currently live? (tick one box only)

Own or purchasing house or flat
Private rental accommodation
Public rental accommodation
Rent-free (e.g. provided by friends, family, etc.)
Community housing/housing co-operative
Other (please describe)

F3) If you are not working, how long ago did you stop working? months years

H4) Do you have private health insurance? Yes No

Health Status variables.

Self-reported health

C8) How would you describe your current state of physical health? *(tick one box only)*

Poor Fair Good Excellent

Physical health functioning

C10) Have you experienced any of the following in the past 12 months? Low

energy/fatigue Yes No

AIDS-defining illness

C11) Have you ever been diagnosed with an AIDS-defining illness? (eg PCP, Kaposi's

Sarcoma) No Yes *(please specify and where possible include year of diagnosis)*

HIV-related illness

C13) Do you have any major health conditions other than HIV/AIDS? No Yes (please specify and where possible include year of diagnosis)

Cognitive functionings

C 10) Have you experienced any of the following in the past 12 months?

Low energy/fatigue Yes No

Confusion/memory loss Yes No

Mental health conditions

C14) Have you been diagnosed with any mental health conditions? No Yes

Biological markers

C16) What was the result of your most recent CD4 test?

C22) What was the result of your most recent viral load test?

Behaviour variables.

G4) Have you ever injected illegal drugs? No, never Yes - in the last 12 months Yes - more than 12 months ago

Beliefs variables

D20) In making major decisions about your life, how far ahead do you make plans? (tick one only)

One day at a time, A few months ahead, 1 year ahead, 5 years into the future,

10 or more years into the future

Appendix 5

Frequency and Percentage of all Demographic Variables

Variables	n	%
Age at time of survey – Years (n = 961)		
19 – 50	680	70.8
51 – 78	281	29.2
Sex (n = 962)		
Males	876	91.1
Females	86	8.9
Sexuality (n = 948)		
Gay/Lesbian	767	80.9
Heterosexual	127	13.4
Bisexual/Other	54	5.7
Marital status (n = 946)		
Regular relationship/ Married	428	44.8
Single individual	527	55.2
Place of birth (n = 962)		
Australia	737	76.6
Abroad	225	23.1
Place of residence (n = 962)		
Capital city/Inner suburban	612	63.6

Variables	n	%
Outer suburban	104	10.8
Regional centre	160	16.6
Rural	86	8.9
Time since diagnosis (n = 960)		
0-5	270	28.1
6-10	193	19.8
11-15	201	20.9
16 and over	296	30.8

Frequency and Percentage of Socioeconomic variables

Variables	N	%
Occupation status (n = 945)		
Student/Home duties/Other	105	11.1
Unemployed	103	10.9
Not working/ Retired	245	25.9
Full-time work	321	34
Part-time work	171	18.1
Educational attainment (n = 945)		
Primary school/3 years of high school / Year 10	229	24.2
Year 12	168	17.8
TAFE/Trade	267	28.3

Variables	N	%
University degree	281	29.7
Accommodation type (n = 966)		
Own or purchasing home	335	34.7
Private rental	373	38.6
Public rental	144	14.9
Other	114	11.8

Minimum, Maximum, Mean, Median, and Standard Deviation of Weekly Income After Tax (n = 856)

Variables	Minimum	Maximum	Mean (SD)	Median	Mode
Weekly income after tax (AUD$ - n = 856)	0	3500	541.38 (398.70)	420	250

Frequency and Percentage of the Behavioural Variable Injecting illegal drugs

Variables	n	%
Injected illegal drugs (n = 728)		
Never	448	61.5
In the last year	128	17.6
More than 1 year ago	152	20.9

Frequency and Percentage of Support Variables

Variable	n	%
Support from Partner/Spouse (n = 450)		

Variable	n	%
A lot	348	77.3
Some	57	12.7
A little	21	4.7
None	24	5.3
Support from close friends (n = 871)		
A lot	410	47.1
Some	268	30.8
A little	140	16.1
None	53	6.1
Support from parents (n = 619)		
A lot	240	38.8
Some	126	20.4
A little	106	17.1
None	147	23.7
Support from family (n = 639)		
A lot	168	26.3
Some	156	24.4
A little	156	24.4
None	159	24.9

Minimum, Maximum, Mean, Median, and Standard Deviation of Created Support Variable (n = 871)

Variables	Minimum	Maximum	Mean (SD)	Median	Mode
Created support variable	0.00	1.00	9.22 (0.17)	1.00	1.00

Frequency and Percentage of Belief variables

Variable	n	%
Future planning time frame (n = 941)		
One day	180	19.1
A few months	244	25.9
One year	177	18.8
Five years	180	19.1
Ten or more years	160	17.0

Frequency and Percentage of Health Variables

Variables	n	%
Health Status (n = 974)		
Poor	43	4.5
Fair	261	27.1
Good	425	44.1
Excellent	234	24.3
Other major health conditions (n = 974)		
Yes	417	43.9

Variables	n	%
No	533	56.1
Mental health conditions (n = 974)		
Yes	415	43.1
No	547	56.9
AIDS-defining illness (n = 974)		
Yes	232	24.3
No	772	75.7
HIV-related illness (n = 974)		
Yes	260	28
No	667	72

Frequency and Percentage of Objective Housing Stability and Number of Accommodation Changes

Variables	n	%
Objective Housing Stability (n = 948)	184	19.4
Stably housed	158	16.7
Unstably housed_Buying	363	38.3
Unstably housed_Public rental	138	14.6
Unstably housed_Other	105	11.1
Number of accommodation changes (n = 974)		
None	874	89.7

Variables	n	%
1 change	69	7.1
2 or more changes	31	3.2

Minimum, Maximum, Mean, Median, and Standard Deviation of Crowding Conditions (n = 969)

Variables	Minimum	Maximum	Mean (SD)	Median	Mode
Crowding conditions (n = 955)	0.17	4	0.71 (0.41)	0.50	0.50

Appendix 6

Predictors of opportunity to enjoy adequate housing (binary logistic)

Interactions tested in Model 1:

Weekly income: the interaction with time since diagnosis was tested and was not found to be significant.

Accommodation type: the interactions with both weekly income after tax and age were tested and were not found to be significant.

Self-reported health: the interactions with weekly income after tax, age, and accommodation type were tested and were not found to be significant.

Mental health conditions: the interactions with self-reported health, other major health conditions, weekly income after tax, and age were tested and were not found to be significant.

Predictors of number of accommodation changes

Time since diagnosis: the interaction with age was tested and was not found to be significant.

Weekly income after tax: the interaction with age was tested and was not found to be significant.

Self-reported health: the interactions with time since diagnosis and weekly income after tax were tested and were not found to be significant.

Mental health conditions: the interactions with weekly income after tax, time since diagnosis, and self-reported health were tested and were not found to be significant.

Fourfold typology of opportunities: the interactions with income quartiles, time since diagnosis, and mental health were tested and were not found to be significant.

Predictors of objective housing stability.

Age: the interaction with marital status was tested was not found to be significant.

Place of residence: the interactions with marital status and age were tested and were not found to be significant.

Time since diagnosis: the interactions with marital status and place of residence resulted to be significant, so they were kept in the model. The relationship with age was tested and not found to be significant.

Weekly income after tax: the interactions with time since diagnosis, marital status, and place of residence were tested and not found to be significant. The interaction with age was found to be significant, so it was kept in the model.

Employment status: the interactions with weekly income after tax, time since diagnosis, and place of residence resulted to be significant, so they were kept in the model. The interaction with age was tested and was not found to be significant.

Injecting illegal drugs: the interactions with time since diagnosis, age, weekly income after tax, employment status, and marital status were tested and were not found to be significant.

Predictors of Crowding Conditions.

Marital status: the interaction between marital status and sex was tested and found to be significant, so it was kept in the model.

Live with children: the interactions with sex and regular relationship were tested and were not found to be significant.

Age: The interaction with living with children and marital status were tested and were not found to be significant.

Time since diagnosis: the interactions with age was tested and was not found to be significant, so age was removed, as it became not significant when time since diagnosis was entered in the model. The interactions between living with children, marital status, sex and time since diagnosis were tested and were not found to be significant.

Place of residence: the interactions with marital status, time since diagnosis, sex, and living with children were tested and were not found to be significant.

Weekly income after tax: the interactions with living with children, time since diagnosis, and sex were tested and not found to be significant.

Accommodation types: the interactions with marital status, time since diagnosis, sex, living wit children, and place of residence were tested and were not found to be significant.

Appendix 7

Table_Appendix 7-1

Summary of Multinomial Logistic Regression Predicting Number of Accommodation Changes from Time Since Diagnosis, Income Quartiles, and Mental Health Conditions (n = 846).

							95% Confidence Interval for Exp(B)	
	B	Std. Error	Wald	df	Sig.	Odds Ratio	Lower Bound	Upper Bound
1 time								
Intercept	-1.22	.41	8.71	1.00	.003			
possince	-.07	.02	10.24	1.00	.001	.93	.90	.97
inc_ownNOOutliers	.00	.00	10.95	1.00	.001	1.00	1.00	1.00
[hment=1]	.69	.28	6.06	1.00	.014	2.00	1.15	3.47
[hment=2]	.00[b]	.	.	.00	.	.	.	.
2 or more times								
Intercept	-1.93	.65	8.77	1.00	.003			
possince	-.10	.03	9.28	1.00	.002	.90	.85	.96
inc_ownNOOutliers	.00	.00	6.39	1.00	.011	1.00	1.00	1.00
[hment=1]	1.26	.46	7.44	1.00	.006	3.52	1.43	8.69
[hment=2]	.00[b]	.	.	.00	.	.	.	.

Note. Reference category: Never

[a] Reference category

Appendix 8

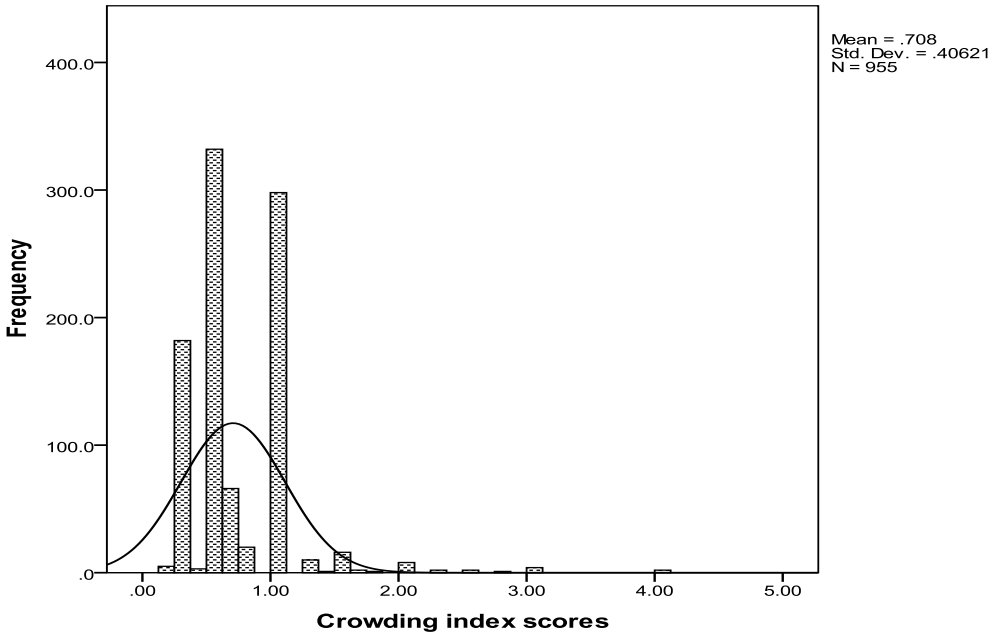
Chapter IV – Predictors of crowding conditions

The variable crowding conditions did not show a normal distribution (see Figure_Appendix 8-1), it had a Skewness of 2.68 and a Kurtosis of 13.89; its mean was 0.70 and its median 0.50. The one sample Kolmogorov-Smirnov Test indicated that the crowding index was significantly non-normal, $D(955) = .239$, $p < .001$ (see Figure_Appendix 8-2 for the normal Q-Q plot).

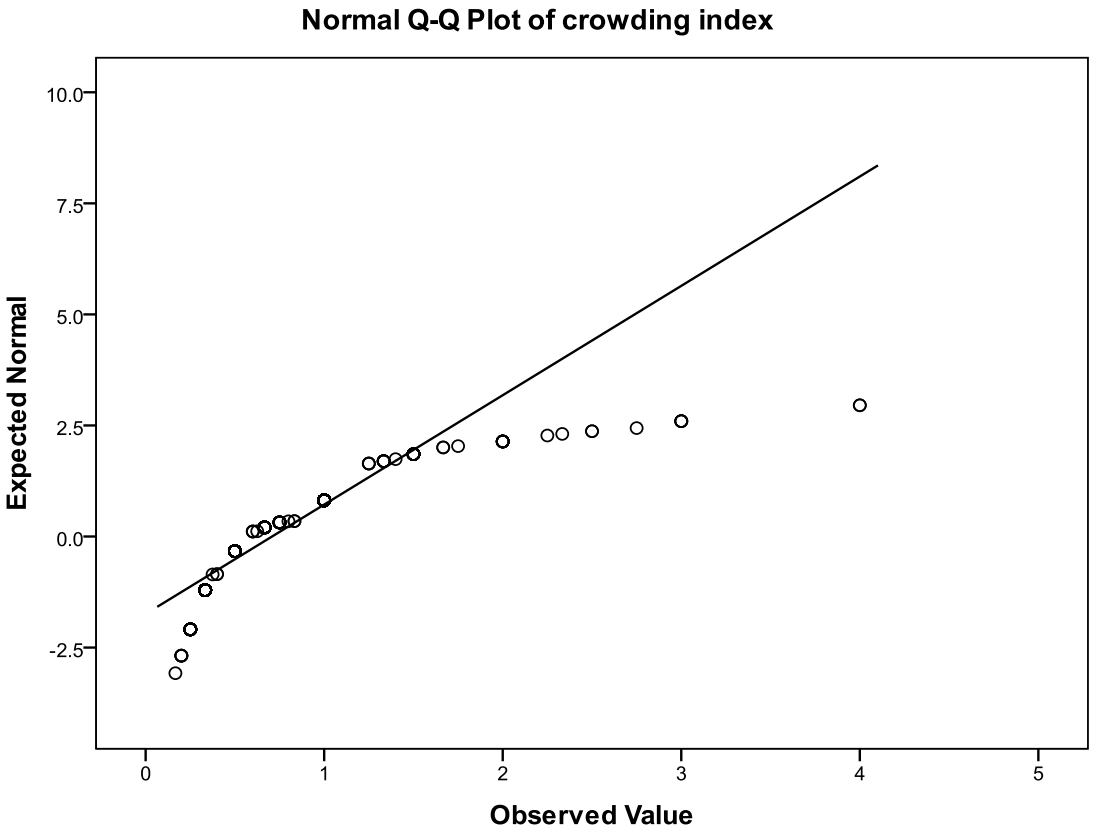
Three transformation were tried to normalize the distribution, a square root transformation, a log transformation (base 10) and an inverse transformation (i.e. 1/x). Considering the fact that the variable had values between 0 and 1, a constant (1) was added to the distribution before performing the square and the log transformations. However, the transformations were not successful in normalizing the distribution (see Figure_Appendix 8-3, Figure_Appendix 8-5, and Figure_Appendix 8-7). The Kolmogorov-Smirnov Test confirmed that the transformed variables were significantly non-normal: for the squared transformation it was $D(955) = .244$, $p < .001$, for the log10 it was $D(955) = .244$, $p < .001$, for the inverse transformation it was, $D(955) = .244$, $p < .001$. Consequently, linear regression could not be performed on this data.

Figure_Appendix 8-1

Distribution of the Crowding Conditions Index

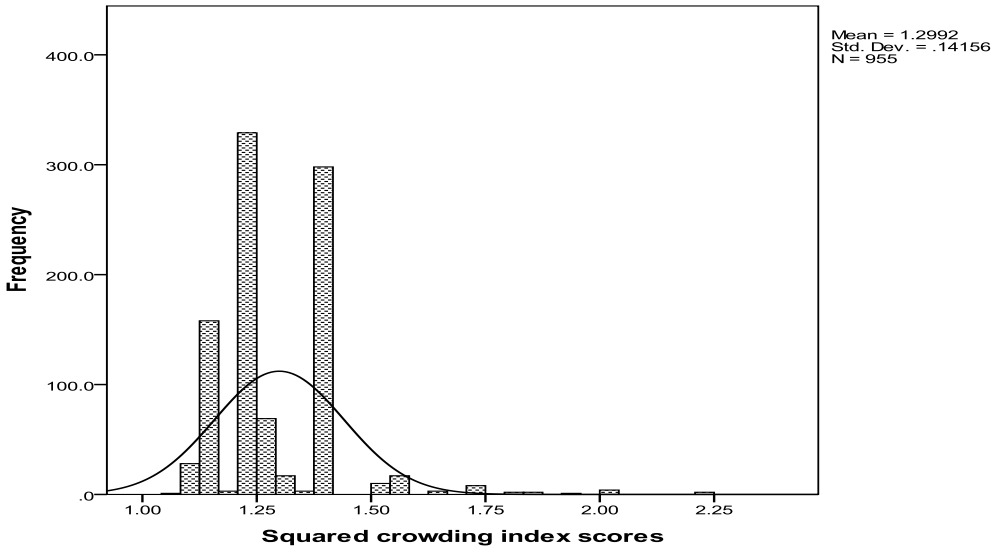


Figure_Appendix 8-2

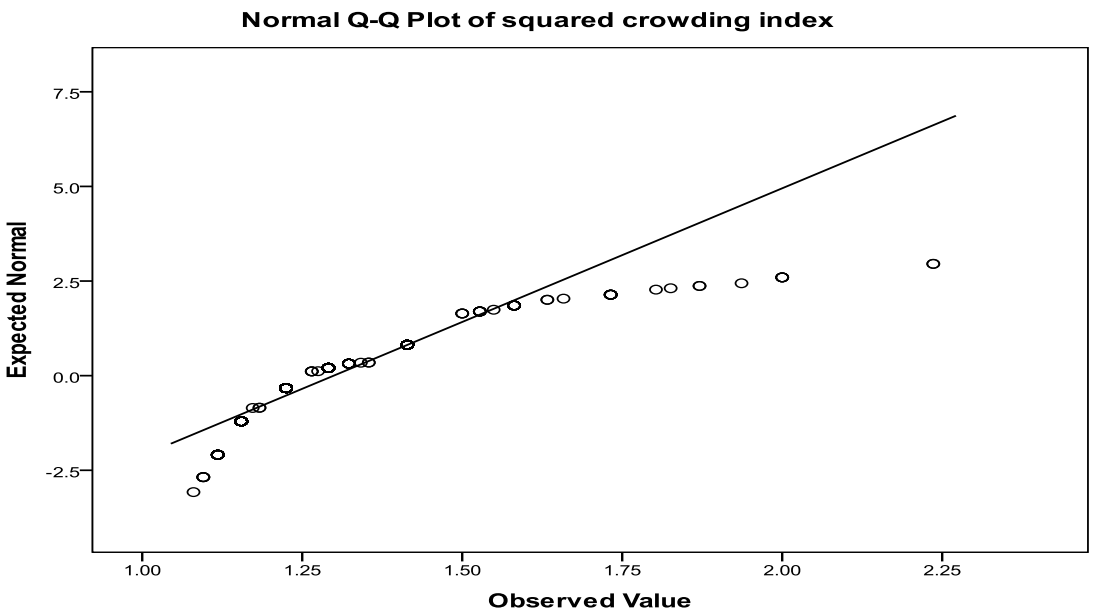


Figure_Appendix 8-3

Distribution of the Crowding Conditions Index after a Squared Transformation, D(955) = .244, p < .001.

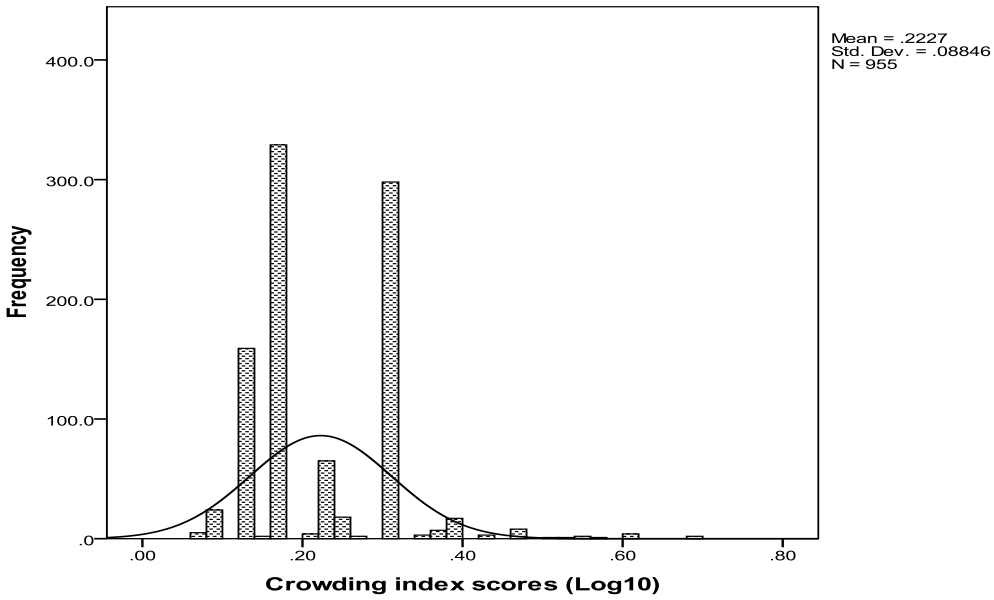


Figure_Appendix 8-4

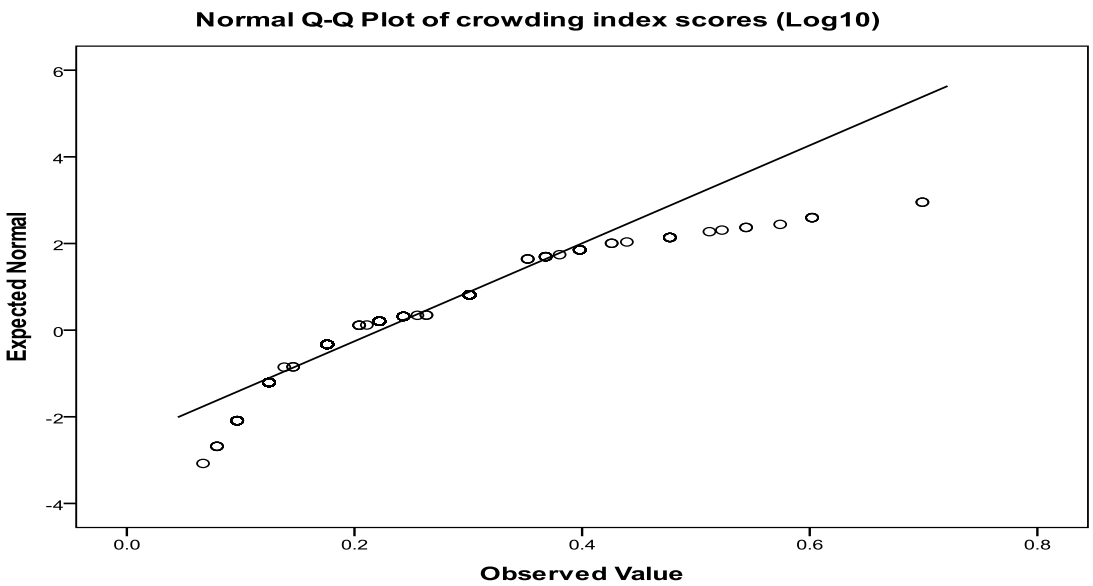


Figure_Appendix 8-5

Distribution of the Crowding Conditions Index after a Log Transformation (Log10), D(955) = .244, p < .001.

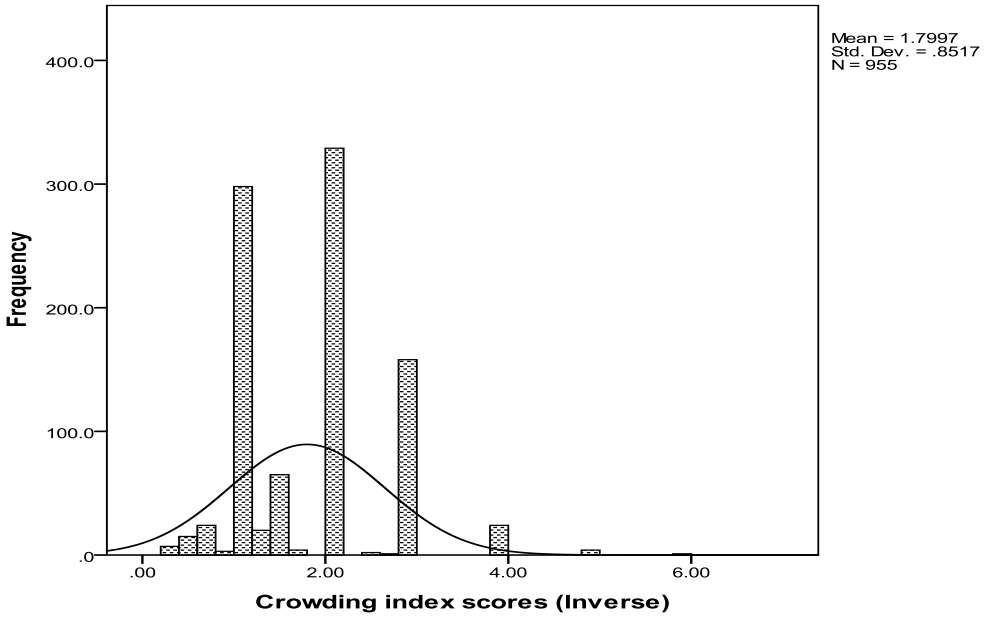


Figure_Appendix 8-6

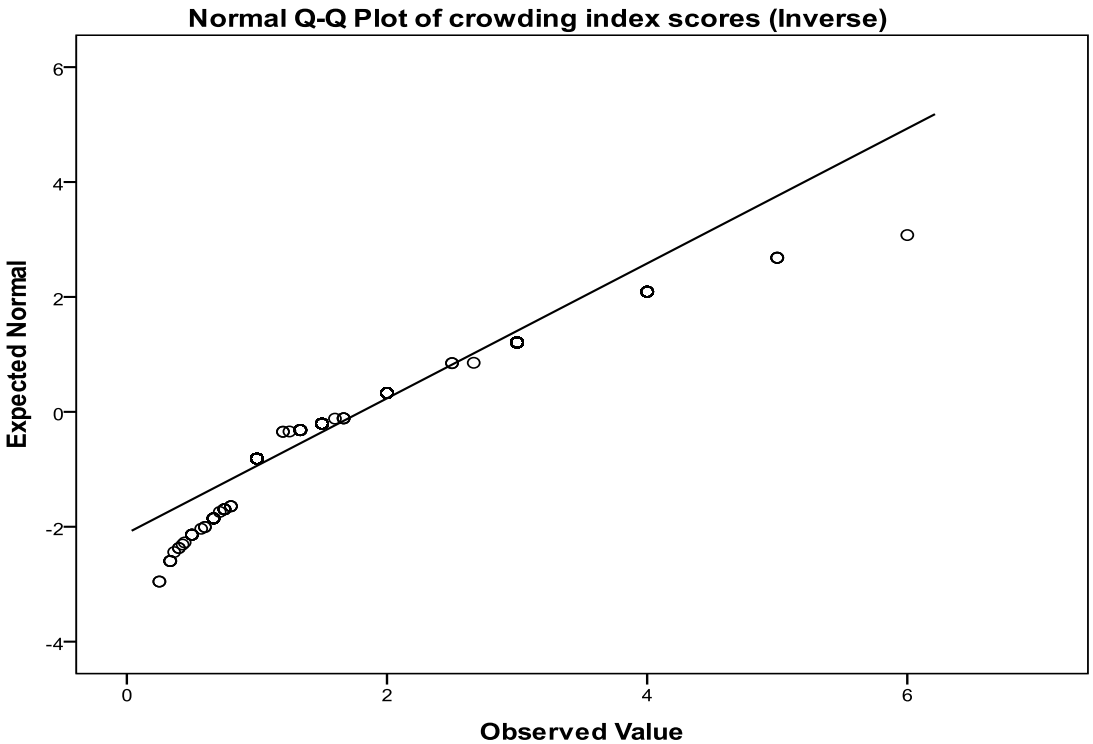


Figure_Appendix 8-7

Distribution of the Crowding Conditions Index after an Inverse Transformation, D(955) = 0.208, p < .001.



Figure_Appendix 8-8



Appendix 9

Model 2 was run both with a Logit Link function and a Negative Log-Log function; this latter function reflected the fact that the lower values of the dependent variable were more likely, i.e. the collapsed category poor and fair well-being. Model 2 with the Negative Log-Log Link function was highly significant, χ^2 (72) = 282.60, p < .001, its Nagelkerke R squared was .770, and did not violate the assumption of parallel lines (p = 1.000). A summary of the model can be found in Table_Appendix 9-4). However, this model had a very high number of empty cells (66.7%), many predictors that were not significant at the .05 level, and analyzed only 249 cases of the 974. As for Model 1, in order to reduce the number of cells with 0 frequencies, the variables whose Wald statistics were not significant at the .05 level were removed. The final reduced version of Model 1 rejected the null hypothesis of the test of parallel lines (p < .001) both with the negative log-log and with the Logit link function, consequently Model 2 was discarded and is not displayed.

Interaction terms tested in Model 1.

Self-reported health: the interaction with accommodation status was significant and therefore was kept in the model.

Other major health conditions: the interaction with occupation status was significant and therefore was kept in the model.

HIV-related illness: the interaction with other major health conditions was significant and therefore was kept in the model.

Loss of memory/confusion: the interaction with self-reported health status was significant and therefore was kept in the model.

Support from close friends: the interaction with employment status was significant and therefore was kept in the model.

Support from parents: the interaction with self-reported health was significant and therefore was kept in the model.

Table_Appendix 9-1

Summary of Ordinal Logistic Regression Predicting Well-Being.

					95% Confidence Interval	
	Estimate	Std. Error	Wald	Sig.	Lower Bound	Upper Bound
Employment status						
Part-time work	-0.38	0.68	0.31	0.577	-1.71	0.95
Student/Home duties/Other	0.55	0.85	0.41	0.521	-1.13	2.22
Unemployed	-1.92	1.21	2.50	0.114	-4.29	0.46
Not working/Retired	4.27	1.59	7.24	0.007	1.16	7.39
Full-time work	0.00[a]	.	.	.	.	.
Educational attainment						
Primary school/3 years of high school/Year 10	-1.27	0.60	4.52	0.034	-2.44	-0.10
Year 12	-0.22	0.55	0.17	0.685	-1.31	0.86
TAFE/Trade	-0.40	0.47	0.73	0.393	-1.32	0.52
University degree	0.00[a]	.	.	.	.	.
Accommodation types						
Private rental	-0.57	1.26	0.20	0.652	-3.05	1.91
Public rental	2.64	6.76	0.15	0.696	-10.61	15.88
Other	0.49	4.31	0.01	0.910	-7.96	8.93
Own or purchasing home	0.00[a]	.	.	.	.	.

	Estimate	Std. Error	Wald	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Weekly income after tax	0.00	0.00	0.01	0.930	0.00	0.00
Self-reported health						
Poor health	4.12	11.54	0.13	0.721	-18.50	26.74
Fair health	-3.32	1.30	6.53	0.011	-5.87	-0.77
Good health	-1.48	1.22	1.46	0.226	-3.87	0.92
Excellent health	0.00[a]	.	.	.	.	.
Intearction: Accommodation type * Self-reported health						
Private rental * Poor health	-3.58	5.59	0.41	0.522	-14.53	7.38
Private rental * Fair health	0.59	1.38	0.18	0.670	-2.12	3.30
Private rental * Good health	1.24	1.36	0.83	0.363	-1.43	3.91
Private rental * Excellent health	0.00[a]	.	.	.	.	.
Public rental * Poor health	-9.12	9.14	1.00	0.318	-27.03	8.79
Public rental * Fair health	-2.81	6.81	0.17	0.679	-16.15	10.53
Public rental * Good health	-3.28	6.79	0.23	0.630	-16.59	10.04
Public rental * Excellent health	0.00[a]	.	.	.	.	.
Other * Poor health	0.00[a]	.	.	.	.	.
Other * Fair health	-1.05	4.37	0.06	0.811	-9.62	7.52
Other * Good health	-0.56	4.38	0.02	0.899	-9.14	8.02
Other * Excellent health	0.00[a]	.	.	.	.	.
Own or purchasing home * Fair health	0.00[a]	.	.	.	.	.

	Estimate	Std. Error	Wald	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Own or purchasing home * Good health	0.00[a]	.	.	.	.	.
Own or purchasing home * Excellent health	0.00[a]	.	.	.	.	.
Other major health conditions						
Yes	-1.31	0.60	4.71	0.030	-2.49	-0.13
No	0.00[a]	.	.	.	.	.
Interaction: Employment status * Other major health conditions						
Part-time work * Yes	1.57	0.92	2.94	0.086	-0.22	3.36
Part-time work * No	0.00[a]	.	.	.	.	.
Student/Home duties/Other * Yes	0.32	1.18	0.07	0.790	-2.01	2.64
Student/Home duties/Other * No	0.00[a]	.	.	.	.	.
Unemployed * Yes	1.83	1.16	2.49	0.114	-0.44	4.11
Unemployed * No	0.00[a]	.	.	.	.	.
Not working/Retired * Yes	-2.54	1.42	3.18	0.074	-5.33	0.25
Not working/Retired * No	0.00[a]	.	.	.	.	.
Full-time work * Yes	0.00[a]	.	.	.	.	.
Full-time work * No	0.00[a]	.	.	.	.	.

	Estimate	Std. Error	Wald	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Mental health conditions						
Yes	-1.51	0.41	13.28	0.000	-2.32	-0.70
No	0.00[a]	.	.	.	.	.
HIV-related illnesses						
Yes	-1.45	0.54	7.25	0.007	-2.51	-0.40
No	0.00[a]	.	.	.	.	.
Interaction: Other major health conditions * HIV-related illnesses						
Yes * Yes	2.34	0.81	8.39	0.004	0.76	3.93
Yes * No	0.00[a]	.	.	.	.	.
No * Yes	0.00[a]	.	.	.	.	.
No * No	0.00[a]	.	.	.	.	.
CD4 cells counts	0.00	0.00	0.37	0.542	0.00	0.00
Fatigue						
Yes	-0.27	0.60	0.20	0.653	-1.43	0.90
No	0.00[a]	.	.	.	.	.
Memory loss/Confusion						
Yes	2.18	1.64	1.76	0.184	-1.04	5.39
No	0.00[a]	.	.	.	.	.
Intearction: Self-reported health * Memory loss/Confusion						
Poor health * Yes	-12.54	10.62	1.39	0.238	-33.36	8.28
Poor health * No	0.00[a]	.	.	.	.	.
Fair health * Yes	-2.26	1.79	1.59	0.208	-5.77	1.26
Fair health * No	0.00[a]	.	.	.	.	.
Good health * Yes	-2.22	1.71	1.68	0.195	-5.57	1.14
Good health * No	0.00[a]	.	.	.	.	.

	Estimate	Std. Error	Wald	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Excellent health * Yes	0.00[a]	.	.	.	.	.
Excellent health * No	0.00[a]	.	.	.	.	.
Injecting illegal drugs						
In the last year	-0.27	0.42	0.43	0.513	-1.09	0.54
Longer than one year ago	0.53	0.46	1.29	0.256	-0.38	1.43
Never	0.00[a]	.	.	.	.	.
Support from close friends						
Some	-0.18	0.64	0.08	0.783	-1.43	1.08
A little	-0.46	1.06	0.19	0.660	-2.53	1.60
None	3.43	1.52	5.08	0.024	0.45	6.41
A lot	0.00[a]	.	.	.	.	.
Interaction: Employment status * Support from close friends						
Part-time work * Some	-0.24	0.89	0.07	0.790	-1.99	1.51
Part-time work * A little	-0.20	1.55	0.02	0.900	-3.24	2.85
Part-time work * None	-1.47	2.06	0.51	0.474	-5.51	2.56
Part-time work * A lot	0.00[a]	.	.	.	.	.
Student/Home duties/Other * Some	-1.08	1.23	0.77	0.382	-3.50	1.34
Student/Home duties/Other * A little	-0.19	1.77	0.01	0.917	-3.66	3.29
Student/Home duties/Other * None	-0.84	9.58	0.01	0.930	-19.61	17.94
Student/Home duties/Other * A lot	0.00[a]	.	.	.	.	.

	Estimate	Std. Error	Wald	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Unemployed * Some	1.86	1.48	1.59	0.207	-1.03	4.76
Unemployed * A little	-2.38	1.73	1.88	0.170	-5.77	1.02
Unemployed * None	0.41	1.70	0.06	0.810	-2.93	3.75
Unemployed * A lot	0.00[a]	.	.	.	.	.
Not working/Retired * Some	-2.00	1.34	2.23	0.135	-4.62	0.62
Not working/Retired * A little	-1.09	1.56	0.49	0.483	-4.15	1.96
Not working/Retired * None	-1.14	7.73	0.02	0.882	-16.30	14.01
Not working/Retired * A lot	0.00[a]	.	.	.	.	.
Full-time work * Some	0.00[a]	.	.	.	.	.
Full-time work * A little	0.00[a]	.	.	.	.	.
Full-time work * None	0.00[a]	.	.	.	.	.
Full-time work * A lot	0.00[a]	.	.	.	.	.
Support from parents						
Some	0.62	2.88	0.05	0.829	-5.02	6.26
A little	-0.29	1.32	0.05	0.825	-2.87	2.29
None	4.30	2.40	3.20	0.074	-0.41	9.00
A lot	0.00[a]	.	.	.	.	.
Interaction: Self-reported health * Support from parents						
Poor health * Some	6.79	4.75	2.05	0.153	-2.51	16.09

	Estimate	Std. Error	Wald	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Poor health * A little	7.33	5.01	2.14	0.143	-2.49	17.14
Poor health * None	0.00[a]	.	.	.	.	.
Poor health * A lot	0.00[a]	.	.	.	.	.
Fair health * Some	-0.27	2.97	0.01	0.927	-6.09	5.55
Fair health * A little	1.94	1.47	1.74	0.188	-0.94	4.81
Fair health * None	-3.75	2.46	2.31	0.129	-8.58	1.08
Fair health * A lot	0.00[a]	.	.	.	.	.
Good health * Some	-0.14	2.96	0.00	0.961	-5.94	5.65
Good health * A little	1.11	1.47	0.57	0.451	-1.78	3.99
Good health * None	-2.47	2.41	1.05	0.304	-7.19	2.25
Good health * A lot	0.00[a]	.	.	.	.	.
Excellent health * Some	0.00[a]	.	.	.	.	.
Excellent health * A little	0.00[a]	.	.	.	.	.
Excellent health * None	0.00[a]	.	.	.	.	.
Excellent health * A lot	0.00[a]	.	.	.	.	.
Support from family						
Some	-1.33	0.55	5.84	0.016	-2.40	-0.25
A little	-0.90	0.61	2.14	0.144	-2.10	0.31
None	0.76	0.98	0.61	0.436	-1.15	2.68
A lot	0.00[a]	.	.	.	.	.
Support_Recoded	6.93	2.55	7.35	0.007	1.92	11.93
Future planning						
One day	-0.99	0.90	1.21	0.271	-2.74	0.77
A few months	-1.99	0.85	5.43	0.020	-3.66	-0.32

	Estimate	Std. Error	Wald	Sig.	95% Confidence Interval Lower Bound	95% Confidence Interval Upper Bound
One year	-1.03	0.90	1.30	0.255	-2.80	0.74
Five years	-0.71	0.85	0.69	0.406	-2.38	0.96
Ten or more years	0.00[a]	.	.	.	.	.

Note. Link function: Complementary Log-Log

[a] Reference category

Table_Appendix 9-2

Summary of Ordinal Logistic Regression Predicting Well-Being with the Categories Good and Excellent Collapsed Together.

	B	Std. Error	Wald	Sig.	95% Confidence Interval Lower bound	95% Confidence Interval Upper bound
Employment status						
Part-time work	-0.63	0.43	2.16	.142	-1.48	0.21
Student/Home duties/Other	-0.27	0.56	0.23	.628	-1.37	0.83
Unemployed	-1.45	0.54	7.37	.007	-2.50	-0.40
Not working/Retired	-0.17	0.50	0.12	.731	-1.15	0.81
Full-time work	0.00[a]	.	.	.	.	.
Educational attainment						
Primary school/3 years of high school/Year 10	-0.22	0.24	0.85	.356	-0.69	0.25
Year 12	0.02	0.27	0.01	.941	-0.51	0.55
TAFE/Trade	-0.14	0.23	0.38	.535	-0.60	0.31
University degree	0.00[a]	.	.	.	.	.
Self-reported health						
Poor health	-4.25	0.53	65.15	.000	-5.29	-3.22
Fair health	-2.72	0.39	49.23	.000	-3.48	-1.96
Good health	-1.35	0.38	12.41	.000	-2.09	-0.60
Excellent health	0.00[a]	.	.	.	.	.
Other major health conditions						
Yes	-0.50	0.36	1.91	0.167	-1.21	0.21
No	0.00[a]	.	.	.	.	.

	B	Std. Error	Wald	Sig.	95% Confidence Interval	
					Lower bound	Upper bound
Interaction: Employment status * Other major health conditions						
Part-time work * Yes	1.25	0.51	6.07	0.014	0.26	2.24
Part-time work * No	0.00[a]	.	.	.	.	.
Student/Home duties/Other * Yes	1.05	0.64	2.71	0.100	-0.20	2.31
Student/Home duties/Other * No	0.00[a]	.	.	.	.	.
Unemployed * Yes	1.54	0.55	7.72	0.005	0.45	2.63
Unemployed * No	0.00[a]	.	.	.	.	.
Not working/Retired * Yes	0.50	0.50	0.97	0.324	-0.49	1.48
Not working/Retired * No	0.00[a]	.	.	.	.	.
Full-time work * Yes	0.00[a]	.	.	.	.	.
Full-time work * No	0.00[a]	.	.	.	.	.
Mental health conditions						
Yes	-0.88	0.18	24.33	0.000	-1.22	-0.53
No	0.00[a]	.	.	.	.	.
HIV-related illnesses						
Yes	0.08	0.29	0.07	0.787	-0.49	0.64
No	0.00[a]	.	.	.	.	.
Interaction: Other major health conditions * HIV-related illnesses						
Yes * Yes	-0.28	0.37	0.57	0.451	-0.99	0.44
Yes * No	0.00[a]	.	.	.	.	.
No * Yes	0.00[a]	.	.	.	.	.
No * No	0.00[a]	.	.	.	.	.
Support from close friends						
Some	-0.25	0.41	0.38	0.538	-1.06	0.55
A little	-0.79	0.47	2.87	0.090	-1.71	0.12
None	-0.66	0.72	0.83	0.363	-2.08	0.76
A lot	0.00[a]	.	.	.	.	.

	B	Std. Error	Wald	Sig.	95% Confidence Interval	
					Lower bound	Upper bound
Interaction: Employment status * Support from close friends						
Part-time work * Some	0.85	0.59	2.07	0.150	-0.31	2.00
Part-time work * A little	0.67	0.69	0.94	0.333	-0.68	2.02
Part-time work * None	0.93	0.95	0.97	0.325	-0.92	2.79
Part-time work * A lot	0.00[a]	.	.	.	.	.
Student/Home duties/Other * Some	-0.18	0.70	0.07	0.795	-1.56	1.20
Student/Home duties/Other * A little	0.92	0.80	1.33	0.249	-0.65	2.50
Student/Home duties/Other * None	7.01	34.77	0.04	0.840	-61.13	75.15
Student/Home duties/Other * A lot	0.00[a]	.	.	.	.	.
Unemployed * Some	0.96	0.66	2.07	0.151	-0.35	2.26
Unemployed * A little	1.05	0.75	1.95	0.163	-0.43	2.53
Unemployed * None	1.58	0.87	3.31	0.069	-0.12	3.28
Unemployed * A lot	0.00[a]	.	.	.	.	.
Not working/Retired * Some	0.21	0.57	0.14	0.706	-0.90	1.32
Not working/Retired * A little	0.71	0.61	1.36	0.244	-0.48	1.89
Not working/Retired * None	0.93	0.97	0.92	0.338	-0.97	2.83
Not working/Retired * A lot	0.00[a]	.	.	.	.	.
Full-time work * Some	0.00[a]	.	.	.	.	.
Full-time work * A little	0.00[a]	.	.	.	.	.
Full-time work * None	0.00[a]	.	.	.	.	.
Full-time work * A lot	0.00[a]	.	.	.	.	.
Support from family						

	B	Std. Error	Wald	Sig.	95% Confidence Interval	
					Lower bound	Upper bound
Some	-0.56	0.26	4.61	0.032	-1.07	-0.05
A little	-0.68	0.26	6.78	0.009	-1.19	-0.17
None	-0.56	0.41	1.83	0.176	-1.37	0.25
A lot	0.00[a]	.	.	.	.	.
Support_Recoded	0.84	0.93	0.80	0.370	-0.99	2.67
Future planning						
One day	-1.62	0.43	14.25	0.000	-2.46	-0.78
A few months	-1.39	0.42	11.19	0.001	-2.21	-0.58
One year	-1.37	0.44	9.53	0.002	-2.23	-0.50
Five years	-0.98	0.44	4.97	0.026	-1.84	-0.12
Ten or more years	0[a]	.	.	.	.	.

Note. Link function: Complementary Log-Log

[a] Reference category

Table_Appendix 9-3

Summary of Ordinal Logistic Regression Predicting Well-Being with the Categories Good and Excellent Collapsed Together.

	B	Std. Error	Wald	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
[wellbein_3Categories = 1.00]	-7.97	0.63	159.58	0.000	-9.21	-6.73
[wellbein_3Categories = 2.00]	-4.74	0.56	72.80	0.000	-5.83	-3.65
Employment status						
Part-time work	0.29	0.30	0.97	0.325	-0.29	0.88
Student/Home duties/Other	0.51	0.37	1.88	0.171	-0.22	1.24
Unemployed	-0.22	0.34	0.42	0.516	-0.88	0.44
Not working/Retired	0.08	0.29	0.08	0.782	-0.48	0.64
Full-time work	0.00[a]	.	.		.	.
Self-reported health						
Poor health	-5.38	0.58	85.65	0.000	-6.52	-4.24
Fair health	-3.32	0.39	73.55	0.000	-4.08	-2.56
Good health	-1.32	0.36	13.11	0.000	-2.03	-0.60
Excellent health	0.00[a]	.	.		.	.
Mental health conditions						

Yes	-1.11	0.21	28.75	0.000	-1.51	-0.70
No	0.00[a]	.	.		.	.
Support from family				.		
Some	-0.62	0.30	4.25	0.039	-1.22	-0.03
A little	-0.88	0.30	8.70	0.003	-1.47	-0.30
None	-0.93	0.29	10.21	0.001	-1.51	-0.36
A lot	0.00[a]	.	.		.	.
Future planning						
One day	-2.13	0.44	23.44	0.000	-3.00	-1.27
A few months	-1.48	0.42	12.38	0.000	-2.31	-0.66
One year	-1.58	0.44	12.72	0.000	-2.45	-0.71
Five years	-1.00	0.45	5.04	0.025	-1.87	-0.13
Ten or more years	0.00[a]	.	.	.	.	.

Note. Link function: Complementary Log-Log

[a] Reference category

Table_Appendix 9-4

Summary of Ordinal Logistic Regression Predicting Well-Being with the Categories Poor and Fair Collapsed Together.

					95% Confidence Interval	
	B	Std. Error	Wald	Sig.	Lower Bound	Upper Bound
[wellbein_3Cat_Poor Fair = 1.00]	-0.58	3.45	.03	0.867	-7.35	6.19
[wellbein_3Cat_Poor Fair = 2.00]	4.41	3.46	1.63	0.202	-2.37	11.19
Employment status						
Part-time work	-0.62	0.79	0.62	0.430	-2.17	0.92
Student/Home duties/Other	-0.05	0.95	0.00	0.958	-1.91	1.81
Unemployed	-2.78	1.69	2.71	0.100	-6.10	0.53
Not working/Retired	4.36	1.39	9.79	0.002	1.63	7.09
Full-time work	0.00[a]	.	.	.	.	.
Educational attainment						
Primary school/3 years of high school/Year 10	-1.05	0.72	2.17	0.141	-2.46	0.35
Year 12	0.06	0.57	0.01	0.912	-1.06	1.19
TAFE/Trade	-0.39	0.46	0.70	0.404	-1.29	0.52
University degree	0.00[a]	.	.	.	.	.

Accommodation type						
Private rental	0.55	0.83	0.45	0.503	-1.07	2.18
Public rental	20.77	5923.88	0.00	0.997	-11589.81	11631.35
Other	17.27	4146.10	0.00	0.997	-8108.94	8143.49
Own or purchasing home	0.00[a]	.	.	.	.	.
inc_ownNOOutliers	0.00	0.00	0.65	0.420	0.00	0.00
Self-reported health						
Poor health	14.45	18643.85	0.00	0.999	-36526.82	36555.72
Fair health	-7.52	1.55	23.63	0.000	-10.55	-4.49
Good health	-4.57	1.10	17.42	0.000	-6.72	-2.42
Excellent health	0.00[a]	.	.	.	.	.
Interaction: Accommodation type* Self-reported health						
Private rental * Poor health	-1.65	12198.79	0.00	1.000	-23910.85	23907.54
Private rental * Fair health	-0.54	1.29	0.18	0.674	-3.08	1.99
Private rental * Good health	0.02	0.97	0.00	0.985	-1.89	1.93
Private rental * Excellent health	0.00[a]	.	.	.	.	.
Public rental * Poor health	-20.61	17351.33	0.00	0.999	-34028.60	33987.38
Public rental * Fair health	-20.69	5923.88	0.00	0.997	-11631.27	11589.90
Public rental * Good health	-20.48	5923.88	0.00	0.997	-11631.06	11590.10
Public rental * Excellent health	0.00[a]	.	.	.	.	.
Other * Poor health	0.00[a]	.	.	.	.	.
Other * Fair health	-19.81	4146.10	0.00	0.996	-8146.02	8106.41
Other * Good health	-16.69	4146.10	0.00	0.997	-8142.90	8109.52
Other * Excellent health	0.00[a]	.	.	.	.	.
Own or purchasing home * Fair health	0.00[a]	.	.	.	.	.
Own or purchasing home * Good health	0.00[a]	.	.	.	.	.
Own or purchasing home * Excellent health	0.00[a]	.	.	.	.	.

Other major health conditions						
Yes	-1.29	0.66	3.79	0.052	-2.59	0.01
No	0.00[a]	.	.	.	.	.
Interaction: Employment status * Other major health conditions						
Part-time work * Yes	0.87	1.10	0.62	0.430	-1.29	3.03
Part-time work * No	0.00[a]	.	.	.	.	.
Student/Home duties/Other * Yes	0.24	1.30	0.03	0.856	-2.32	2.79
Student/Home duties/Other * No	0.00[a]	.	.	.	.	.
Unemployed * Yes	1.86	1.64	1.29	0.257	-1.36	5.08
Unemployed * No	0.00[a]	.	.	.	.	.
Not working/Retired * Yes	-2.79	1.35	4.30	0.038	-5.43	-0.15
Not working/Retired * No	0.00[a]	.	.	.	.	.
Full-time work * Yes	0.00[a]	.	.	.	.	.
Full-time work * No	0.00[a]	.	.	.	.	.
Mental health condtions						
Yes	-1.58	0.45	12.66	0.000	-2.46	-0.71
No	0.00[a]	.	.	.	.	.
HIV-related conditions						
Yes	-2.12	0.63	11.29	0.001	-3.35	-0.88
No	0.00[a]	.	.	.	.	.
Interaction: Other major health conditions * HIV-related conditions						
Yes * Yes	3.18	0.94	11.47	0.001	1.34	5.01
Yes * No	0.00[a]	.	.	.	.	.
No * Yes	0.00[a]	.	.	.	.	.
No * No	0.00[a]	.	.	.	.	.
CD4 count	0.00	0.00	0.06	0.814	0.00	0.00
Fatigue						
Yes	-1.16	0.53	4.73	0.030	-2.20	-0.11
No	0.00[a]	.	.	.	.	.
Memory loss/Confusion						
Yes	0.26	0.89	0.09	0.769	-1.48	2.00

No	0.00[a]	.	.	.	.	.
Interaction: Self-reported health * Memory loss/Confusion						
Poor health * Yes	-38.65	14924.86	0.00	0.998	-29290.85	29213.54
Poor health * No	0.00[a]	.	.	.	.	.
Fair health * Yes	0.37	1.33	0.08	0.784	-2.25	2.98
Fair health * No	0.00[a]	.	.	.	.	.
Good health * Yes	-0.14	1.01	0.02	0.889	-2.12	1.83
Good health * No	0.00[a]	.	.	.	.	.
Excellent health * Yes	0.00[a]	.	.	.	.	.
Excellent health * No	0.00[a]	.	.	.	.	.
Injecting illegal drugs						
In the last year	-0.50	0.52	0.93	0.336	-1.52	0.52
Longer than one year ago	1.08	0.52	4.34	0.037	0.06	2.10
Never	0.00[a]	.	.	.	.	.
Support from close friends						
Some	-0.78	0.61	1.62	0.203	-1.98	0.42
A little	-0.48	1.16	0.17	0.677	-2.76	1.80
None	4.78	2.32	4.23	0.040	0.22	9.33
A lot	0.00[a]	.	.	.	.	.
Interaction: Employment status * Support from close friends						
Part-time work * Some	1.86	1.04	3.16	0.075	-0.19	3.91
Part-time work * A little	1.22	1.80	0.46	0.497	-2.30	4.75
Part-time work * None	-20.72	5790.75	0.00	0.997	-11370.39	11328.95
Part-time work * A lot	0.00[a]	.	.	.	.	.
Student/Home duties/Other * Some	0.08	1.41	0.00	0.953	-2.67	2.84
Student/Home duties/Other * A little	0.85	2.07	0.17	0.683	-3.22	4.91
Student/Home duties/Other * None	-4.79	3.83	1.56	0.212	-12.30	2.73

Student/Home duties/Other * A lot	0.00[a]	.	.	.	.	.
Unemployed * Some	4.28	1.98	4.70	0.030	0.41	8.15
Unemployed * A little	-16.77	3626.65	0.00	0.996	-7124.87	7091.34
Unemployed * None	-0.99	2.56	0.15	0.698	-6.01	4.02
Unemployed * A lot	0.00[a]	.	.	.	.	.
Not working/Retired * Some	-2.29	1.30	3.09	0.079	-4.85	0.26
Not working/Retired * A little	-1.46	1.99	0.54	0.463	-5.36	2.44
Not working/Retired * None	-5.38	3.04	3.12	0.077	-11.34	0.59
Not working/Retired * A lot	0.00[a]	.	.	.	.	.
Full-time work * Some	0.00[a]	.	.	.	.	.
Full-time work * A little	0.00[a]	.	.	.	.	.
Full-time work * None	0.00[a]	.	.	.	.	.
Full-time work * A lot	0.00[a]	.	.	.	.	.
Support from parents						
Some	-1.20	1.10	1.20	0.274	-3.35	0.95
A little	-1.16	1.17	0.98	0.321	-3.44	1.13
None	0.75	1.28	0.35	0.555	-1.75	3.26
A lot	0.00[a]	.	.	.	.	.
Interaction: Support from parents * Self-reported health						
Poor health * Some	4.28	13216.19	0.00	1.000	-25898.98	25907.55
Poor health * A little	4.08	15350.37	0.00	1.000	-30082.09	30090.24
Poor health * None	0.00[a]	.	.	.	.	.
Poor health * A lot	0.00[a]	.	.	.	.	.
Fair health * Some	1.70	1.81	0.88	0.349	-1.85	5.25
Fair health * A little	3.35	1.69	3.93	0.047	0.04	6.66
Fair health * None	-0.06	1.81	0.00	0.973	-3.60	3.48
Fair health * A lot	0.00[a]	.	.	.	.	.
Good health * Some	1.20	1.27	0.89	0.347	-1.30	3.70
Good health * A little	2.56	1.37	3.51	0.061	-0.12	5.24
Good health * None	0.37	1.25	0.09	0.766	-2.07	2.82
Good health * A lot	0.00[a]	.	.	.	.	.

Excellent health * Some	0.00[a]	.	.	.	.	.
Excellent health * A little	0.00[a]	.	.	.	.	.
Excellent health * None	0.00[a]	.	.	.	.	.
Excellent health * A lot	0.00[a]	.	.	.	.	.
Support from family						
Some	-0.85	0.61	1.91	0.167	-2.05	0.35
A little	-0.72	0.64	1.24	0.265	-1.98	0.54
None	2.23	1.13	3.94	0.047	0.03	4.44
A lot	0.00[a]	.	.	.	.	.
Support_Recoded	8.14	3.26	6.24	0.012	1.75	14.53
Future planning						
One day	-0.78	0.83	0.89	0.347	-2.40	0.84
A few months	-1.40	0.63	4.89	0.027	-2.64	-0.16
One year	-0.23	0.68	0.11	0.741	-1.57	1.11
Five years	0.13	0.63	0.04	0.840	-1.11	1.37
Ten or more years	0.00[a]	.	.	.	.	.

Note. Link function: Complementary Log-Log

[a] Reference category

Table_Appendix 9-5

Summary of Ordinal Logistic Regression Predicting Well-Being from Self-reported Health, Mental Health Conditions, Future Planning, and Objective Housing Conditions.

						95% Confidence Interval	
	Estimate	Std. Error	Wald	df	Sig.	Lower Bound	Upper Bound
Self-reported health							
Poor health	-4.744	.406	136.310	1	.000	-5.540	-3.947
Fair health	-2.512	.188	178.092	1	.000	-2.881	-2.143
Good/Excellent	0[a]	.	.	0	.	.	.
Mental health conditions							
Yes	-1.068	.166	41.286	1	.000	-1.394	-.742
No	0[a]	.	.	0	.	.	.

Future planning							
One day	-1.494	.235	40.562	1	.000	-1.954	-1.035
A few months	-.933	.215	18.865	1	.000	-1.354	-.512
One year	-.594	.240	6.129	1	.013	-1.065	-.124
Five or more years	0[a]	.	.	0	.	.	.
Objective housing stability							
Unstably housed_Buying	-.195	.283	.476	1	.490	-.749	.359
Unstably housed_Public rent	-.268	.225	1.413	1	.235	-.710	.174
Unstably housed_Private rent	.117	.275	.181	1	.671	-.422	.656
Unstably housed_Other accommodation	-.655	.289	5.127	1	.024	-1.221	-.088
Stably housed_Owns home	0[a]	.	.	0	.	.	.

Note. Link function: Logit

[a] Reference category

Table_Appendix 9-6

Summary of Ordinal Logistic Regression Predicting Well-Being from Self-reported Health, Mental Health Conditions, Future Planning, the Four Experiences of Opportunities to Enjoy Adequate Housing and Objective Housing Conditions.

						95% Confidence Interval	
	Estimate	Std. Error	Wald	df	Sig.	Lower Bound	Upper Bound
Self-reported health							
Poor health	-4.467	.419	113.892	1	.000	-5.288	-3.647
Fair health	-2.498	.190	173.062	1	.000	-2.871	-2.126
Good/Excellent	0[a]	.	.	0	.	.	.
Mental health conditions							
Yes	-1.030	.171	36.082	1	.000	-1.366	-.694
No	0[a]	.	.	0	.	.	.
Future planning							

One day	-1.443	.240	36.244	1	.000	-1.913	-.973
A few months	-.923	.217	18.097	1	.000	-1.348	-.498
One year	-.597	.244	5.969	1	.015	-1.075	-.118
Five or more years	0[a]	.	.	0	.	.	.
Fourfold typology of opportunities							
Availability disadvantage	-.624	.229	7.442	1	.006	-1.073	-.176
Achievability disadvantage	-.251	.418	.361	1	.548	-1.069	.568
Low capability	-.442	.427	1.069	1	.301	-1.279	.396
High capability	0[a]	.	.	0	.	.	.
Objective housing stability							
Unstably housed_Buying	-.233	.285	.669	1	.413	-.793	.326
Unstably housed_Public rent	-.177	.232	.581	1	.446	-.632	.278
Unstably housed_Private rent	.152	.280	.296	1	.586	-.396	.701
Unstably housed_Other accommodation	-.577	.298	3.745	1	.053	-1.162	.007
Stably housed_Owns home	0[a]	.	.	0	.	.	.

Note. Link function: Logit

[a] Reference category

Table_Appendix 9-7

Summary of Ordinal Logistic Regression Predicting Well-Being from Self-reported Health, Mental Health Conditions, Support from Family, Future Planning, and Crowding Condition Index.

						95% Confidence Interval	
	Estimate	Std. Error	Wald	df	Sig.	Lower Bound	Upper Bound
Crowding conditions	-.070	.196	.127	1	.722	-.454	.314
Self-reported health							

Poor health	-4.613	.398	134.464	1	.000	-5.393	-3.834
Fair health	-2.473	.186	177.013	1	.000	-2.837	-2.109
Good/Excellent	0[a]	.	.	0	.	.	.
Mental health conditions							
Yes	-1.055	.163	41.742	1	.000	-1.375	-.735
No	0[a]	.	.	0	.	.	.
Future planning							
One day	-1.404	.228	37.914	1	.000	-1.851	-.957
A few months	-.898	.214	17.648	1	.000	-1.317	-.479
One year	-.590	.239	6.078	1	.014	-1.059	-.121
Five or more years	0[a]	.	.	0	.	.	.

Note. Link function: Logit

[a] Reference category

Table_Appendix 9-8

Summary of Ordinal Logistic Regression Predicting Well-Being from Self-reported Health, Mental Health Conditions, Support from Family, Future Planning, and the Number of Accommodation Changes in the Last Two Years.

						95% Confidence Interval	
	Estimate	Std. Error	Wald	df	Sig.	Lower Bound	Upper Bound
Self-reported health							
Poor health	-4.628	.394	137.897	1	.000	-5.401	-3.856
Fair health	-2.427	.183	176.123	1	.000	-2.785	-2.068
Good/Excellent	0[a]	.	.	0	.	.	.
Mental health conditions							
Yes	-1.043	.163	41.091	1	.000	-1.362	-.724
No	0[a]	.	.	0	.	.	.
Future planning							
One day	-1.417	.228	38.622	1	.000	-1.864	-.970
A few months	-.923	.212	18.924	1	.000	-1.339	-.507
One year	-.580	.237	6.006	1	.014	-1.043	-.116
Five or more years	0[a]	.	.	0	.	.	.

Number of accommodation changes							
One change	.195	.294	.438	1	.508	-.382	.771
Two or more changes	-.509	.399	1.626	1	.202	-1.292	.273
No changes	0[a]	.	.	0	.	.	.

Note. Link function: Logit. [a] Reference category

Appendix 10

Relationship between unemployed people who intend to return to work and unemployed people who do not intend to return to work with:

Demographic factors

3. Sex: Fisher exact test = 1.000

4. Age: $t(100) = .889$, $p = .376$

5. Time since diagnosis: $t(99) = -.001$, $p = 1.000$

Socioeconomic factors

6. Educational attainment: $\chi^2(3, N = 101) = 6.70$, $p = .082$

7. Private health insurance: $\chi^2(1, N = 101) = 0.335$, $p = .563$

8. Number of years unemployed: $U = 327$, p

Behavioural factors

9. Injecting illegal drugs: $\chi^2(2, N = 77) = 4.31$, $p = .116$

Belief factors

10. Therapy stop working (uncertainty): $\chi^2(2, N = 75) = 1.29$, $p = .116$

11. Life plans: $\chi^2(4, N = 98) = 0.579$, $p = .966$

Health factors

12. Self-reported health: $\chi^2(3, N = 102) = 0.131$, $p = .988$

13. AIDS-defining illness: $\chi^2(1, N = 101) = 0.774$, $p = .379$

14. HIV-related illness: $\chi^2(1, N = 95) = 0.084$, $p = .379$

15. Mental health conditions: $\chi^2(1, N = 102) = 0.002$, $p = .968$

16. Low energy/fatigue: $\chi^2(1, N = 97) = -0.103$, $p = .309$

17. Confusion/memory loss: $\chi^2(1, N = 79) = -0.071$, $p = .309$

18. CD4-count: $U = 923$, $p = 923$

19. Viral load: U = 8.14count: $\chi^2(1, N = 79) = -0.071$, $p = .309$

Appendix 11

Introductory letter of La Trobe

Hi,

Thank you for your continued interest in HIV social research.

We would like to let you know about a new research project that is looking at issues around quality of life for people living with HIV/AIDS. The project is being conducted by Mr Gianfranco Giuntoli, a PhD student at the Australian National University, and is being supported by the Living with HIV Program at the Australian Research Centre in Sex, Health and Society (ARCSHS), La Trobe University.

Mr Giuntoli wishes to interview a range of people living with HIV about quality of life issues in their day-to-day lives. Interviews will take about an hour and can be conducted in a place that is convenient for you.

Currently Gianfranco plans to conduct interviews in your area in APRIL and MAY 2005.

If you are interested in participating please contact the staff at ARCSHS on the phone number below or send us an email. We can explain what the research involves and help set up a time and place for the interview. (Please note ARCSHS will be closed between December 24th and January 4th).

I've attached an introductory letter from Mr Giuntoli that describes the research and its aims.

We will not pass any contact details on to other researchers without your express consent.

Thank you again for your continued support.

Dr Jeffrey Grierson

Senior Research Fellow

Australian Research Centre in Sex, Health and Society

Phone: 1-800-064-398 (freecall) Email hivfutures@latrobe.edu.au

Appendix 12

Contacting letter

Mr. Gianfranco Giuntoli
School of Psychology
The Australian National University
Canberra, A.C.T. 0200

Telephone: +61 (02) 6125 2783
Facsimile: +61 (02) 6125 0499
Email: Gianfranco.Giuntoli@anu.edu.au

April , 2005

Dear,

Re: Quality of life and opportunities living with HIV

My name is Gianfranco Giuntoli, I am a PhD student at the School of Psychology of the Australian National University of Canberra. You have already received a letter from the Living with HIV Program of the Australian Research Center in Sex, Health & Society at La Trobe University in Melbourne (contact person is Dr. Jeffrey Grierson, e-mail hivfutures@latrobe.edu.au and phone 1-800 064 398). I am now personally writing to you to introduce myself and ask for your help with my research.My PhD thesis is about the assessment of quality of life for people living with HIV. In particular, I am using the idea of "capability" to understand not only the level of people's functioning – that is what people manage to do – but also their opportunities to pursue valued life goals, to achieve a desired lifestyle. The study will allow us to understand for the first time what opportunities and quality of life mean for people living with HIV.

I would like to interview people who are HIV positive from a range of backgrounds and locations. Participation is voluntary and participants are free to withdraw at any time until four weeks after interview.

The interview would take from approximately 30 minutes to one hour and may be taped.

Information obtained from the interview may be published in my PhD thesis, and journal articles. However no personal or identifying information will be made public or published in any way. Interview transcript and tapes will not be linked with anyone's identity. All data will be confidential within the confines of the law.

All notes and tapes from interviews will be securely stored in locked filing cabinets, which only I have access to and any notes recorded on computer will be protected by computer password.

This research has been approved by the Australian National University's Human Research Ethics Committee and by the La Trobe University's Human Ethics Committee.

The contact person for the ANU's committee is:
Sylvia Deutsch
Human Ethics Officer
Research Services Office
The Australian National University, ACT 0200
Tel: 02 6125 2900
Fax: 02 6125 4807
Email: Human.Ethics.Officer@anu.edu.au

The contact person for the La Trobe's committee is:

Ethics Liaison Officer
Human Ethics Committee
La Trobe University, Victoria 3086

Ph: 03 9479 1443
E-mail: humanethics@latrobe.edu.au

If you are willing to be interviewed, I would be grateful if you would contact the staff at ARCSHS on 1-800-064-398 (freecall) or by email at hivfutures@latrobe.edu.au. The staff will be able to arrange a time and place for the interview or, if you prefer, forward your details to me so that I can contact you directly.

If you have any questions about this research please feel free to contact me or the staff at ARCSHS.

Thank you again for your time and cooperation.

Yours sincerely,

Gianfranco Giuntoli

Appendix 13

Consent form

Mr. Gianfranco Giuntoli
School of Psychology
The Australian National University
Canberra, A.C.T. 0200

Telephone: +61 (02) 6125 2783
Facsimile: +61 (02) 6125 0499
Email: Gianfranco.Giuntoli@anu.edu.au

CONSENT FORM

I, ……, agree to be interviewed by Mr. Gianfranco Giuntoli regarding the elicitation of a list of capabilities. I have read and understand the information:

1. The interviews will contribute to elicit for the first time a list of capabilities relevant for HIV-positive people.

2. Participation is voluntary and interviewees are free to withdraw at any time until four weeks following interview.

3. The research will contribute to a PhD thesis and potentially journal articles. Mr Giuntoli's supervisors are respectively Dr. Michael Smithson of the School of Psychology of The Australian National University in Canberra, who is his principal supervisor, and Dr. Jeffrey Grierson of the "Living with HIV Program" at the Australian Research Centre in Sex, Health & Society of La Trobe University in Melbourne, who is his co-supervisor.

4. The interview will be audio taped and Mr. Giuntoli, Dr. Smithosn and Dr. Grierson only will access the tapes.

5. No personal or identifying information will be made public or published in any way. Interview transcript and tapes will not be linked with anyone's identity. All data will be confidential within the confines of the law.

6. All raw data and transcripts from the interviews will be securely stored in locked filing cabinets and on password protected computer, which only Gianfranco Giuntoli has access to, so far as the law allows.

7. I would like to be able to be given feedback by receiving a brief summary of the results of the research. In this case my contact details will be added to a mailing list and kept separate from and unconnected to the data collected in the interview.

YES NO

8. I would like to have a copy of my interview transcripts.

YES NO

9. I permit the de-identified use of the data collected in this interview in future research conducted in this area

YES NO

10. Further questions about the research may be directed to:

Gianfranco Giuntoli
School of Psychology – Faculty of Science
Building 39
The Australian National University
Canberra (ACT) 0200

Tel. (02) 6125 2783
Fax (02) 6125 0499
E-mail: Gianfranco.Giuntoli@anu.edu.au

11. Ethical concerns about the research may be directed to the ANU's Human Research Ethics Committee, care of:

Sylvia Deutsch
Human Ethics Officer
Research Services Office
The Australian National University, ACT 0200
Tel: 02 6125 2900
Fax: 02 6125 4807
Email: Human.Ethics.Officer@anu.edu.au

or you may contact the:

Ethics Liaison Officer
Human Ethics Committee
La Trobe University, Victoria 3086

Ph: 03 9479 1443
E-mail: humanethics@latrobe.edu.au

Signed Date

Appendix 14

Information sheet

Mr. Gianfranco Giuntoli
School of Psychology
The Australian National University
Canberra, A.C.T. 0200

Telephone: +61 (02) 6125 2783
Facsimile: +61 (02) 6125 0499
Email: Gianfranco.Giuntoli@anu.edu.au

INFORMATION SHEET
(For you to keep)

You are invited to be interviewed by Mr. Gianfranco Giuntoli regarding the elicitation of a list of capabilities relevant for people who are HIV positive. Mr. Gianfranco Giuntoli is a PhD student at the School of Psychology of The Australian National University, Room 116, Building 39, Ph 6125 2783. Gianfranco is being supervised by Professor Michael Smithson of the School of Psychology and by Dr. Jeffrey Grierson, Research Fellow at the "Living with HIV Program" of the Australian Research Center in Sex, Health & Society at La Trobe University in Melbourne.

12. The interviews will contribute to elicit for the first time a list of capabilities relevant for HIV-positive people.

13. Participation is voluntary and interviewees are free to withdraw at any time up to four weeks after interview.

14. The research will contribute to a PhD thesis and potentially journal articles. Mr Giuntoli's supervisors are respectively Dr. Michael Smithson of the School of Psychology of The Australian National University in Canberra, who is his principal supervisor, and Dr. Jeffrey Grierson of the "Living with HIV Program" at the Australian Research Centre in Sex, Health & Society of La Trobe University in Melbourne, who is his co-supervisor.

15. The interview will be audio taped and Mr. Giuntoli, Dr. Smithosn and Dr. Grierson only will access the tapes.

16. No personal or identifying information will be made public or published in any way. Interview transcript and tapes will not be linked with anyone's identity. All data will be confidential within the confines of the law.

17. All raw data from interviews will be securely stored in locked filing cabinets and on password protected computer, which only Gianfranco Giuntoli has access to, so far as the law allows.

18. You permit the de-identified use of the data collected in this interview in future research conducted in this area

YES NO

19. Further questions about the research may be directed to:

Gianfranco Giuntoli
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Building 39
The Australian National University
Canberra (ACT) 0200

Tel. (02) 6125 2783
Fax (02) 6125 0499
E-mail: Gianfranco.Giuntoli@anu.edu.au

20. Ethical concerns about the research may be directed to the Human Research Ethics Committee, care of:

Sylvia Deutsch
Human Ethics Officer
Research Services Office
The Australian National University, ACT 0200
Tel: 02 6125 2900
Fax: 02 6125 4807
Email: Human.Ethics.Officer@anu.edu.au

Or you may contact the:

Ethics Liaison Officer
Human Ethics Committee
La Trobe University, Victoria 3086

Ph: 03 9479 1443
E-mail: humanethics@latrobe.edu.au

Signed Date

Appendix 15

Interview schedule of qualitative study

RESEARCH QUESTIONS:

3) What social, cognitive and emotional factors helped and what hindered the study participants' perception of valued opportunities?

4) How did the respondents construe the meaning of their opportunities to access health care services?

THEORY QUESTION 1: What are the most valued functionings in the respondents' everyday life?

- Informant question 1: Can you tell me about the time that you first found out that you were HIV+? Both in terms of when and the circumstances around it.
- 2) Informant question 2: What thoughts stood out for you at that time? What was it like to discover that you were HIV+?
- 3) Informant question 3: Now, I would like you to take your time to answer this question. Can you tell me what you have been spending your time doing in the past week and what you plan to do this weekend. [How did you spend last Monday, Tuesday, Wednesday….]
- 4) Informant question 4: Was this a typical week for you?
- 5) Informant question 5: Can you tell me what are the objectives, the goals that you characteristically try or hope to achieve in your daily behaviour? I will give you a few examples of what I mean. There are objectives and goals that one might seek, for example "trying to be physically attractive", or

"trying to seek new and exciting experiences", or even "trying to achieve a spiritual oneness with God". And there are objectives and goals that are about something that one might try to avoid or prevent, for example: "trying to avoid being noticed" or "trying to avoid being dependent on my boyfriend". I would like you to focus on your own behaviours, not to compare the things that you typically do with what others try to do. It doesn't matter if you have been successful or not in reaching these goals . So can you give me any example of such objectives or goals?

The objective of "trying to be physically attractive" can be achieved in a variety of ways, for example by exercising, dressing in a certain way, having a new hair style, and so on. So can you think of your personal behaviours and tell me any examples of the objectives that you try to accomplish by doing them?

- 6) Informant question 6:Can you give me any examples of things that you find yourself thinking a great deal about?
- 7) Informant question 7: What are the most important things for you at the moment?

THEORY QUESTION 2: What factors make the respondents see certain opportunities as not available, achievable or desirable?

- Informant question 8: Can you tell me about your experiences of pursuing your goals in your everyday life? [For example goals related to your work, social, health life] What factors do you find help, and what factors do you find hinder your efforts to pursue your goals?

- nformant question 9: Please take your time to answer this question. Can you give me any example of an occasion when you found yourself thinking that you could not pursue a certain goal or plan?
- Can you give me any example of an occasion when you found yourself thinking that you could not pursue a certain goal or plan because of the implications of being HIV+?
- Informant question 10: What were the issues at the time that made you think that?
- Informant question 11: Is there anything that you find yourself thinking a great deal about and that you would like to do or achieve, but must do without because you think that you cannot do it?
- Informant question 12: Can you give any example of a situation were, on the contrary, you felt that you had a chance to achieve a certain goal?
- Informant question 13: What were the issues at the time that made you think that?
- Informant question 14: Sometimes after people find out to be HIV positive they change the goals that they try to pursue with their everyday behaviours, sometimes they don't. What is the case with you? (Do the goals that you try to pursue with your everyday behaviour differ from the goals that you tried to achieve before knowing you were HIV+?)
- Informant question 15: Can you give me example of any aspect of your life in which you felt that being HIV + worked to your advantage?
- Informant question 16: How do you think things could be at this stage if you were not HIV+?

- Informant question 17: How do you think they could have been worse?

FURTHER QUESTIONS:

- What incidents related to your experience of being HIV+ stands out for you?
- Do you feel that you have shared with me everything that is significant with regard to the way you experience opportunities in your daily life?
- Is there any other question that you would have liked me to ask you to better understand the way you perceive your opportunities in your daily life?

Question from the WHOQOL-HIV BREF questionnaire:

1) To what extent do you have the opportunity for leisure activities?

1	2	3	4	5
Not at all	A little	Moderately	Mostly	Completely