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Portfolio for professional Doctorate in
Counselling Psychology (DPsyc)

Sacha Lawrence

City University, London

Department of Psychology

Submitted November 2011

HIV: a biopsychosocial context

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Acknowledgements

I would like to thank my supervisor Dr Malcolm Cross and my previous supervisor Dr Paul Holland, for their support, advice and input in the development and the completion of this doctoral research. I am also grateful to Amanda Evans and Dr Amy Saunders at the Royal Free Hospital who have inspired, motivated, sustained and encouraged me throughout the final year. I am also greatly appreciative to my peers, Gaille MacKinnon, Elaine Mayon-White and Ruth Jennings, for their professionalism, support and insight. Many thanks to my family for continuous support and encouragement throughout my three years of training and appreciating the challenges this training involves on both personal and professional levels. A separate thank you to the eight participants and the management of Helios centre for investing their valuable time and sharing sacred experiences.

City University Declaration

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Preface

The preface will introduce the various components of the Doctoral Thesis Portfolio. The portfolio focuses on three different areas related to HIV and the practice of counselling psychology. Firstly, there is an exploratory piece of research focusing on the experience of growing older with HIV. Secondly, a case study presents a reflexive exploration of the clinical journey undertaken with a client with poor adherence to antiretroviral drugs. Finally, there is a critical review of the literature that explores an understanding of Sexual Risk Behaviour amongst gay men from a counselling psychology perspective. A brief overview of each piece of work will now be presented, explaining more fully the areas that it covers, its aims and objectives. The preface will be concluded with a summary of how each of the set-pieces are connected by a more personal theme.

Part 1: The research

This section consists of an original piece of research that aims to explore in-depth the experience of growing older with HIV. The study uses semi-structured interviews. Data was gathered from a homogenous sample of seven men and one woman who have a history of HIV diagnosis. The data was analysed using the qualitative methodology of Interpretative Phenomenological Analysis (IPA). The research focuses on the perceived experience of growing older amongst an aging HIV cohort. The analysis focuses on perception of time and life transition with HIV. Implications for counselling psychology practice are identified and discussed.

Part 2: Professional practice

This section contains an example of clinical work in the form of a case study. The focus here is on the professional practice of counselling psychology. The aim of this piece is to demonstrate the complexity of HIV psychological work and show the relevance of an existential perspective in this particular context. The study is a summary over the course of 36 sessions of an integrative approach. The clients' difficulties were formulated within the CBT model, the original model of choice. It further demonstrates how the depth of client trauma and the complexity of a wider biopsychosocial context invites different psychological models to explore the true nature of poor adherence. This particular case was chosen not so much to

demonstrate the advantages of any particular therapeutic approach, but to invite an open-minded dialogue within various psychological theories. It shows how the understanding of self has become more relevant and appropriate and becomes a focus of therapy. It then allows one to appreciate the choices one makes under the circumstantial constraints and limitations. Those choices represent the ultimate freedom of deciding how one can move on with one's life.

Part 3: Critical literature review

The aim of this section is to present a systemic and critical appraisal of the literature on the topic of unprotected sex amongst gay men. The topic is relevant to counselling psychology from the point of view of a dual role of an HIV psychology. It helps to understand some possible psychological challenges to a client's understanding of HIV management in clinical work. It also attempts to keep public health interests in mind when devising HIV transmission prevention tools. The review explores the current studies on Sexual Risk Behaviour and is interested in what might be missing in existing research and tries to allocate the meaning of unprotected sex for gay men. The idea is to demonstrate the depth of the problem and raise an awareness of various dimensions of sexual health work for counselling psychology.

Thematic connection to the portfolio

The portfolio represents the outcome of three years of training as a counselling psychologist and as a researcher. The thematic connection of this portfolio ties in with my own philosophical views on the meaning of life and one's experience. It attends the Heideggerian concept of *thrownness* and questions the extent of personal choice in given circumstances and a given context. It is interested in the role of own agency as well as the role of self-actualisation in a wider biopsychosocial context and self-development.

The portfolio tries to avoid ideological polarities between cognitive, humanistic and dynamic views and attempts to bring them together within the phenomenological framework of this research.

Section A: the Research

Growing Older with HIV: Phenomenological Perspective

Sacha Lawrence

City University, London

Supervisor: Dr. Malcolm Cross

Abstract

It seems, in fact, as though the second half of a man's life is made up of nothing, but the habits he has accumulated during the first half.

Fyodor Dostoevsky

Personality is only ripe when a man has made the truth his own.

Soren Kierkegaard

This research has attempted to get an insight into the phenomenon of growing older with HIV. It attends the experience of the first aging HIV cohort and tries to understand what it means for the participants to grow older with this particular condition. The study was conducted using semi-structured interviews and data was analysed using Interpretative Phenomenological Analysis (IPA). The participants were seven gay men and heterosexual woman age between 43 and 70 years of age. They were united by a history of living with HIV from some six to twenty-eight years in duration.

Four superordinate themes emerged from the interview data. All the participants recognised the fact that they belonged to the first wave of long-term HIV survivors and their experience with growing older was collectively linked to anxieties of an unknown future. Participants reported stigma as an ongoing experience of living with HIV and were concerned that this stigma seemingly increased with age. Individual identities of the participants were affected by stigma and trauma of initial diagnosis. With increasing age these identities have a tendency to evoke a sense of 'not belonging'. It seemed that participants were feeling difficulty with placing themselves contextually into wider society.

The research unveils a various number of coping strategies of the participants, which includes split, knowledge, fantasy and spirituality. These were designed to increase a sense of internal Control and stabilise perceived disempowerment. In many cases, they were aiming to facilitate an escape from the harsh realities of HIV treatment. Although these strategies were initiated by the shock of the diagnosis, they haven't seemed to have become redundant over the

years. To the contrary, participants seemed to be employing more coping strategies with increasing age.

There is a link between the experience of the Past and Present and expectations of the Future. This has been elucidated in a separate chapter by using one generic account which seems to sum up the eight individual client stories. It is further argued that this study provides an insight into the lived experience of these individuals and can therefore be useful for advancing a therapeutic, counselling knowledge when working with this particular group.

Ch.1 Introduction

1.1 HIV & brief pathogenesis

Human Immunodeficiency Virus (HIV) had first been mentioned by the scientific community in 1981 and was strongly linked to the acquisition of AIDS (Acquired Immunodeficiency Syndrome). The first understanding of this disease was very vague and it was thought that the virus affected only the Black African and gay population. There was no treatment available until the introduction of Azidothymidine (AZT) in the 1990s (BHIVA, 2010).

The main challenge for scientists is that HIV, unlike other known viruses, appears to target the immune system directly by affecting T-cells¹; it then uses them to produce more HIV copies. This made the idea of being able to create a HIV/AIDS vaccine redundant, as any known vaccine requires a measured exposure to the pathogenic agent in order to create an effective immune system response (Watkins, 2008). This was impossible to create in a situation where the immune system itself becomes a primary target and a feeding ground for the virus. It is important to acknowledge that from a clinical perspective, unlike with other infections, a HIV positive person might look and feel well, while millions of T-cells are still getting infected and destroyed by the virus on a daily basis. Such unusual pathogenesis and representations of HIV remains a great challenge for effective prevention and intervention programmes.

1.2 Antiretroviral drugs

With scientific advances and the introduction of Highly Active Antiretroviral Therapy (HAART), the treatment outcome for HIV has improved. For the first time, HIV positive people started to survive with treatment, finding themselves living longer, and having better quality lives (Vanable et al., 2006).

¹CD4 cells, or T-helper cells, are white blood cells which organise the immune system's response to bacteria, fungi and viruses.

The treatment itself, however, has also introduced a number of challenges in regard to HIV management. Despite saving lives, in the early days, HAART used to require complex treatment regimens and was difficult for many people to adhere to. It caused an array of side effects, from physical fatigue and diarrhoea, to serious liver and kidney damage and body disfigurement (BHIVA, 2001). Although the life expectancy of those individuals newly diagnosed with HIV has now vastly improved, the contemporary drugs, nevertheless, are still causing numerous side effects and new concerns are being raised about the heightened toxicity and long-term effects of antiretroviral medication on the aging HIV population (Lyons et al., 2010).

1.3 Social epidemiology

Despite significant improvements in treatment, the epidemiological perspective remains worrying as the rate of acquisition of HIV remains high, while the uptake of HIV testing is relatively poor. In the UK, for example, around 86,500 people were living with HIV at the end of 2009, a quarter of whom were unaware of their infected status. In 2010, there were 6,136 new diagnoses of HIV, contributing to a cumulative total of 114,766 cases reported by the end of that year. As of December 2010, there have been 26,791 diagnoses of AIDS in the UK, whilst 19,912 people diagnosed with HIV have died (AVERT UK, 2011).

Newly diagnosed sexually transmitted infections (STI's) are now also on the increase and, according to the Health Protection Agency (HPA), have reached the 500,000 mark for all new STI diagnoses in 2009 alone (HPA, 2009). HIV prevalence for those who engage in unprotected sex also remains high, with men who have sex with men (MSM) and heterosexual women being most at risk (Dougan, Evans & Elford, 2007).

Emerging groups

Over 50 group

For the first time in the UK, we are witnessing higher numbers of newly diagnosed HIV amongst those who are aged 50 years or over. According to the British Broadcasting Corporation (BBC), the over-50s infection rate in England,

Wales and Northern Ireland has more than doubled in under a decade – from 299 new cases in 2000 to 710 in 2007 (BBC, 2010). The risk comes from late diagnosis, as well as from an increase in unsafe sex practices within this group (Lovejoy et al., 2008).

Heterosexual group

In the UK, a major component of the rapid increase in HIV diagnosis has been attributed to infections that have been heterosexually acquired. For the first time - and over the past 15 years - this group accounted for 42% of all HIV diagnoses in 2010, while MSM accounted for 38.5%, compared to 1995 when 31% of diagnoses were a result of heterosexual sex and 58% of new HIV diagnoses resulted from sex between men.

Immigration

Most of the new diagnoses among the heterosexual group belong to people who were infected whilst in other countries, particularly from Africa and Eastern Europe (Avert UK, 2011). The influx in immigration from these countries brings new challenges, as these communities are often difficult to reach. Many of these immigrants are unaware of their own HIV status or they avoid testing for fear of deportation (POST, 2007), which imposes a serious challenge for infection control in the UK.

In summary, the epidemiological picture in the UK shows both an increase in those individuals newly diagnosed with HIV, as well as an improved life expectancy of the already positive cohort. Both factors represent a growing pressure on HIV services to provide an effective and sustainable model of care and prevention of the disease.

1.4 Aging with HIV

In the late nineties, a newly diagnosed HIV positive person in his/her late 30s could have only expected to live until the age of 60 , but can now expect to live until 73 years, according to a 2008 study (The Lancet, 2008).

The extended life span of the HIV positive group is now starting to give rise to a changing demographic pattern. In New York, for example, over 64% of the HIV positive cohort are now over the age of 40 (Shippy & Karpiak, 2005). HIV positive adults aged 50 and over now represent approximately 25% of the entire HIV population in the United States (Vance et al., 2009). This represents a dramatic increase from just five years ago, when 17% of those living with AIDS were aged 50 and older (Frain, 2010). Last year, the British HIV Association (BHIVA) seminar in Brighton outlined that one in six HIV positive people in the UK is now over 50 years of age and in Brighton that figure rises to one in three. There are also approximately 2,500 people in the over 60's age group being seen for HIV care in the UK, compared with 350 people in 2000 (BHIVA, 2010).

With the aging of HIV populations, there is currently a great deal of speculation, but less evidence-based understanding, on the impact of aging on the various aspects of HIV and the long-term perspectives of its treatment from both medical and psychological perspectives (Bhavan, Kampalath & Overton, 2008; Gorman, 2006) . As the chronic disease phase is extended under the new treatment regimes, people with HIV now potentially face age-related cardiac and cognitive problems (Valcur et al., 2004). Yet the effect of the underlying HIV infection on psychological well-being is still unclear (Groves et al., 2010). Literature searches do not indicate the current studies on ageing and its broader impact on either adherence; physical or psychological copings; quality of life; toleration of side effects of the treatment; and risk behaviours in this group (Alisky, 2007; Emler, 2006).

The first UK study by Sherr et al. (2009) examined clinical and behavioural changes, as well as consistent differences in the experience of HIV treatment between older and younger HIV positive people. The older group, for example, was found more likely to be adherent to antiretroviral medication (ART) and was significantly more optimistic about treatment. However, the researchers were

cautious that special understanding and consideration needs to be given as ageing adds to an increase in psychological and physical burden for HIV positive people (Shah & Mildvan, 2006). What they considered as strategically important was the need for the provision of supportive care and services in that group (Sherr et al., 2009; Lyons et al., 2010).

There is a different etiology amongst the older HIV positive population (referred to further in the text as Aging HIV or AHIV) which needs to be clearly distinguished. Elford et al., (2008) suggested the consideration of two distinct groups of older HIV positive men based on the time of the diagnosis. His classification would appear to be appropriate to the current study on the basis that it helps to situate the contextual experience of participants.

(1) The first group comprises those who were diagnosed with HIV under the age of 50 and belongs to the aging cohort. This group was well represented in the current study, with the participants reporting being diagnosed with HIV on average 14 years ago and reporting a current median physical age of 50 years old.

(2) Another group includes those who were diagnosed with HIV over the age of 50 and can be considered as a relatively newly diagnosed cohort. This group contains two major sub-groups and differs by the point of time of HIV diagnosis:

(a) People who were infected with HIV in their 30s and 40s (so called 'late diagnosis'), but weren't tested for HIV until recently.

(b) Those who were infected late in life ('late seroconverters') and described by Schmid et al., (2009) as secondary peaks of HIV. One participant in the current study belongs to this particular group.

The late acquisitions of HIV are becoming increasingly common as the risk is often overlooked by both service providers and clients alike (Elford, 2006; Orchi et al., 2008). According to Help Age International (2010), older people are becoming

invisible in existing data sets. A routine HIV screening that is normally offered by GUM and HIV clinics in the UK is not frequently visited by older people (Kohli et al., 2006). They are not fully recognised as an existing risk group, possibly due to the common beliefs that older adults are not using recreational drugs and are sexually inactive. Because of that misconception, educational programs are mainly targeted at young people (Kohli et al., 2006).

On the other hand, those from the older generation are more likely to be divorced, separated or widowed by that age. They are likely to live independently and engage in novel sexual relationships which, in turn, can increase the risk of HIV acquisition in that group (Kohli et al., 2006) This happens mainly because they are more likely to engage in unprotected sex. The assumption that condoms are mainly used for birth control is common in the heterosexual community and was explored Schmid et al. (2009). Older gay men, respectively, are more likely to keep their sexual life secret as they are likely to be stigmatised amongst aging peers. Their own perception of their own sexuality is likely to be tainted by internalised homophobia or denial which prevents them from using the sexual health service (Murray & Adam, 2001). Those factors are just examples of the complexity of the risks of HIV transmission in that group.

1.4.1 Health service and AHIV

Health service providers often fail to differentiate HIV-related illnesses from similar medical conditions (Shippy & Karpiak, 2005). Differential diagnosis in an aging cohort is likely to overlook AIDS-defining illness, especially if this was masked by a more common illness more representative of the aged health condition (Ress, 2003). For example, weight loss, anaemia, memory loss and neuropathy are overlapping with the age-related presentations of depression, Alzheimer's dementia and chronic inflammation (Kohli et al., 2006). In many cases, doctors are less likely to suspect HIV in the elderly group as illustrated in the example by Ress (2003). He uses the case of a 72-year-old man who was admitted to A&E with a high temperature (39C), severe hypoxia and a resistance to antibiotics. His medical tests were not indicative of any particular condition. The extended life history eventually revealed intravenous drug use and unprotected sex for the past six years. It allowed for a HIV test and successful antiretroviral treatment intervention. The point of this

example is that the medical team had difficulties recognising or ruling out HIV. This would be unlikely in a case where the client belonged to a younger generation group.

Service providers are now expecting a 'grey wave' (BHIVA, 2010; Murray, McDonald & Law, 2006) of HIV that will lead to increasing demand on the service in the years to come. Changing demographics are also implying a change in service needs, which in a time of finite resources, might be more focused on high quality and sustainable service models (UK HP Commissioner Report, 2010).

1.4.2 Physical comorbidity

Physical comorbidity doesn't form a part of the current research, but it is important to acknowledge the complexity of the impact on aging health from the HIV virus. The consequences of lifelong treatment have numerous effects on the physical body. The aging HIV population (AHIV) have less capacity for immune recovery than their younger peers (Gebo et al., 2006). Frailty and acceleration of aging in the elderly HIV group was a point of concern for Onen et al. (2010), with premature frailty occurring in 9% of his participants, with a median age of 42 years old. Frailty costs more to service providers in treatment and hospitalisation, as well as leaving a psychological impact on the service users (Onen et al., 2009).

Metabolic and hormonal disorders are common in the older age group and are normally associated either with HIV itself or the side effects of ART (Sharma et al., 2010). This includes bone density loss; early onset of menopause; hypogonadism; diabetes; and cardiovascular diseases (Kohli et al., 2006).

Many medical conditions associated with aging are exacerbated by HIV/AIDS, too. These include cardiovascular disease, high blood pressure and dementia. Oursler et al. (2011) believes that comorbidity affects physical functioning and might modify the effects of aging. The interaction of advanced age on the risk and progression of diabetes among AHIV with long-term exposure to ART requires further attention (Kohli et al., 2006). Early menopause may also increase the risk of diabetes in HIV positive women (Schoenbaum et al., 2005), while a history of chronic opiate use may contribute to abnormal glucose metabolism in AHIV women (Howard et al., 2005).

Although the physiological implications of long-term HIV, as well as ongoing ART medication, are still under-researched, the preliminary data indicates a higher rate of comorbidity compared to HIV negative peers.

1.4.3. Psychological comorbidity

Mental health issues are prominent in older persons living with HIV/AIDS.

Stigma, isolation and poor overall health are all major triggers for depression, and need to be addressed and assessed on an ongoing basis (Gebo, 2006). Depressive symptomatology has a significant association with cognitive decline in this group and the HIV positive group performed worse than healthy peers on a number of neurocognitive tests (Vance, Woodley, Burrage, 2007). The rates of depression are also higher in this demographic group, yet depression remains under-diagnosed and under-treated for this population (Gebo, 2006; Pitts et al., 2005, Grov et al., 2010).

Current data demonstrates that a HIV infected person is at higher risk of psychiatric illness and neurocognitive impairment (Kohli et al., 2006). Aging with HIV appears to confer additional risks for brain abnormalities compared to HIV alone. It is likely to exacerbate metabolic changes in the brain which associates with HIV and consequentially increases the risk of cognitive impairment (Gonzales & Cherner, 2008).

The veteran cohort study (Justice et al., 2004) examined the needs of 1803 Americans of a median age of 50. According to the researchers, the HIV cohort demonstrated a greater prevalence for depression and drug and alcohol abuse than in HIV negative peers. Similar findings, especially those related to depression, were replicated in further studies (Gebo, 2006; Gonzales & Cherner, 2008; Grov et al., 2010; Simone & Appelbaum, 2008). Brain functionality of aging AHIV people can be compared to of a HIV negative peers who are 15 to 20 years older (Ances et al., 2010).

The combination of psychological and physical decline and increasing social isolation puts the AHIV group at a higher risk for depression and suicide (Vance, Struzick & Raper, 2008). At the same time, the risk of suicidal ideation is already known to increase with age within the general population (Gallagher-Thompson &

Osgood, 1997) and is likely to be higher in the already stigmatised HIV positive community (Robertson et al., 2006; Parker & Aggleton, 2003).

A literature review showed some contradictions in the current research of the psychological well-being of aging HIV positive individuals. Not all of the research, however, indicates a worsening of mental health and depression, particularly within the older HIV group. Despite endorsing greater medical comorbidity, older adults reported significantly lower depressive symptomatology and greater positive effects in some recent studies (Sherr et al., 2009; Mavandadi et al., 2009). AHIV populations were less likely to report seeing a behavioral health specialist than their younger counterparts. Older adults reported higher emotional support which, in turn, was associated with lower depressive symptomatology, greater positive effects, and non-utilisation of behavioral health services. This resonates with Socioemotional Selectivity Theory (SST) which supports the notions that, at the final stages of life transition, people often feel more driven to satisfy their emotional needs. This also makes them different to their younger peers (Carstensen et al., 1999).

The discrepancy in the studies is likely to be routed in the wider biopsychosocial context of their participants and issues with generalisation across the sample. Variables such as socioeconomic status; their general outlook on the extent of the problem; and the presence or absence of close networks are all expected to impact on age-related re-adjustment (Lyons et al., 2010).

In conclusion, AHIV is a new and ever-increasing client group. They present with complex needs and are under particular risk of complications from poor management of HIV. This often arises due to false assumptions from service users and service providers alike; misinformation; stigma and ageism in many cases (Ibrahim, Anderson, Bukutu & Elford, 2008; Chenard, 2007). According to Pitts et al., (2005), AHIV are less likely to rate their health and well-being as excellent; less likely to be in contact with service providers; and receive less personal support than healthy peers.

1.4.4 Support network

Social support

Psychological well-being cannot be seen outside the wider social context and more attention should be paid to the social environment of individuals diagnosed with HIV. The quality of social relationships may be particularly important for successful psychological adaptation to HIV (Mavandadi et al., 2009).

Age-related changes in HIV positive people often consists of ongoing challenges that may eventually have a negative impact on mental health. People face issues of social isolation; loss, and grief due to age-related factors; they face their own morbidity and mortality, and a decline in physiological functioning due to pathological changes in the body (Ress, 2003).

Cycle of depression in relation to network of support

Approaching the final stages of a lifespan (retirement; illness; relocation and death) often results in a shrinking of one's social network and reduces social reciprocity in this group (Shippy & Karpiak, 2005). The difference with HIV sufferers, as opposed to any other chronic condition, is that they are still stigmatised. Unlike those with high blood pressure or diabetes, AHIV might find it difficult to discuss their health problems with their relatives at the dinner table. The more they find disclosure difficult, the more likely they are to retreat into isolation from family and friends. In return, a self-imposed isolation results in reduced likelihood of adequate support, as family and friends might find it difficult to understand the changing needs of AHIV (Shippy & Karpiak, 2005). Those who receive less informal support were also less likely to access formal support and tended to report higher rates of depression and anxiety (Heckman et al., 2002).

Such a tendency can be self-defeating as the older age group depends largely on their own individual network of support. In the heterosexual community this will often include children and other members of the extended family. Gay men, on the other hand, see friends as members of their extended family and use their support as their only carers (Shippy & Karplak, 2005); they found that only 49% of

their gay male respondents disclosed to their friends, which is a surprisingly low number given the primacy of friends as a major resource in this group.

Spirituality

Spirituality can play an important part in one's process of readjustment. Some authors consider separating the meanings of spirituality and religion. The definition of spirituality often seems varied, however, the author of the portfolio uses Brennan's (2008) definition of spirituality as a personal sense of transcendence over one's immediate circumstances. Religion, on the other hand, can be seen also as an adherence to a set of ideological beliefs and rituals (ibid). Such definitions can be useful in counselling, in order for psychologist to relate to individual and collective latitudes of definitions and meanings. However, in practical terms, it seems that both religion and spirituality can offer a capacity to support HIV-related re-adjustment (Dalmida, 2006).

Over the years, a number of studies have acknowledged the importance of spirituality in coping with HIV-related stressors, such as: the loss of loved ones (Richards, Acree & Folkman, 1999); a sense of guilt, shame and self-blame (Kaldjian, Jekel & Friedland, 1998); and finding purpose and increased coping skills (Siegel & Schrimshaw, 2002). Spirituality has increasingly been recognised as an important resource and it has shown a strong association with Conscientiousness, Openness and Agreeableness in Five-Factor Model Personality Traits (Lockenhoff et al., 2009). The authors considered religiousness and spirituality as characteristic adaptations that develops a basic personality trait and is culture and environment dependable. This conclusion is somewhat questionable, as another study on a sample of 1399 adults, ranging age from 17 to 68 years, found a significant and nonlinear increase in spirituality with age (Argue, Johnson & White, 1999) which might indicate the fact that spirituality is – rather - an acquired skill which is likely to develop with increasing age.

Spirituality has shown a capacity to accommodate successful aging as it was explored in detailed by Vance et al. (2008). In his study, 72% of HIV positive adults reported that their spirituality had changed after their diagnosis, with 44% of these participants considering their HIV status to be a blessing (Vance & Burrage, 2006).

Parker et al. (2002) believe that spirituality is an important aspect of successful aging in the context of one's own developmental process and utilisation of resources, so as to manage the negative effects of chronic conditions. Several other studies also indicate the positive role of spirituality in AHIV and its effect on a positive outlook to life and psychological well-being (Hernandez, 2005; Simoni & Ortiz, 2003). However, it is important to be mindful of the fact that some religious institutions assert HIV as an act of God's vengeance for wrongdoings and homosexuality in particular (Holt, Houg & Romano, 1999). This in itself was defined as negative spiritual coping by Tarakeshwar, Pearce & Sikkema (2005) and can re-enforce alienation and further stigmatisation in some AHIV patients. The authors believe that comprehensive counselling skills are required to accommodate the varying spiritual and existential experiences of clients.

What is important to consider with AHIV is that both spirituality and religion have been linked to a number of positive psychosocial outcomes and therefore they help to maintain a focus on quality of an extended life. This seems paramount in aging with HIV and answers the emerging needs in that group (Vance et al., 2008; Mavandadi et al., 2009; Shippy & Karplak, 2005; Brennan, 2008).

1.5 Implications for counselling psychology

This project was formulated predominantly with a counselling psychology perspective in mind. The aim was to offer a better understanding of the experience of growing older with HIV. It is important, however, to recognise that HIV itself might not necessarily be the major challenge to some clients, while a life transition, midlife crisis, or living with chronic illness might be at the forefront of the client's needs. This is not to say that HIV is irrelevant in the context and it is up to the psychologist to collaboratively decide and prioritise the direction and focus of the counselling process.

(a) Midlife

A midlife transition which is often referred to as midlife crisis is a psychologically challenging period of one's life which is characterised by crisis due to change in one's sense of identity, personality and manifest behaviour (Brim, 1976).

There are no clear age attributes to the midlife crisis. Wethington (2000) asked 724 American participants to share their own experience of the challenges of midlife. Most participants reported the onset of midlife crisis in their 40s with significantly more men reporting crisis than women. Participants describe it as a growing awareness of impending mortality or a shortened future and associate it with major life events and radical life changes. The most frequently mentioned age was between 40 and 50. However, the youngest age reported was as young as 17 and the oldest age 75 years (Wethington, 2000).

Socially imposed values and ideas of age, beauty and achievement can seriously influence this process. Stories of the aging 'midlife man' who drive red sports cars and who have abandoned their aging wives has become a well-worn and acknowledged cliché in our society. Women, however, are also seen as victims of aging. With the end of fertility and departure of their children, they are often left to fight the natural changes of the bodies, often with the help of cosmetic surgery and HRT (Degges-White, 2001).

The psychodynamic theories tend to see midlife transition as yet another developmental stage. Erik Erikson (1968) believed that every human being goes through a certain number of stages in order to achieve full development. He devised eight stages that a human being goes through from birth to death. According to him, during middle age adulthood, the primary developmental task is one of finding a socially viable purpose and helping to guide future generations (ibid). However, it also implies the need to express love through more than sexual contacts; create a meaningful and fulfilling environment at home and with close ones; and to adjust to the physical changes experienced in middle age. When a person is unable or unwilling to engage with these tasks, he/she develops a feeling of stagnation and dissatisfaction with the relative lack of productivity (Erikson, 1968).

According to Carl Jung, the development of an individual comprises of two main phases of life which are corresponding to the first and a second half of a life cycle (Jung, 1970). He sees a midlife as a bridge between those two phases. Although he did not describe midlife crisis *per se*, Jung sees it as an expansion of gender boundaries where women become more connected to their masculine aspects and men to the feminine sides. According to him, this can be seen as a

positive change to those who are capable of integrating their change by expanding their personality (ibid).

When Levinson (1978) studied middle-aged men from different socio-economic backgrounds, he discovered that midlife is characterised by negotiations with death and finality. He therefore allocated three major tasks of midlife:

1. Reviewing accomplishments of the past.
2. Taking first steps into the future.
3. Dealing with the polarities such as young vs. old; attachment vs. separation; feminine vs. masculine, and so on.

Existential psychologists, on the other hand, tend to focus on the meaning of life (Yalom, 1980) and owning experience of midlife (Spinelli, 1994). According to Yalom (1980), one of the main reasons why people need meaning in life is because it creates values. In turn, values allow for confirmation of our own individual meaning. The meaning of life, according to him, is masked by our existential anxieties of isolation, freedom and death.

Spinelli is more explicit about a sense of ownership -the notion of self, according to him, is typified by undergoing transition when one eventually faces incongruence between one's own beliefs and the way one is experiencing self (Spinelli, 1994).

Kierkegaard identifies three ways of relating in the world and describes them as stages of life (Kierkegaard, 1845). These are aesthetic, ethic, and religious stages respectively. According to him each successive stage represents a more enlightened form of life. In an existential view, midlife offers a choice of exploring and transcending life changes or conversely fighting it. The appropriate support can be seen in helping a person to face, to accept, and to explore the changes rather than trying to re-invent and construct a new self (Weaver, 2000). For that, an individual who faces issues of midlife transition is confronted with a sense of isolation and questions of their own free will and responsibility (Becker, 2006), and it seems that an exploration of existential issues might be highly appropriate in a counselling room.

(b) Chronic illnesses

Nichols and Hunt (2011) looked at chronic illness not only as physical, but also as a mental and spiritual challenge. When the body succumbs to illness early in life, it is often accompanied by considerable distress which remains with the person for many years to come. Attitudes to stress vary hugely in different cultures as they are ultimately based on the culture's attitude to suffering. In Western culture, the tolerance for suffering is notoriously low which is proven by the wide use of tranquillisers and painkillers in this society (Jacobsen, 2007). Suffering can be seen also as an existential part of life; it can be minimised, but it is also ultimately unavoidable. According to Jacobsen (2007), we can all be divided into four categories of how we deal with suffering:

- (1) See suffering as something to be controlled and mastered.
- (2) See suffering as an opportunity and enter a dialogue with it.
- (3) See it as a challenge or a gift.
- (4) See it as fate to which one has no any control over.

Jacobsen elaborates further on the human attitude to suffering. He believes that any disease presents itself with two separate aspects - one is the medical side which is the disease itself. The second is the psychological aspect of how we construe our relationship with that particular disease and how we relate to it (Jacobsen, 2007). This can be closely linked to the previous theme of spirituality, as Nichols and Hunt (2011) believe that an understanding and validation of spirituality has important implications for helping clients with chronic health issues in order to derive meanings from their experience. Relationships with HIV in this context could be more complex, as it is an infectious disease which transmits through intimate contact, and therefore is more feared by the general public.

(c) HIV psychology

The role of HIV psychology follows the changes in the HIV dynamic and has adapted itself accordingly over the years. It has moved from being predominantly a form of bereavement counselling to that focusing on transmission prevention and helping HIV clients to plan for the future (Aidsmap, 2011).

In the current forms, it covers an immense area of HIV-related issues and tends to take a biopsychosocial perspective by addressing holistically different areas of the client's life. The usual areas include: anxiety or depression related to the diagnosis; negotiating safer sex; planning for pregnancy; caring for and dealing with children with or affected by HIV infection; starting or stopping treatment; coping with body shape changes; bereavement; sexual problems; sleep disturbance; relationship difficulties; sexuality; disclosure of HIV status to partners, family, children or others; and exploring life options after significant changes in health and planning for the future, i.e. living well with a chronic condition (UCL partnership meeting, 2010).

There is a possibility that the restructuring of the NHS may result in changes in commissioning for HIV services in times to come. For service providers, this may imply that more research needs to be done in the areas of the changing needs of aging HIV patients; the long-term condition management; and patient and public engagement needs, in order to secure future funding (ibid, 2010). For counselling psychologists, it could also mean an increase in HIV positive clients in their practice outside the usual domain of HIV psychology within the framework of the NHS.

1.6 Personal reflexivity

I believe that my journey into this research started over five years ago when I joined a HIV charity as an alternative health practitioner. Working with the HIV positive population has revealed the difficulties and challenges people are going through, from the initial adjustment to the diagnosis to dealing with stigma, disclosure and health-related issues. As a HIV negative gay man myself, I was not aware of the extent of the struggle and the amount of will power used by my positive peers in order to regroup and reconstruct their lives.

Another area of my personal interest relates to life transitions. My first research idea, for example, was focused on the understanding of vicarious trauma and its experience in day-to-day living. My interest was mainly inspired by the experience of close friends who are continuously witnessing the transience of life in their professional capacity. Although the theme has changed significantly since then, it has been kept as one of the main elements of my personal and professional interest in the existential experience of life transitions. I believe that this interest originally emanated from my first professional training and career as a medical

doctor when, as a young intern in my early 20's, I first witnessed the impermanence of life and the frequent occurrence of death at the local Accident and Emergency departments of hospitals within which I worked. These experiences and encounters were later to be instrumental in my enhanced interest in meditation and the exploration of alternative health practices primarily based on the Eastern philosophical ideas of Dao and Zen.

I subsequently changed my research topic in the second year of my training and research. I felt a sense of vague dissatisfaction with my chosen topic and felt it was offering more of a reflection on the subject of the impact of death, rather than an exploration of the life process. And, as I am approaching middle age myself, I felt it was more natural for me to rather explore the transient nature of our individual being(s).

I subsequently placed the focus of my research on sexual risk behaviour and moved closer to the perspective of why people decide to engage in unprotected sex, even if they are aware of the risk of HIV. To me, this was a paradox of integration polarities and an acceptance of the interconnectedness between the vitality and morbidity of human life.

Long waiting lists for the NHS research clearance dates made me concerned about not being able to complete the project on time. I engaged myself in a parallel process, trying to think laterally for an alternative idea as a back-up plan. I was convinced that alternative research should be carried out outside of the confines of the NHS. Thanks to conversations with my then supervisor Dr Paul Holland and regular attendance at HIV meetings at my clinical placement at the Royal Free Hospital, I learned about the emerging group of people who are aging with HIV.

The group is currently under the close focus of service providers and there is a necessity for a better understanding of their needs and experiences. I became involved with the theme from the very start and, by the time I have received the NHS approval for my original research, I knew exactly which project I would be attempting to undertake. When I placed my advertisement for volunteers, I was surprised at the ease with which I was able to undertake the recruitment for this research. I signed up all eight participants in just under two weeks and really felt at the time that what started as a pilot trial was, in fact, a highly relevant project and one which seemed to resonate with many people's hearts and minds. What is also important is that this

research deeply resonated with my own personal and professional interests within the framework of the phenomenon of time, aging and one's life transitions.

Ch.2 Methodology

2.1 Research design

The study employed qualitative data collection. Interpretative Phenomenological Analysis (IPA) was deemed to be the most suitable for this study as it is a qualitative approach with an idiographic focus. It means that IPA aims to offer insights into how a given person or group of people make sense of a particular experience, while also allowing space for interpretation in a wider context (Willig, 2008). The data was collected from a small sample of eight participants by means of semi-structured interviews.

2.2 Why I chose a qualitative methodology

The qualitative study seems to be the most appropriate choice when there is a need to explore age-related transitions and to look into the experiential processes of a particular group.

My own experience of working with HIV positive clients showed that often people of the age of 40 and over tend to ask themselves questions regarding the impact of HIV on their well-being and how it might be changing with age. This would seem to be different to the concept of a so-called existential or midlife crisis. The commonly held view of a midlife crisis, as identified in Yalom's research on the meaning in life and Spinelli's idea of owning experience (as documented in Jacobsen, 2007), is that of an emotional state of doubt and anxiety in which a person becomes uncomfortable with the realisation that life is half over (Weaver, 2009).

Ageing, however, might be different in the context of HIV when clients often elaborate on further loss of health due to the progression of the illness, the side effects of antiretroviral drugs, or question their ability to remain independent in the future and express concerns of the unpredictability of such change. My current interest - as both a researcher and a counselling psychologist - lies in the experience of this unique group of individuals who are growing older with HIV and how their perception of the world can possibly be tainted by their condition which, in itself, has transformed from being a terminal to a chronic illness. This type of knowledge might be useful and relevant, especially when new budgeting policies are in the process of being introduced and questions may very well subsequently emerge on the role and place of HIV psychology in the NHS in the near future.

2.3 Phenomenology - historical background and epistemological underpinnings

Phenomenology as a discipline has its own unique philosophical origins and goals (Giorgi, 2010). However, psychological phenomenology is somehow differentiated from a pure philosophical school as it is used in social science and is based on systemic attempts to observe and describe the world of phenomena as it is presented to us as psychologists (McLeod, 1947).

I chose IPA for various reasons. Firstly, because it originates in phenomenology and presents a qualitative approach which is primarily concerned with participants' *lived experience*. Secondly, IPA has an *idiographic focus*, which means it has a capacity to offer insights into individual life stories. It is committed to a detailed analysis of each case and allows participants to hold a privileged account of their own lived experiences. Finally, IPA applies hermeneutic theory as it considers that experience is only accessible through the process of *interpretation* on the part of both, the participant and the researcher (Smith, 2010).

To sum up, IPA is guided by a particular view of the world and epistemology and because of this ideology it is not simply a research methodology, but also a

philosophical position as it allows space for a wider contextual interpretation (Willig, 2008). Therefore, with the utilisation of epistemological underpinnings; the process in the research and the procedures of the research are crucial for IPA (Smith & Osborn, 2003).

As discussed in Smith (1996), IPA originates in the works of the phenomenological philosophical thought of Husserl (1913) which were later enriched by works of Heidegger, Merleau-Ponté and others. Husserl's main contribution to the development of IPA was an explicit focus on the actual process of reflection in phenomenology (ibid). He suggested that we are too busy in our daily lives and need to disengage from our daily activities before accessing the phenomenon. To enable that process, he introduced "bracketing" as the way to put aside a taken-for-granted world where a series of "reductions" offers a different lens and different way of thinking and reasoning about the phenomenon at hand (Smith, Flowers & Larkin, 2009).

When Husserl introduced the concept of the life-world, he embarked on a path which recognised that, even at its deepest level, consciousness is already embedded in and operating in a world of meanings and pre-judgments that are socially, culturally, and historically constituted (Husserl, 1983). Phenomenology thereby became the study not just of the pure consciousness and meanings of a transcendental ego, as in Husserl's earlier works, but of consciousness and meanings in a given context. The life-world, therefore, is one of the more complicated concepts in phenomenology, mainly because of its status as both personal and inter-subjective (Tabachnik, 2006).

Following that thought, Heidegger offered the "in-der-welt-sein" (or Dasein) concept in the early sixties, whereby he tried to overcome a subject/object divide in the Western tradition, so by using this expression, he was drawing attention to the fact that human beings cannot be taken into account, except for being existent among other things in the middle of a world. By doing this, he brought not only a hermeneutic lens to phenomenology, but also introduced an ontological aspect, claiming that it is not possible for anyone to transcend the life-world, as it is ultimately regarded as an integrative complexity where we live, act and have experiences.

Therefore, Dasein as such cannot be reduced or transcended (Heidegger, 1962) as the individual and the world are mutually dependant upon each other and, through that inter-subjectivity, the meaning of the life-world becomes personal, as well as shared. As interdependency applies to Dasein, it also applies to a researchers' developing knowledge of the phenomena. As we gain access to phenomena through interpretation of other people's lived experiences (Adams, 1999), while the phenomena involves both individual and the surrounding world (Giorgi, 1997), access can be granted by considering a life-world of the researcher himself and his own experience of the shared world. Therefore, interrelation with other people's life-world is as important as sharing of that life-world (Berndtsson, Claesson, Friberg & Ohlen, 2007). This means that only by meeting people, talking to them, listening to their narratives, observing their usage of tools and the environment, we can access the life-world phenomena (Berndtsson et al., 2007). Such a layered approach in IPA was called "double hermeneutics" (Smith & Osborn, 2003), where the participant's meaning making is the first-order research, while the researcher's sense-making is second-order research. This duality means that the researcher is observing and interpreting the phenomena through their own experience of the participant's recall (Smith et al, 2009).

David Parry made an interesting point in his paper "What Makes Me Separate From You?" (2010) where he looked at the interconnectedness in the world from a point of view of difference. He approached it in three different ways: from religious, scientific and philosophical angles and by exploring Heidegger's notion of Dasein through the language of religion, philosophy and particle physics. Parry (ibid) demonstrated an overlap between all the levels of connectedness between us as beings and the outside world, while the difference remained mainly in the discourse, whether it was religious, philosophical or scientific. The most interesting question is how such understanding impacts on me as a researcher and my relationship with a participant. Indeed, how it raises my own awareness of issues concerning intersubjectivity of the world and how that intersubjectivity offers itself within my interpretation and understanding of existence, as a part of the Dasein.

2.4 Epistemological stance

My personal philosophy is based on an existential phenomenology which marries the works of intellectuals such as Nietzsche, Dostoevsky and Sartre, together with Heidegger and Kierkegaard. Facts of experience for existentialists are derived from the human reality of things. This means that rather than beginning with nature and then seeing a human life in light of this, existential phenomenology derives from the human reality and sees the nature in light of the human reality of things. "Leading phenomenological vision back from the apprehension of a being, whatever may be the character of that apprehension, to the understanding of the Being of this being (projecting upon the way it is unconcealed)" (Heidegger, 1985,p.21).

My epistemological stance is based on an attempt to embed an existential phenomenological way of learning about the world. I am aware that this is an emerging view I am holding and therefore my epistemological stance is still developing.

Everyday attitude, according to Husserl (1983), is to take things for granted. Such an attitude is dominant in our society and is not challenged as long as it falls into the category of our usual experiences. This is different to a phenomenological view point where things and events do not simply appear, nor are they always what they seem to be (Giorgi, 1997). The philosophical quest is to understand why there are things and events out there and how they are perceived in the context of a life-long experience.

The phenomenon of ageing with HIV echoes phenomena of changes in life, e.g. due to chronic illness or ageing *per se*. We know that the changed body implies a changed world and since human beings are related to dimensions of time and space, a changed life situation also implies changes in how people perceive and relate to time and space (Berndtsson et al., 2007). This area of spatial perception interests me. I assume that many of those who survived HIV in the pre-HAART era of the late 90's did not expect to live and now have a different perception of time and space and now require an increasing support with social and psychological re-adjustment (Trussler & Marchand, 2005; Williams et al., 2008).

At the interpretative stage of the research, this might help to understand the phenomena in relation to a wider social, cultural and theoretical context. In today's world, human reality becomes a separate form and different in kind from the realm of objective nature (Brockelman, 1980). This is the reason as to why I also feel drawn to a post-modern perspective. Post-modern philosophy differs from its predecessors in regard to questions of choice, politics and therapy. It is more about finding ourselves in a place where we will have some agency, but recognising that we will never gain full agency. We will always be subjected to either ethics (Levinas); unconsciousness (Freud); writing and difference (Derrida) or language (Lacan) (Loewental, 2010). A post-existential perspective allows me to look at implications of any of the above aspects for my practice without being fully caught up by their mode of thought. My focus is in finding a place between a natural and social science by starting with notions of existence which, according to Plato, starts with the human soul (Plato, in Cushman, 2001).

2.5 Phenomenological process

Phenomenology uses reductions as a set of lenses to lead the enquirer away from the distraction and misdirection of their own assumptions and rather work towards the essence of the experience (Smith, 1996). The presence of the researcher in IPA is imprinting on the research as the emerging data can be seen as an intellectual construction which is shaped by the "structure of the encounter" between the researcher and participant (Larkin, Watts & Clifton, 2006). This brings the main challenge to qualitative study as to enable the data to speak for itself and to bring a novel insight, rather than just refute the researchers expectation (Willig, 2011). I used the following two strategies to achieve a balanced outcome in my research. At the initial stages of the research I used:

Bracketing

The nature of phenomenological attitude is based on an understanding of the process of retaining a wonder and openness while reflexively restraining any pre-understandings of the world (Finlay, 2008). Husserl was the first to recognise and to

argue the need for a different and special attitude which is required in the phenomenological approach. Thus, to assist phenomenological reflection, one must “suspend the faith in the world only so as to see it” (Merleau-Ponty, 1962, p.13). While both Husserl and Merleau-Ponty seem agreed on the need to rein in the influence of pre-understanding in order to see phenomenon in new ways, for Husserl the focus of the phenomenological project was on managing pre-understanding by bracketing them. This necessitates the researcher to abstain from or suspend his/her own pre-existing knowledge. Bracketing of biases, as Knox et al. (2008) has described in great detail, includes the interview protocol itself, the recruitment, interviewing, transcription and data analysis procedure. As an interpretative researcher, I tried to distance myself from the research material so that later I can expand on the experiential claims and concerns of my participants by embracing the interpretative opportunities of phenomenological analysis.

Fore-understanding

At the interpretative stage, however, I allow myself to explore the meaning and use the context of my “fore-understanding” of the subject, especially in discussion with peers and supervisors. Triangulation of the data with other sources (e.g. peer review, supervision) helped to ensure data quality and impartiality of the researcher (Wong & Ng, 2008). A good way to address this is to ask one’s self to explore where we are in terms of our relational world. Each interview involves us with the world in a very unique way and is characterised by an attempt to explore and make new connections between aspects of this world. The best way to look at the interviews as as an *enquiry* rather than research (du Plock, 2004). In each particular case, I am enquiring about the world of my participant, but by doing so, I am also enquiring about my own world. Both Merleau-Ponty, as well as Heidegger, believed that we cannot totally escape our history and our personal view of the world. They invited the possibility of exploring the meaning, content and impact of our “fore-understanding”. Fore-understanding potentially allows one to perceive the phenomena in more detail at the interpretative stage. Drawing on these developments, psychology suggests the exploration of these horizons of experience and understanding (Finlay, 2008).

The point to note is that the researcher remains objective and detached from the phenomena only to an extent. It does not account for the fact that the researcher indeed observes the phenomena. Such observation becomes eventually internalised and when “ the door is opened to another person’s world, it can never be shut”, as the researcher is merely an observer with no control or shared sense of experience (McGourty, Farrants, Pratt & Cankovic, 2010, pp.65-72).

2.6 IPA stages

I use the five steps of the phenomenological method which, according to Giorgi (1997), includes: collection of verbal data; reading the data; breaking up the data; organisation of the data from a psychological perspective: and synthesis or a summary.

Iris Aravot (2008) offered an inspiring way to describe IPA stages. Within her description, Aravot considers the in-between phenomena in the context of architecture as a process of creation and her way of thinking resonates with the way I relate to the IPA stages in my research. The first stage of phenomenological enquiry, according to Aravot, is “epoche”, which is the bracketing of meanings that are taken for granted, as well as worn-out interpretations. It doesn’t discard the edge of former experience, but turns away from it. At this stage, one’s experience is a sense of wonder. This is exactly why phenomenology is more than just an empirical study, as it looks beyond a natural attitude wherein one takes things for granted. From a philosophical perspective, things and events do not just simply appear, nor are they always what they seem to be (Larkin et al., 2006).

The second stage is the reading of the data and it therefore needs to be explicit. It requires me to read through the interviews carefully and repeatedly before commencing any analysis. This stage, as compared with Aravot (2008), expands upon the initial idea of a new building which is not yet clear and one which doesn’t begin from anything familiar or predetermined.

The third stage requires the division of data into parts in order to discriminate the meaning. This is influenced by the psychological perspective of growing older with HIV. Finding units of meaning requires an attitude which is sensitive to the discipline, as well as to the phenomenon in question (Giorgi, 1997).

Moving on to the fourth phase is that of transcendental intuition of the essence. This is where the first grasp of the entire project - as a unity - takes place. It unveils "the wealth of meanings of the essence; its hidden properties as well as hermeneutic circles of significance" (Aravot, 2008, pp.100-101). It is also an organisation and expression of the data from counselling psychology perspective.

The fifth stage is description, which is a communication of findings with peers and bridging between an individual's views to an intersubjective sharing of meanings. This is when the method of free imaginative variation plays a key role in order to help to establish essential intuition along the lines of psychology. Psychological perspective is therefore much more focused than that of the everyday life of the participants and therefore a transformation of language is required.

All these factors contribute to the trustworthiness of IPA research as they bring a balance between what the participants say and the way I, as a researcher, interpret the meaning of their words. Such a balance of both, subjectivity and reflexivity, brings one closer to a psychodynamic way of understanding of what belongs to whom, and indeed what comes from the participant and what comes from the researcher (Nutt-Williams & Morrow, 2009).

CH.3 Research Design

3.1 Selection Criteria

The phenomenon in question is *growing older with HIV* and what that experience means to the participants. I didn't discriminate my selection sample according to either gender or sexuality. The sample represents a spectrum of interests and includes all individuals who have been diagnosed as HIV positive for the last five years or more and at the age of 40 years old and over.

I used a cut off age of 5 years with HIV as I wanted to exclude all newly diagnosed people and those who maybe going through the initial adjustment process. The literature suggests that initial HIV diagnosis is associated with an initial shock which may last for prolonged period of time during which re-adjustment to the diagnosis required (Kylma, 2005).

The majority of studies on aging with HIV tend to use a cut-off age of 50 as the definition of an elderly group (Ress, 2003; Grov et al., 2010, Elford et al., 2008). This is in line with the National Institute of Mental Health guidelines according to Stoff (2004). However, other studies consider the age of 45 as the point of aging (Cummins & Trotter, 2008). The definition of aging, according to the author of this research, can be therefore be seen in a much broader context and might contain existential, as well as psychological and physiological challenges, and therefore can start much earlier in life.

I chose to use the age of 40 as a cut-off point because in my practice it has repeatedly emerged that clients from around that age group and older start questioning themselves more often about their future. At this stage in life, it appears that they seem to become more aware of the changes in their physical body. The dilemma is for them to know whether this is due to the natural ageing process or HIV itself. As the phenomenon of interest lies in ageing with HIV, I chose to recruit the first eight eligible volunteers and thus to see who would be the first to respond and come forward.

The research was conducted at an HIV charity in London and was organised in close collaboration with its management. Prospective participants were reached via internal leaflets (Appendix D). Of those who responded to the leaflet, the first eight participants who fitted the criteria were provided with a Participant Information Sheet (Appendix B) to read. This was followed up by a request to sign a Consent Form (Appendix C).

The recruitment campaign was then subsequently stopped and the advertising leaflet was removed from the premises once the required number of participants was reached. This was done in order not to turn down late volunteers.

Early in the recruitment process, it emerged that the population chosen was, in fact, easy to reach and the interview process was completed within just 2 weeks of the original schedule.

3.2 IPA questions

Lead in to interview:

Before we proceed with the questions, can you tell me;

1. When were you diagnosed with HIV and what was your initial reaction like? (This question helped to develop rapport and put the participant's story into the perspective of life experience with HIV).

2. What does it mean for you to be HIV positive at this point in your life? How do you make sense of that experience? What is it like to grow older with HIV?

Prompt question- Where/how do you see yourself now?

3. What do you think the future holds?

Prompt question- How do you think it might influence your choices?

Explanation regarding the choice of the questions

All the three main questions refer to the participant's experience of the past, present and perceived future. According to Heidegger (1962), as Dasein is authentically temporal, it is also authentically historical. The repetition of the possibilities of existence are constitutive for the phenomenon of original history which is itself rooted in temporality. In his major work "Being and Time", Heidegger (1962) identifies the primordial phenomenon of the present which is essentially linked to the phenomenon of the past and of the future. Accordingly, Dasein is not temporal for the mere reason that it exists "in time," but because its very being is rooted in temporality: the original unity of the future, the past and the present. Therefore, I might expect an aging experience of my participants to be also temporally interconnected.

3.3 Sampling considerations

The sample does not represent ethnic minorities; those with complex legal status, or language and cultural barriers which restrict them from looking for support. People who do not have a support network from HIV charities might respond differently to the same questions. As the focus of the current research is to understand the experience of those aging with HIV, the homogeneity of the sample was satisfied through the average age of the participants (50 years of age) and the average length with HIV (10 years). Sampling considerations will be discussed further in the discussion section of this portfolio.

3.4 Ethics and Permissions

The ethical considerations were carefully attended at the initial stage with accordance to the BPS ethical guidelines (BPS, 2009); the research proposal has also been given a favourable ethical opinion by the City University, London, research committee on the basis described in the application form, the protocol and the supporting documentation as described below.

All the participants were given an *Information Sheet* to read (Appendix B) and then asked to sign *consent for interviewing and consent to tape form* (Appendix C). They were informed of their rights to withdraw from the interview at any time. This safeguards the participants in case the particular material evokes distressing thoughts, as the nature of experience is subjective and it is impossible to anticipate when a certain verbal recollection could potentially reintroduce emotional material or make the participant re-appraise past experience.

For that reason and, more importantly, to protect the participants, specialised counselling services was made available to those who felt the need for additional support, and provisional arrangements were also put in place between the researcher and the counsellors on site. The researcher liaised with the counselling team prior to the beginning of the project and organised a regular time slot for the duration of the research. All the participants were debriefed on the availability of such services and contact details were provided (Appendix E). I have also drawn upon my own counselling skills, in order to be sure my participants were safe, the boundaries were maintained, and the phenomenology of the research was not affected.

Confidentiality was followed thoroughly throughout the study. All digital material was encoded and was kept on a password-protected computer at the researcher's office. At the end of the project, all digital material will be erased. Hard copies will be held in a locked filing cabinet at the researcher's office for the next six months following the submission. All identifying details of the participants will be coded to preserve anonymity and confidentiality of data.

Ch. 4 Research Method and introduction to the participants

4.1 Method

All the interviews took place on the premises an HIV charity in London. Interviews comprised of 40-minute-long semi-structured interviews and were conducted on a one-to-one basis. The selected participants were asked to answer three main open-ended questions. This was supplemented by additional prompt questions, in order to be reflexive and to stay in touch with the data.

Interviews were tape-recorded and transcribed verbatim. The transcripts included any vocal utterances, broken words and sentences. This was done in order to create text as close to the representation as possible.

All the identifying details were changed and the transcripts were coded to preserve anonymity. A key noting which participant corresponds to which pseudonym has been kept securely and separately from the rest of data at the researcher's home and was destroyed on the completion of the analysis.

4.2 Analytic procedures

The emerging data was clustered into themes and analysed in IPA by attempting to elicit the key experiential themes in each of the participant's accounts. A cluster of themes for each of the participants was later compared and analysed against each other. I used the following procedure throughout the research:

Transcripts were numbered line by line. They were read and re-read a number of times whilst I was simultaneously listening to the recordings of the interviews. Doing this helped me to immerse myself in the data and also to re-experience the momentum of the interview. Notes about the initial thoughts and observations about the transcript were made on the left-hand margin. These notes contained some preliminary observations and summaries of the associations,

speculations and links to the other aspects of the interview. The aim at that stage was to stay as close as possible to the original data and its meaning (Smith & Osborn, 2003).

Emerging themes were later identified and developed from the initial notes. To that point, I was analysing text by the units of meaning and not line by line. This is, according to Willig (personal communication, March 29, 2011), another way of approaching the analysis and is sensitive to the discipline as well as to the phenomenon in question (Giorgi, 1997). Notes were made on the right-hand margin. Examples of this can be found in the Appendix F. At this point, those labels weren't fixed either, as I was aware that they might transform again during the cross-case analysis and, even at later stages, of writing up or peer review process.

Eventually, a table was constructed for each participant with the themes, sub-themes and the corresponding line numbers and quotes (See Appendix G). Once the tables were constructed for each individual transcript, I created a mind map where I placed all the emerging themes in circles around each participant's pseudonym (Appendix I). The maps evoke a visual recognition of data and my interpretation thereof. It also revealed the relationships of emerging themes within and between the participants' accounts (Appendix H). The mind map helped me to draw up an overlap between the themes and see commonalities and differences between the participants' accounts. It also assisted with the further elimination of the material which wasn't contextually specific to AHIV.

Ongoing refining of the material on all the levels including themes, sub-themes and quotes was performed with the support from supervision and peer review. It helped me to reflect back on selected themes and see some of them in a different light to my own understanding and interpretation of the process. The refining stage greatly assisted my personal reflexivity, as it allowed me to see myself and my role as the researcher in a broader interpretative context.

The write-up stage induced further re-evaluation and helped me to settle on my final choice of data immersion. This stage finalised my understanding and reflection on the relationships between the themes, sub-themes and the quotes. It is

only at this stage that the final decision was made as to what would be included in the write-up.

4.3 Reflexivity

Over the process of analysis, I became more aware of the boundaries between the participant's meaning and my own interpretation of it and how this balance can be influenced by factors such as: my own view of the nature of the reality; the relationships I developed during the interview with the participants; as well as the procedures I followed during the research (Ponterotto, 2005). I used triangulation throughout the analysis so as to maintain a more an impartial view on the data. My personal understanding resonates with Heidegger's (1985) view that thought is ephemeral and is little more than a derivate of our intentionality. According to him, we exhibit intentionality as we engage with the world around us. Intentionality transpired in interviews on a subtle level. It stands out and prompts analytic work during interpretation. I see it as being resonant to what Smith (2011) described as a "gem" in IPA. On another level, the participants intention was to deliver their understanding of their experience; as a researcher, I tried not to use pre-existing knowledge to inform my own interpretation of the material. The extensive use of supervision helped me to separate those two processes and to distance myself from the pre-existing framework of knowledge. Looking at the data at the later stages of the research has been informative in itself. It allowed me to reflect on themes I decided not to use; recognise some re-emerging themes; and justify the presence of the final choices made more clearly.

My own experience of working in HIV services had a certain impact on the way I guided the interviews and interpreted the material. This became quite apparent after a peer review with a non-HIV trained psychologist. A good example of this was in my acceptance of participants using medical jargon. I assumed the meaning of the medical labels without questioning it. It felt like we had an unspoken agreement between myself and the participants in that we were all sharing a special knowledge which was not easily accessible to others. The peer review helped me to become more aware of the fact that engagement in the professional discourse doesn't

necessarily involve my full embracing of the overarching meanings. However, at the time of the interviews, I chose to stay with the phenomenon of growing older, instead of trying to explore HIV-related jargon. In hindsight, I believe that being inquisitive and asking participants to elaborate more on the meanings of medical labels could better enhance the integrity of the research process.

As a counselling psychologist, I believe I used my awareness and recognition of the potential pitfalls to my advantage during the transcription and interpretative phases of research. This was done by paying extra attention to the language and the styles of verbal communication used by the participants. For example, the existential themes, like transience of life and fear of death, according to Willig (2011), may only be expressed indirectly and by way of analogy and, indeed, I noted that the majority of my participants used metaphors as a way of expressing themselves. Although I have a chapter dedicated to the use metaphors in this study, I believe that it is important to mention that I am also aware of the power of interpretation which claims to give a deeper meaning to the participants' accounts. I had to make sure that I was not imposing the pre-existing frame of knowledge onto my own process of understanding the phenomenon, to which supervision was an utmost and valuable resource.

My own role as a researcher, therefore, can be identified as a sincere attempt of inclusion into the world of the participants, whilst not influencing the participants' accounts, being irrespective of my own opinion.

4.4 Participants

The first eight eligible volunteers were seven white gay men and one white heterosexual woman. All eight came from similar socio-economic backgrounds inclusive of adult education, social work, arts and music. The sample is likely to reflect on those who are more accessible and therefore more likely to come forward in research.

The average time of participants with HIV ranged from 6 to 28 years living with the condition. The average age ranged from 43 to 70 years old. Seven participants were known users of the HIV charity services. One participant was not a service user, but volunteered to take part after discussing the research with a friend who was participating. See table 1 for brief demographic details of the participants.

The recruitment process was fast and the volunteers expressed a lot of interest in the subject of the study. One female volunteer didn't fulfil eligibility criteria as she had Hepatitis C and not HIV. This made me consider whether the research question had a particular resonance within the wider group of those individuals who age with the burden of chronic illness, and how the emerging themes of AHIV might overlap or contradict with the experience of other chronic conditions. With an increasingly large aging population with extended life spans, such issues may become very important areas to consider and develop across other clinical disciplines, such as those found in oncology, endocrinology, cardiac and renal patients.

Table 1. Socio-Demographic Information

Pseudonym	Gender	Age	Years since HIV diagnosis	Years on ART	Relationships	Employment
Adrian	M	53	28	Adherence issues	Single	DLA
Peter	M	50	12	10	Single	DLA
Monica	F	47	10	10	Single	DLA
Michael	M	70	6	3 mths	Single	Yes - full-time
Colin	M	45	22	10	Single	Yes - self employed
George	M	43	16	12	Lives with a partner of 8 years	Yes - self employed
Joseph	M	53	10	2 mths	Lives with a partner of 6 years	No
David	M	40	8	1.5	Single	DLA

4.5 Metaphors as meanings (vignettes)

It is well established that emotional language is dominated by metaphorical expressions and is highly figurative (Kovecses, 2000). Key psychoanalytic dynamic concepts such as psychological trauma, neurotic defense, transference, free association and interpretation are directly related to the mind's metaphoric functioning (Borbely, 1998; Sontag, 1990). Therefore, metaphor can represent a device for understanding of 'something in terms of something else' (Ricoeur, 1978, p.145).

There is an element of spatial connection that lends depth and authenticity to our daily experience and enriches the understanding of metaphoric expressions (Borbely, 2004). All the information (either conscious or unconscious) originates in the *Here and Now*, but it also elucidates and reframes the experience of *There and Then*. Simultaneously, all the information from the *Past* will illuminate and shape up the *Present* as transference interpretation (Borbely, 1998).

Metaphors have a potential to communicate those experiences and emotions that may have been previously left unexpressed or were too painful to address directly (Shinebourne & Smith, 2010).

I decided to include this chapter in order to illustrate the participants' accounts of their journey with a life-threatening illness. I noticed from the start that most of my participants were using evocative language when they were describing their experience. Being aware of my own limitations in the context of the current research, I have decided to use those expressions by weaving them into the body of the text as if they were one individual story. In order to do this, I have chosen different extracts from few separate interviews and put them together as if they belong to one person. By doing this, I avoided a risk of recognition of any one particular individual. I also believe that by being presented in this way, the stories evoke a transference interpretation for the reader, too. According to Gordon (1978), the words can represent and convey a layered level of meaning. This applies to the participant and the researcher alike. I also invite the readers of this research to create their own layer of meaning and understanding of this study and hope that this chapter will also give my participants a clear voice within this research.

Life journey with HIV in participants words:

*“...err... I was put... I... I... I was told really that at that point I was going to die. I had a terminal illness. Err... really basically to take everything that I was offered that I would be awarded X, Y and Z. Really to just go and enjoy what life I had left and the information, because they didn't know what they were dealing with, any information they could give me was very limited..... you know, **it was like, it was like being shut, it was like being shut in a prison...** Yeah... err... it was a very frightening time. It was a very... very frightening time... A lot of the press and media in this country were actually... err... were fuelling with stuff about it being a gay plague. So it was a very dangerous time.” (10-20).*

*“Some people were **dropping like flies**, some people were dead within 2 weeks of being told they had it and 2 weeks later we were standing at their grave side. Err... it was just, it was a time of despair and panic.” (23-25).*

*“I always was quite estranged from my family coz they were very religious Christians, so there (has) been always issue about my sexuality and religion anyway so you know it would be **throwing another iron into the fire**. I can't remember what happened.... I think they might were in a state of denial about it, erm, yeah... **very cold you know just very cold about the whole thing.**” (47-56).*

“...it was just probably after Christmas, or apparently, I was traveling to them for 2 days...I told them when I was in a car and they didn't ask me any questions about it. The conversation just stopped and they went very quiet without asking me how I am, what I am and

whatever and situation has never been touched since....” (58-65).

*“I didn’t start (treatment) until it starts getting closer to a sarcoma or whatever and my consultant said look you really should stop resenting antiretrovirals. By that time I got to a year probably erhm... But as soon as they actually gave it to me I was saying wow they actually feel amazing in my hand and I feel **like I am keeping my head above the water** sort of health wise’.” (81-87)*

*“...It was like **a real wake up call** and it was also a wake up call to actually realise that they (ART) do actually work and after being so chemically fed for so long, hmm... actually, yeah, well I have problems with it, but they do work as well. So yeah **it was an epiphany** but it was like yeah...” (99-103).*

*”...by juicing, doing my meditation, you know doing all the things, doing exercise; you know doing all sensible things about looking after yourself. Err..so you up to a certain extent you are in control or rather you can help the situation. **You can stack the cards in your favour**” (301-304).*

*“...because it’s **not that plain sailing** and I already know of people who have some horrific things to deal with because of the side effects. So I think the next big thing, **don’t mean to make it a nightmare scenario** I think they may well, to be looking at the management of the long term use of antiretrovirals...” (146-150).*

“I have often thought, not to be disrespectful to Western medicine and how they manage it. It sometimes, it looks to me, like

*they are trying to break open a walnut with a sledge hammer and I think as a gay man living with AIDS it has given me the ability to look at it, from many different directions, to **marry and bring together**, bring together what Western medicine does today, especially today. Err... but being able to marry things together and be able to know that it's really, really, really, is up to me to find what suits me, and to, to truly **listen to the language of my being**, the language of my spirit, language of my soul to tell me when something is working and working well and **marry so many different concepts and so many different approaches that help to enrich the quality of my life, you** ” (101-110).*

*“ Well I think that your needs have already changed by the fact that you have less energy than a healthy cohort, let's say, and I think that will accelerate with the age and HIV because your are taking lots of medication and you are actually dealing with the disease and you are using up your resources to deal with that and to deal with quite toxic medication, **well it is chemotherapy really on a full time basis** ...ehm as they (AHIV) are more fragile or more vulnerable then some, you know, healthy peers. I think of a good analogy, which I heard years ago when I first was diagnosed. **You should think of yourself as someone who is retired** in terms of how you should look after yourself...you got to be very careful and treat yourself as you are elderly” (125-133)*

“...maybe I can take less of the drugs and have less of a side effects and my wish will come true that I can go back to work and get on with my life. My fear is being disabled in today's time of cut tax and cost cutting its quite terrifying.” (124-126).

*“ because I see I know what it is like to be ill and what it is like to be old, in some respects very old from before going on medication **it is pretty much like being 70** and being frail so you are aware of your fragility and I found I am being prepared for it or trying a little bit more to be prepared for it and yeah... that’s it...**I know what it is like to be a very frail old person** when it takes all day just to go to the post office and do shopping that’s how it used to be and just before I went on medication ...”(86-99)*

I find enchanting the synchronicity with which individual interviews were merging into a bigger, generic story of a human journey on a road of fear; hope and survival. This chapter underlines the relatedness; uncertainty and anxiety of the HIV life-long experience and how it manifests throughout the lives of the participants. The quotes identify and illustrate the themes of fear, stigma, the unknown, and the process of adaptation to a new life which will be explored in detail in the Analysis section.

Ch.5 Theoretical model and formation of themes

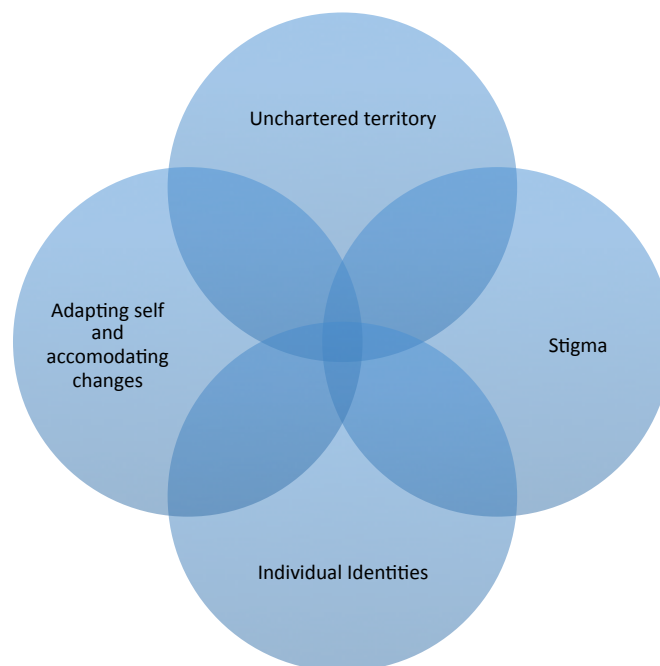
OVERVIEW

There are four major experiential themes emerging from this research. It is important to acknowledge that the participants presented me with rich material and that the actual number of themes was much higher than the four presented.

The huge variation in themes was likely to happen because the interview was designed in such a way so as to reconnect the participants with their past in order to gain a contextual understanding of the present. The themes which were not connected with, or influencing of, the aging experience, were omitted. For example, a theme of control was prominent in participants’ accounts. They use control to maintain a specific lifestyle in order to secure more effective rehabilitation on ART and to maintain a survival instinct. However, I didn’t observe a significant change in

the dynamic of control with age and therefore excluded it from the final analysis section. The themes such as that of initial shock of the diagnosis and stigma were only used and interpreted in the context of age-related transition. In respect of the initial shock, for example, many remember the exact time and date, or the relevant circumstances, of the diagnosis. As a researcher, I was particularly interested in the emotional context of that experience and how that stayed throughout the participant's life and potentially informed an outlook of a future. In this I attempted to employ Heidegger's perspective of interconnectedness of *Time*, where the *Present* informs our perception of the *Past* and *Future*. (Heidegger, 1985). Therefore, all four themes are spatially and conceptually interrelated (see table 2).

Table 2. Overlap and interrelatedness of the emerged themes.



5.1 Main Theme-Uncharted territory

The unknown underlines life transition. It faces us from the moment we are born until the moment we die and forms a part of existential life experience (Jacobsen, 2007). Chronic and terminal illnesses bring with that experience a specific range of unique dimensions, as people often give up their usual lifestyle and

routine to go through the numerous physical and psychological re-adjustments in order to survive (Dell Orto & Power, 2007). I decided to include this theme in order to demonstrate a degree of uncertainty expressed by the participants over a life transition and to investigate a potential role of HIV in that process.

Sub-themes

5.1.1 Uncertainties about future

Many participants were struggling in a sense-making process of aging. However, most were convinced that HIV played a significant part in that process, although they weren't sure about its exact role:

Peter: *“You know it is just like I think it is, a whole new generation, people with HIV never got old before, so it is uncharted territory, so... ahm, I don't know.”* (122-125)

Peter shares his thoughts about the future. This could be an anxiety-provoking experience for him. He refers to the lack of information regarding what might happen to him as an HIV-afflicted person. He sounds anxious in his expectations of the unknown. What emerges was the participants' curiosity as to what extent changes are a consequence of HIV alone and what belongs to the more global aspects of growing older.

Joseph links his current experience with the time of the initial diagnosis:

*“Err, well, obviously, I was upset (**when he was first diagnosed-SL**) I mean, I'm of a generation where I've seen lots of very unfortunate AIDS deaths and suicides, so it's, you don't know quite*

how it's going to affect you and what it actually means for you. So very apprehensive.” (6-8)

He appeared emotionally reserved. He feels uneasy and finds it difficult to hide his anxiety about future. Joseph is also confused about the meaning of HIV in his life. He draws from the past fatalities of the AIDS era. Joseph described them as ill-fated and this doesn't encourage his vision of the future.

Aging with HIV for Monica is an anxiety-provoking process:

Monica “.... Anything affects you, any decision that you make you know anything can happen related to HIV, even a couple of times it's not related to HIV... or even psychologically, even if it's not... you just think about things twice or there are things that you would not consider.” (108-110)

She feels insecure and vulnerable. She anticipates that HIV will affect her more with age, but she is unsure of when or how this is going to happen or what to expect from it. Monica is likely to feel fearful that it will affect her further in the future one way or another.

Joseph: *“I think the thing is with HIV, I mean, although now there is a whole batch of 50-year-olds, err, there aren't that many people over 65. I think because at that time, err, at that time it was before the medication, so most of those have died off... Err... I think that there may well be all sorts of thing but I don't know yet what they are going to be. You know, it's a speculative thing...” (128-130)*

Joseph is also preparing himself for the unexpected. There is no point of reference from previous generations for him. He is already guessing what might happen by picturing various scenarios in his head. He explains further:

Joseph: *“With general old age one knows what to expect. We still don’t know the long-term side effects of drugs; we still don’t know all sorts of things about, you know, what happens when you get older and how long you can actually survive on these drugs. A lot of it is speculative, so a lot is unknown.”* (119-122)

Joseph refers to the aging process of healthy peers as predictable. He worries and he is anxious about his own uncertain future with AHIV and long-term medication. He describes the treatment regime as a “survival” on ART. There is no sense of a treatment outcome from that expression, but just a sense of an ongoing struggle. The longer he takes drugs, the closer he is supposed to get to an advanced age. However, with increasing age, that process is becoming less certain. He is apprehensive about the safety of the medication and unsure of his future.

Adrian sees the unknown in the long-term use of antiretroviral medication:

“I have issues about it. I really do have issues about it. I have issues about it, that’s why I chose to back away from them; they really don’t know enough about these drugs. The majority of them are toxic to the human body. My greatest fear is that, really, as a man living with AIDS today.” (151-156)

He is fearful and highly suspicious about ART and the impact it could have on him. He explains his poor adherence as being due to a lack of trust in doctors and professional opinion in general. He ultimately perceives ART as unknown and dangerous in a world where no one has absolute knowledge. If no one has the

knowledge that could also mean that there is no one to provide a guarantee for Adrian.

George shares similar thoughts:

“It's only just now that we are beginning to think of old age and it truly is only now. That in my, err... you know, early 40s, I'm 43 nearly 44, that I am beginning to think in the last year or two of what does happen when I get to old age. What will happen. I don't want to be poor in my old age and I don't want to be unwell. I cannot see the use of living err...(pause) an existence in my old age. I want to live and enjoy my old age and so if I am going to enjoy my old age I've got to find some way of creating an income. I see I am going to have to do that.”
(101-106)

George looks at retirement and sees it as a two dimensional category - enjoyable vs. not enjoyable. He is likely to be resentful and fearful of becoming frail and dependent with age. He expresses determination in preventing himself from becoming dependent. George tries to convince himself that he still can enjoy his advanced years as long as he provides for himself financially. It feels like he has already put a lot of thought into it. Financial security is the only predictable outcome from the uncertainty of the unknown for George.

Joseph sums up his experience which, in a way, might be seen as relevant to many of those individuals with AHIV:

Joseph: *“Err, (deep breath), well, it meant a complete change of, err, how one is going to live, and, also, I question one's mortality (which) is something that nobody likes to have to do and I'm so not an exception.”* (10-11)

Joseph recognises the inevitability of transition. He sounds resistant in thinking about change. The process of readjustment to HIV becomes a process of readjustment to life limitations to which there is no opting out. He recognises that the absolute change lies for all of us within the boundaries of the ultimate life existence.

Not all the participants, however, shared those concerns. Michael, the oldest of the participants, expressed the following thought:

Michael: *“To the best of my knowledge, my, err, my, I would say my health is probably better than it has been for probably a long, long time, and err, personally I can’t see any potential problems. I expect to live a completely normal life and just because I am taking ART doesn’t mean that I will have any problems, I don’t think... the opposite.”* (72-75)

On one level, Michael displays confidence in the way he sees future. On the other hand, he sounds rigid in his determination to have a normal life and avoiding the changes it may bring. He actively overlooks the possibility of adverse effects of ART on his general well-being. It feels like he has convinced himself in the predictability of life and denies the element of the unknown or unexpected.

5.1.2 Accelerated aging

Many participants questioned the pace of their aging process. They were confused as to whether to attribute these to the natural changes or to the impact of HIV.

Monica struggles to understand what might and might not be related to HIV:

Monica: *“Actually, I was thinking about that recently, before I wasn’t thinking about it, but I think now. I’m thinking about that because whenever something happens I think you know the normal process of a normal woman growing older, you know. I don’t know if, in my case, if it’s going to be the same or not, you know. Because there are already things, you know, the menopause and things like that, things that you don’t know if in your case it is going to be more complicated or more difficult... or... yeah... things like that.”* (116-121)

She has already experienced the early onset of a menopause and now anticipates further complications. Monica sees herself as abnormal and because of that she sees her transition as less predictable and more difficult.

Peter: *“Being in my 50s? Eh, ha ha, concerns about getting older for a lot of people, concern about... I need to solve that frozen shoulder and my consultant says ‘Well, it is not really HIV-related.’ And to see if it is not HIV-related, so I Google it to see if it is not HIV-related.”* (119-121)

Peter laughs, which comes across as somehow defensive. He shares his ongoing worries about his health and anxieties about the pace of aging. He feels suspicious and anticipates more complications with time and might feel the need to find reassurance elsewhere, so he goes online. Monica also expresses similar doubts:

Monica: *“I just think sometimes, if it (is) health-related, you know, which is like, erm, osteoporosis, erm, I heard that this is something that kind of affects old people and I heard that people with HIV are more prone, so I am already thinking that, should I do something to avoid it or is it going to happen to me definitely (because) of this... but that is only a health issue, I am sure... I don’t know, psychologically there will be other issues.”* (132-139)

Anxiety appears to arise from not knowing exactly what to expect. Monica suspects that the age-related illnesses are becoming fast-tracked by HIV. She is not sure whether she already belongs to the category of “old people” or not. She is trying to learn which preventive steps to take so as to prevent further problems. This desire to protect a self from the unknown was also a common theme which emerged from this study. Monica is also anxious of developing a mental health problem which she

has already mentioned during the interview (see Monica 108-110, p.56). This could potentially increase the fear of being not normal for Monica (see 116-121, p.60).

Antiretroviral drugs in their own right provoked a great deal of suspicion in participants:

Peter: *“Yeah, yes, yes, absolutely I feel like my ageing process has accelerated since starting antiretrovirals. I have notice(d) that things deteriorate a lot quicker than they probably would, and I may be wrong, maybe they haven’t, but I always, my whole family always looked young for their age but now I am looking older than my brother.”* (146-150)

He finds the comparison to the rest of his family both unfavourable and a matter of some concern. Peter suspects that the aging process in his case might already become uncontrollable due to the obscure effects from antiretroviral treatment.

Michael, however, was the only participant who contextualised the changes he experienced in terms of what he saw as the natural aging process.

Michael: *“... (pause)...I mean, my sex life has kind of taken a back seat. It’s not really important. Err, I don’t know if that is necessary to deal with that, I don’t know if it is part of being HIV positive, it’s just a natural change in one’s life. One gets to the last stages of one’s life and, after all, I’m not 30 (laugh) I’m 70. You’d be very lucky if you got another 30 years.”* (41-45)

He tries to understand the nature of the changes in his life. He prefers to see

it as part of the natural process of biological changes. Although quite dismissive, he still expresses some doubts of whether or not HIV might have an impact on his sex life. He recognises that he is approaching the end of a life cycle, therefore he prefers to discard all the potentially disturbing thoughts of a future by concentrating on the predictability of life cycle.

5.1.3 Summary

The participants have already experienced issues of survival at the time they were diagnosed with HIV. They learned about uncertainties of life from the past and were recalling experiences of old fears in the interview. They were likely to feel confused and anxious. They feel that their aging has accelerated, which they were trying to explain as being a result of the side effects of HIV drugs.

The inevitability of life transition could also play a hidden part in that process. They are possibly trying to deny that aspect of the phenomenon by concentrating on HIV- and ART-related changes in the body. Having had a life-threatening condition for many years seems to constantly remind them about their own limitations and feeds their anxieties about the future.

The fear of the unknown seem largely linked to the fact that many of the participants are now asking themselves the ultimate question, as to whether they had ever lived their lives, or were they just busy fighting for survival?

On a personal level, I recognise that the issues of life and death are universal to all of us. I am aware of my own aging process and understand it from my own perspective of life transition. I have noticed that my personal existential perception was closer to those participants who were from my own age group. In a similar way, I find myself growing aware of the time I have left to fulfill for the future. However, I also recognise that I haven't had a serious traumatic past experience and have never had to question my own vitality before. Therefore, my own understanding could still come from a completely different point of reference to that of the participants. By contrast, the majority of the participants have reported a familiarity with a near death experience in the past. They had already survived one fight with death and now feel somehow resistant to face that experience again. I wonder to

what extent they are already familiar with the unknown and are anxious of the prospect of re-experiencing the past.

5.2 Main Theme- Stigma

All participants reported experience of stigma at certain points of their lives. Apart from feeling judged, they expressed feelings of self-blame and guilt. With age, those feelings add to further confusion in a meaning-making process. There are internal and external stigmas which are likely to intensify with age and contribute to further withdrawal and isolation.

Sub-themes

5.2.1 Stigma in a wider community

Prejudices in a community are not uncommon and often reminds the participants about the previous experiences of stigma.

*Peter: "I think stigma is still a really big issue. I noticed when I recycle rubbish I tear all my name off the cardboards, because, you know, there is lots of cartons on all that antiretrovirals so I make sure that I take my name off from all that. It takes me ages to destroy any evidence so no one can see my name on HIV boxes in the recycling bin outside my flat, you know. So, I think that (there) is a real stigma because if it was diabetes... but you know... I can live with it. So, stigma generates in the communities... I am quite happy I can say I am HIV positive, but you know, you can get an over-concern, or people get a bit distant, but being a gay man you always had that to some degree, you always had that stigma. It is pretty much the same sort of thing, you know, it is almost like it was back in the '70-'80s (**short laugh**)."(157-168)*

Peter takes precautions not to reveal his HIV status in his local neighborhood. It takes a lot of his time to make sure he remains unidentified as a HIV positive man. Peter somehow contradicts himself by saying that he is happy to disclose, whilst at the same time destroying all the identifying material. I wonder whether he sincerely expects his neighbors to search through his recycling bins and to what extent his concern could be attributed to his fear of being found out. To him, HIV and gay stigmas are closely related. He might even indicate that HIV stigma becomes an extension of his gay identity. There is a sense of regret of having HIV vs. any other chronic illness, which is less socially taxing. With HIV, Peter has an ongoing life experience of being outcast by a society.

David identified issues with his social circle:

*“It’s difficult, it depends on your circle of friends, depends on where you are, where you work, what you do, it depends (**sigh**). A lot of people don’t disclose. Some places, I don’t know, I think I have removed myself from society largely because of my HIV status and perhaps my illness. Following on from my status, my status was one thing, err... it reminded me of prejudices that I experienced before I became positive. So (I) became quite wary of certain environments obviously, disclosing in certain environments. I would isolate myself from those places. I chose my working in a more therapeutic nature and perhaps a more understanding group of people. Not in the mainstream.” (87-93)*

David has also experienced an ongoing stigma, first through being gay and later as an HIV positive man. This is now affecting his self-esteem and ability to engage with the wider world. He strives for a more alternative community which is perhaps more empathic and more supportive. David would rather alienate himself from a mainstream society than to allow for disclosure.

Colin expressed a similar tendency amongst his HIV positive peers:

“And in some ways because they (HIV positive people) are already quite isolated, they have already and they are not adjusted very well they didn’t find a group to hang out with or some alternative to do ...and that what it was and they are not part of it, they are quite frightened because they operate quite well in their circle but not outside of it ...I think that the chances of someone of that age....that isolated...to be honest for anyone who is gay, age has that problem, so you see that is not going to be a unique group for HIV...it just felt a little bit like a loner really....and anyone single...the same difference ...”
(184-190)

He expands on his concerns about a general loneliness amongst a wider community. He speaks of that experience in the third person, which could indicate his way of removing himself from that experience. It might therefore indicate the way he feels about himself too. According to Colin, HIV positive people are in vicious circle of exclusion from an outside world. Isolation and lack of adjustment inevitably bring more loneliness, which increases with advancing age. Colin shares the experience of a burden of isolation and a strong sense of not being a part of a society. He links HIV stigma with sexuality and age. He is doing that in order to prove that issues of HIV are no longer exclusive to the condition. In doing so, in fact, he is revealing one of the most vulnerable groups in a society: elderly HIV positive gay people.

HIV stigma is widespread and can be found in the most unusual places, even in doctor’s surgeries:

Joseph: "... I mean, in my GP surgery, for instance, you know, certain doctors, you know, they really don't like the idea of HIV at all. They don't want to touch you and things like that. It is very hard to..." (64-66)

He shares his suspicion of not being welcomed by GPs. The expression of not being touched offers connotations with the past times when people used to believe that HIV could be transmitted through touch or a handshake, the time when HIV/AIDS was perceived as a "gay plague". As such, Joseph is likely to draw from that past experience to contextualise the present experience.

Interviewer: *"Am I right to say that the doctors don't want to see you because you are HIV positive?"*

Joseph: "That's correct. I mean, it's very difficult. My GP, I mean, I think he is good, it's a practice so there are a lot of doctors there. Err... I think the one in charge, he said oh no no problem here and he made a big number by shaking my hand but when I actually pointed out ah... yes, the problem that I had was with this doctor err... and err, you know, he was just embarrassed. I mean, yes, they have the right intention but clearly people do pass through their net." (68-72)

Joseph feels that the doctors have an attitude towards him and the rest of the HIV positive patients. Even a senior GP, according to Joseph, has difficulties expressing a stigma-free attitude. Joseph feels that people around him are making an effort to demonstrate their acceptance of him and his status. He expects people feel awkward in his presence.

Joseph: *" No, no, no, it's just err..(short pause) when*

I...oh, I've kind of blanked it from my mind because it was quite unpleasant. It was the first time I actually felt that, hold on a minute, this HIV there is stigma. I saw a doctor, oh I err... then asked her, that's right because there was... I had a bad cough or something and I hadn't divulged at that time to my doctor about my medical condition and I asked whether I could tell her and this could be confidential and not put in my files and she said oh, no, no, no that's fine and then I told her and then she said, immediately said, are you a "drug addict" or a "promiscuous homosexual" and I didn't really like that err.. Then after that, the next day I was called in and she said by the way I told, you might have misunderstood me err.. I have to put it in your records." (73-81)

The first experience of stigma was very painful for Joseph. He was likely to feel patronised and belittled. He might also feel disempowered and let down by someone who should be trusted. Joseph might even feel manipulated. The expression of being "put on records" has various connotations. Medical records also imply that label becomes permanent and cannot be changed. To Joseph, it might also mean solidification of stigma. My personal association lies with the discourse of the sex offenders register is where GP "has to put it" in his records the fact that Joseph is a "promiscuous homosexual" and an HIV positive individual.

Stigma in a community also has a detrimental effect on one's expectations of aging.

Peter: "It is just a fact that elderly people go into care homes and gay people might have stigma with particularly older generations, their peers, you know, so a...And particularly if they are HIV positive, you can imagine people who are in their 60s or 70s if you are HIV positive and gay in a sort of care home while heterosexuals might have more issues about being gay and HIV positive because of their generation and it will be quite difficult for them because they are not well enough

to live at home.” (187-193)

To Peter, moving to a care home is almost like moving back in time when he came out as a gay man in the '60s-'70s. He conveys his fear of a two-way stigma of being surrounded by prejudiced peers and overcautious care staff. This resonates with earlier comments from Colin (184-190) and evokes his fear of further exclusion and isolation at the age when one feels the most vulnerable and frail.

5.2.2 Self-stigma

Apart from issues in a community, many participants expressed self-blame in relation to their HIV status. As David described it:

“I had been ill through my demise.” (97)

There is a sense of doom and self-blame in his expression. This thought prompts David to seek reassurance by looking into other people's experiences:

David: *“I try to, yeah, what I found was people who have contracted (HIV) we share similar backgrounds, similar childhoods, similar experiences, similar abuses, similar dysfunctions... umm... I don't know how true that is in the group, my circle of friends, yes... err... HIV or becoming ill, the illness was there and perhaps it was inevitable that we would (short pause) pick it up. My perspective...” (83-86)*

David sees his HIV as unavoidable and predetermined. He draws from other

people's stories. He concentrates on similarities, but is likely to ignore the differences and diversity of those experiences. His quest for meaning is likely to be formed by internalised guilt and self-stigma. He looks for confirmation that his infection was unavoidable.

Monica finds her own status embarrassing:

“But, yeah, I don’t know, you know, and all that with HIV, the stress (chuckles). I’ve never heard of it, you know, it’s like, I’ve never heard of it, you know, it’s like a woman on HIV, you know... .. it’s now that you start seeing kind of older women with HIV and it’s a bit comical, really. Oh.” (121-125)

She describes her status as something unusual, rare and unique. A sense of identity will be addressed in the following chapter in more details. In regards to self-stigma, Monica expects other people to find her circumstances and experience odd and funny. She possibly feels ashamed as she chuckles at inappropriate moments, which might also indicate the depth of her distress.

She then elaborates on her issue with disclosure which seems primarily based on self-stigma, lack of self-acceptance, and expectations of hostility from others:

Monica: “... I just don’t want to be like HIV people, I just don’t want to tell people and (have them) behave, act and think differently about me because of that, so I just don’t tell anyone. It’s always a very unpleasant thing, a very negative err... situation. The only time I tell is when I, normally, not always, but normally, when I am in a relationship with... It’s hard enough, I just leave that hard enough situation for when it is necessary rather than when I meet someone, or either way, you know. So, if I can avoid it, I avoid it, so if I cannot avoid it then I have to deal with it, but, as I said, if I can avoid it, I avoid it.” (63-69)

Monica's resentment originates in her fear of being stigmatised. The only way she can deal with that feeling is by limiting her disclosure to when it is absolutely necessary. Her account is an ongoing struggle with herself and with an outside world. Relationships just complicate that further as they bring a further challenge to disclosure and possibly accentuates a pre-existing sense of shame and guilt for Monica.

5.2.3 Summary

Stigma still represents a serious issue in our society and makes HIV unique in comparison to many other chronic illnesses. Participants were expressing concern about the lack of knowledge and understanding in the general public. There is a consistent link between HIV, age, and one's sexuality, which causes concern for the aging HIV population. Difficulties with disclosure are likely to bring further problems of isolation and increased vulnerability in that particular group.

AHIV stigma is two-directional: it generates in the communities, but it also impacts on people's perception of themselves by causing a sense of shame, guilt and remorse. It affects people on three different levels in relation to HIV, age and sexuality. Stigma has a tendency to make people unwilling to access the relevant services and induces further withdrawal and isolation in the aging cohort. This process appears to be ongoing and has a tendency to increase with age.

Stigma is likely to remind the participants of how they were left on their own ('untouched') during the epidemic of AIDS; it also brings fears that they will be left again in their advanced years, too. My personal experience of witnessing age-related discrimination and homophobic attitudes puts me in a position of a deeper understanding of the meaning of stigma for participants.

5.3 Main Theme - Individual identities

This theme is conceptually linked to the previous theme of stigma, as the relationship with self is often mirrored by an outside world and relationships with others (Merleau-Ponty, 1962). The meaning-making process goes through life towards either reconciliation, or further loss and exclusion. There is no indication that the process slows with age. The impact on individual identities from HIV, stigma and aging transpired in many of the interviews. Participants often expressed a sense of uniqueness of their experience as they were seeing themselves differently to the rest of the world and sometimes to the rest of the HIV community. They have also expressed difficulties with identifying themselves with this community.

Sub-themes

5.3.1 Uniqueness

Medical definitions played a significant part in participants understanding of their own specialness as HIV positive patients. Two of the eight participants in the study were identified as non-progressors by the medics; this term is usually defines the speed of HIV progression in the body (BHIVA, 2010). For the participants, however, the personal meaning of the term was much broader and caused some confusion.

Michael, who has just started ART three months ago, sees the same label as a manifestation of an unusual course of illness:

Michael: *“So err ... I was completely a non-progressor for most of the time, since the doctor’s diagnosis (said in a very proud voice-S.L.)... Erm which is very unusual, unusually low viral... err lower hundreds...”* (26-27)

It is likely that Michael might sees the label as sign of his personal achievement in dealing with the virus. The proof for him lies in the exceptionally low levels of viral copies in his blood. Michael, however, sounds unsure about the meaning of the viral numbers in his test results. He struggled to recall more accurate

figures, which to me indicates a lack of clarity on his part. I observed Michael as someone who is feeling rather proud of being called a non-progressor, as if the term allowed him to question the presence of the virus in his body.

Joseph: *“Okay, we're prepared to spend the £20,000 a year on drugs but we are not prepared to spend £1000 on you keeping well which really didn't make sense. So I think that this one hat fits all policy, which is also the same as the benefit thing. If you sit in the middle, it's err... life can be a little trickier.”* (154-160)

Joseph talks about financial issues in regards to HIV care and support. It is interesting to note the way he chooses to describe the state's policy. The one hat which fits all policy, doesn't fit Joseph. He is left in the middle as a non-progressor. By placing himself in the middle, Joseph could also feel forgotten. He can't identify himself fully as HIV positive, nor does he see himself as completely healthy.

David has numerous issues with the tolerance of ART:

“I am on my fifth medication now and err.. I'm a non-typical patient. My last blood test, because I had some extraordinary side effect my blood was measured for the level of drugs in it in case it was too high. The test came back with such a... an incredible result...umm... they need to repeat it. However, I suffered so much from my side effects that I stopped taking my medication.” (108-111)

He sees his side effects as exceptional in comparison to other HIV positive people, thus setting him apart. The blood test results were unbelievable and needed to be re-taken. This is likely to provoke a sense of fear, helplessness, and possibly unfairness, in his strive for recovery on antiretroviral medication. David cannot be sure as to how successful his treatment was. The meaning of not being a typical patient to him is likely to be associated with a danger to the quality of his life. This is likely to provoke further anxieties. His decision to stop medication is likely to be

driven by the need to normalise his physiological experience of the unique side effects of ART.

The main issue for Monica is that she believes that she sees herself as somehow exceptional because she believes that the people around her know very little about HIV:

Monica: *“I am not under shock, you know, but erm... as the time goes by I make less sense. First of all because it is something that is kind of forgotten in the outside world, you know. I've had the reaction of telling someone and they said, you know, but I think that it didn't happen anymore and there were no people with AIDS because its incredible how little people know outside.”* (80-84)

She is likely to believe that she is in a possession of a rare condition of which most people are unaware of. Such a sense of uniqueness is likely to lead Monica to feel alone on her journey. She possibly feels forgotten in a society which has already moved on from the danger of HIV/AIDS. She suspects that people do not believe her and are likely to treat her as an odd case, irrespective of whether they trust her or not. This is likely to affect how she feels about herself throughout the experience with HIV. A sense of being disadvantaged and different is increasing with age for Monica.

Some of the participants reported a struggle with placing and accepting their identities in relation to HIV. In many cases, this is happening because of their deceptive physical appearance or over a perceived risk of infection. For Michael, confusion began at the time when he was first diagnosed six years ago:

Michael: *“So, my conclusion is that I must be one of those unfortunate people who might have got infected through the mouth (pause) because it is quite unusual for gay people to use condoms with oral sex. It has always been regarded as a fairly, you know, not completely safe but low risk but it's the only way that I can think of how it could have infected me.”* (12-15)

There is an indication that Michael might be questioning the risk of what he perceives as relatively safe sex. He sees that everybody around him does it, but he considers himself as an unlucky one who gets it. Everything seems to be confusing to him as it is as unusual to use condoms and to then get infected through oral sex. He attributes HIV to bad luck and sees it as an accidental and rare experience of which he was a random victim.

David: *“Gosh, right now, err... it’s living a life like an old person in what appears to be a young man’s body... being quite debilitating in many ways.”* (117-118)

There is a dissonance between the way he feels and the way others see him. David finds such an experience confusing and disabling on many levels. He might be referring to difficulties in explaining his difficulties to others. Listening to and observing David made me think that I would probably find it hard to believe that he is unwell if I had less specialist knowledge. At that time I felt as if I was influenced by a social perception of HIV which was born and mass-distributed during the times of AIDS pandemic. That thought made me feel more empathic with his struggle in proving his illness to others, especially to those who might need to know about it, e.g. close relationships, benefits agencies, and so on.

Monica: *“...A lot of times the reaction I got is, but you are not ill, which seems very stupid because the reaction you got is, I got, you know, whenever I tell anyone is like but you are not ill like. You smoke, drink, you know. It’s like that... so.”* (89-92)

Monica doesn’t look ill, she possibly doesn’t even feel ill, but the other people’s responses annoy her because they are lacking in comprehension and an understanding of her circumstances. Deceptive looks seem also to contribute to a diminishing sense of self. I wonder if the conflict for Monica lies in not wanting to

believe it herself? It is likely that Monica, on some level, chooses to smoke and to drink in order to prove to others and, perhaps, to herself, that she doesn't belong to the rest of the HIV community. As the result of that ongoing process, Monica loses sense of her own identity:

Monica: *“Err... hmmm... (short pause) to be honest, I think that I make less sense; again, it should be the other way round, but you know, that’s me. I think less sense... as time goes by, I make less sense.”* (78-81)

She might be expecting to gain more sense with time, but in reality she is getting more confused. This situation is likely to be mirrored in the HIV service, which is on my professional experience is currently encounters very few Caucasian female patients. This situation is mirrored in the research study where Monica was the only female participant. In interviews with both David and Monica, I saw young and healthy-looking people with good eye contact and good communication skills. The nature of their message about deceptive appearance had slipped my attention at that time, which I see now as a reflection of how they might feel in the outside world. They convey the message of the invisibility of their struggle and that they were left unheard and misunderstood by society. The discrepancy between the internal and external world forms a very unique experience for them. Participants were echoing each other in that sense of disbelief and dismay to the uniqueness of the given circumstances.

Michael, on the contrary, seems to have embraced his HIV status, but has moved away from his gay identity. He merges with the heterosexual community and undergoes a dramatic makeover of his perception of self, as well as the social network of support.

Michael: *“ Erm.. I suppose in my case, I mean the... being a gay person is no longer really something that... how can I put this? There was a*

*time when being a gay when I was, you know, I lived as a gay man. I would go into gay clubs, I would do gay this, gay that but and most of the friends I had were gay men. All the places I'd go to would be gay. Erm... that has changed, that has certainly changed my social life now is really no different from a heterosexual person. I no longer live an exclusively gay life where I feel that I have to do something within the gay community. I have lots of ordinary heterosexual friends; the gay people I usually do know are couples who I might go out to dinner with or go for walks with and, in fact, in many ways during the years where I used to identify myself as a gay man my life was much more confined. It's, you know, it's opened up in many ways since HIV diagnosis, my life. I know I feel very comfortable living in the wider world. In fact, having contact with a place that, say, is catering just for gay people is now a very rare exp...rare experience, it's very occasional. I think, I don't feel that need to always be socialising with gay people and gay places. Err... part of the reason why I would have done that years ago would have been because I would be looking out for potential sexual partners and because I'm not looking for that anymore I don't feel that need to (**short pause**) live like that". (77-91)*

I wonder what it means for Michael to be gay and why he refers to his sexuality in the past tense. I assume that in his explorations, Michael links gay lifestyle with sex, which, consequently, he connects with HIV. That's possibly why he chooses to avoid gay places so as to avoid temptation and the consequent risk of sexual encounters. Furthermore, by saying he is no longer a gay man, he perhaps discards any further links with HIV. According to him, his life has transformed and he is no longer identifying himself as a gay man. He sees the function of the heterosexual community to help him to protect himself from the accessibility of gay sex. It could be also seen that his identity has grown beyond one dimension of a gay life style and he recognises sexuality as just one defining feature of personhood. Then again, he describes his heterosexual friends as "ordinary" which brings a whole new layer of definitions and meanings of sexuality for Michael. The HIV related sense of uniqueness has had the reverse effect on Michael as he seeks refuge in the safety of ordinary life with "ordinary" friends.

5.3.2 Not-belonging

Some convey strong feelings of not-belonging:

Monica: *"I still find it, (that) in my 30's I was okay. My normal life and that ..err.. maybe deep inside I find it quite difficult and I am still thinking that I don't belong to that (laugh) you know that group of people, you know, basically. Because, you know, I remember when I was in hospital I was like well I'm not a gay man, I'm not African, you know. These are the people who gets it even when I knew it wasn't because I used to, part of when I was teaching Spanish, one of the topics I used to teach was HIV and AIDS err..so I knew a bit about it. More than the normal person but when you are ill you forget about when you know a bit and you just say, you know, I don't belong here...and now I still think the same. I just find it, yea I still think the same"*
Monica(48-55)

Monica conveys a strong sense of not-belonging. She knew about the risk of HIV, but she also has forgotten that knowledge at a crucial moment. She is likely now to blame herself and she deals with a feeling of constant resistance to her circumstances. Monica denies the situation she has found herself in and because of this she is acting out in that particular denial.

Joseph: *"Well, what was a bit strange was that you don't fall into any bracket either with the doctors err...or other fellow people who have got HIV because other people who've got HIV, you know, they erm, if you say you're non -progressor, your immune system is still fine, it's almost like, oh, you don't count. You haven't got it."* (33-36)

Joseph is likely to feel confused over the pace of his illness. The term seems vague to him. Joseph tends to feel that he is not fully accepted by both doctors and HIV positive peers. He might even feel undermined and not taken seriously enough

or not feel included. This causes confusion with his identification as an HIV positive person and with the state of his own health.

Michael: *“There was a time for many years it would be that if I’m going out it would be to a gay pub, or going out to a gay club or even going out to have a meal it would be going out to a gay restaurant. It would be going to gay this and gay that, you know what I mean, so, err... so that’s changed, that’s a very narrow way of life when I look back at it and now I don’t feel that it is necessary and, in fact, it’s almost kind of the ghetto.”*

Interviewer: *So, would it be right to say that HIV let you come out of the ghetto?*

Michael: *“Definitely, that’s a positive thing, so...”* (93-98)

He compares the gay community with a neglected, impoverished, or otherwise disadvantaged part of a society or with a life style with a limited context. Michael left that “ghetto” for a new mainstream world. He sounded content in his choice. Perhaps that might have made him feel like a more normal and open-minded person. He is likely to blame his sexuality for letting him down at the late stages of his life. He is also likely to blame the gay community for becoming infected with HIV. Michael is likely to be running away from himself and his old ways of living by settling into a new identity. The term “ghetto” by definition separates communities and reduces any form of integration between the two. Therefore, I excluded interpretation of growth beyond one sexual identity which could have also been considered in this context. Like Monica, he has a strong feeling of not belonging and he appears settled in his decision that it was not him who forms a part of the segregated world of the HIV community.

Peter brings ideological conflict to his experience:

Peter: *“I always used to kid myself that I am a free spirit but I actually have never been. I always was a part of counter culture movement all that hippie new age. Sort of outside the society outside life and I always felt, you know, I am sort of a part of a counter culture you know, Not until all that big multinationals, all of a sudden I feel, you know... I was suddenly kept alive by all those chemicals made by those big multinational companies...”* (93-99)

Peter had to alter his beliefs in order to survive and to be able to start the treatment in that he had to reconsider his identity, so as to allow the possibility of being rescued by pharmaceutical companies. This has implications for his understanding of freedom and his own choices and his identity.

“...Beside of it all being Mr. Natural, you know, yoga and meditation and whatever and being so chemically free but (I) also have issues about drug-taking. It was strange to rely on those big multicultural companies as I always was quite an anarchist socialist libertarian sort of anti-corporate things and chemical companies (laughs). So, yeah I just realised that we all, in fact, tied to the society and until it snows and you go to a supermarket shelves are empty and we all tied to the whole thing anyway so it was a wakeup call in several ways.” (104-112)

He used to lead a free life on many levels. He was independent from the mainstream ideology, living in a community without regular dependency on medication. He now lives alone and depends on a regular supply of ART. He is likely to feel tied up to the society in his reliance on the proximity of an NHS service. Peter becomes more dependent on the society he is living in and can no longer afford his former political views. This ultimately requires him to revisit his own identity. He suffers loss on many levels and has denounced his rebellious side. I wonder if that makes him feel incongruent with himself. He laughs a lot throughout the interview

and I find it difficult to get a better sense of what he may be hiding behind that bravado. Both Michael and Peter went through a stage when they had to reinvent themselves in order to survive on treatment. Both had to trade off their individual identity so to feel more relatedness to a mainstream society.

5.3.3 SUMMARY

The individual identities of the participants was shaped by the initial shock of the diagnosis and by the ongoing experience of stigma. The identities were often influenced by the medical labels and the way participants experienced ART. The medical labels were adding to the confusion, with the participant finding it difficult to relate to some of the meanings of HIV jargon.

As time progressed, participants appeared to learn how to conform and compromise their lifestyles and even their beliefs in order to accommodate changes and, ultimately, to survive. Such processes require a revision of the existing identity and finding ways as to how that can or cannot be integrated in an individual's process of re-adjustment to life experience with HIV. This, in turn, enhances a sense of not-belonging in the participants and increases the sense of isolation as time goes by.

My personal observation was that although HIV plays a major part in the participants' lives and they were finding numerous ways to see their personal circumstances as special and unique. They were fighting HIV to become a part of their personal identity. On the other hand, in the process of acquiring a sense of their own uniqueness, I suspect that, on some level, they have already accepted HIV as a part of a broader sense of self. Even Monica, who reported ever diminishing sense of self, has somehow become accustomed to her feeling of being the only HIV positive woman in the world. As HIV was also a big source of worries about the future (see the first theme), it calls for an ongoing evaluation of how they fit or don't fit into an aging society. Such a process once again demands a revision of one's own identity.

5.4 Main Theme- Adapting self and accommodating changes

This theme is conceptually linked to the previous three and illustrates how the participants were dealing with their own uncertainties about the future; stigma and general confusion over one's sense of identity.

Sub-themes

5.4.1 Knowledge

All the participants were employing knowledge to support their views on life and aging. The thought process was based on their personal experience with HIV or socio-political changes in their past. Most of the participants were knowledgeable about HIV and ART and were fluent with medical labels. Participants were often selective and at times black and white in their appraisal of the future.

Michael: "Err.. I really didn't want to risk getting re-infected err... so, I know for a fact that the virus that I was infected with is, that is completely, has no resistance to any of the available therapies they have. That's why I wanted to keep it. Keep me infected perhaps other mutations of that can build up resistance to other therapies. So I didn't want to take that chance." (54-60)

Michael rationalises his choice of celibacy as an effective method of prevention of further re-infection. By taking that stance he potentially punishes himself for wrongdoings of the past. He takes time to explain his reasons, indicating that the process is not fully settled yet. His interpretations are grounded in knowledge of HIV transmission and were designed to support his choice and need for control. It doesn't include any alternative options of satisfying his existing sexual needs. He sounds confident, well informed, and distant from the emotional content of the subject. There is a sense of ownership of the virus. He accepts it and settles in a knowledge of perceived safety of his future choices.

Adrian: "...I really think having being around it from almost the beginning, I do have a friend who was diagnosed in 1979 and he got a recall, had a recall to say that's what it was and he is still alive, he is still alive and living since 1979...(pause) I think they may well, may well need to be looking at the management of the long term use of antiretrovirals, I don't mean that to be a nightmare scenario. I sincerely hope that people are not going to become disabled in some way because of the long term use of them. I have issues about it. I really do have issues about it." (147-156)

Adrian discloses poor medical adherence to ART. This is based on his deep fears of a detrimental impact of side effects of ART on his physical health. He appeals to his friend's experience who has, according to Adrian, lived for over 30 years with HIV. It is not clear whether or not his friend is currently on medication or whether Adrian talks about himself. He uses that knowledge to back up his stance on non-adherence to minimise fear and to increase hope. He also seeks proof in his own experience of longevity and expresses concern about the toxic effect of drugs and the unknown long-term consequences of ART.

Colin uses his knowledge for more pessimistic predictions:

Colin: "Well, in your late 60s and 70s.....you are gonna have a few problems, your liver is certainly have to deal with more than most other people's livers, not like alcoholics, you know, but probably semi-alcoholic...Then, you know, your heart cholesterol ...this is probably the most obvious things but also another damage is going in the body, just more underlying ...So, I imagine at the age of 70 I guess you wouldn't be as bright as you wish, I am sure you will feel crappy, if you know what I mean..." (169-174)

His predictions are based on his understanding of a medical model. Colin is logical in dissecting HIV into smaller pieces of fragmented medical issues. Colin speaks in the second person as if he wants to remove himself from that group. His knowledge is likely to induce his fear to become someone else, someone he doesn't want to be.

George predicts his own life span:

"...I mean, I have taken lots of drugs. I've taken a lot of alcohol. I've abused my body hugely. I don't realistically see myself being old age. My father died in his early 60s and also my grandparents had cancer. So, the reality is that even with HIV or without HIV I can't see myself an old, old person. It just doesn't equate with my family. So, I see myself (statistically) being a medium tail person and I see myself have to work till the day die. I find that very depressing." (George, 56-61)

George rationalises his prospective life span by reducing his life to a number of risk factors. His forecast allows him to escape fears of becoming a part of an elderly HIV cohort as it doesn't fit with his views of a fulfilling and happy retirement. He explains further:

George: "So, I don't think HIV in itself is the big factor. I think the biggest factor is going to be people just can't afford, we're keeping people alive for longer. We've got a lot more medications, people are living for longer and we can't afford to pay for people's retirement. So, people are going to have to go on working for longer. The HIV I don't see making a huge amount of difference anyway." (69-72)

George is anxious over an increasing life span and worried about changing demographics. He is fearful of a future in an over populated society which is lacking resources to look after its elderly. He is likely to be afraid of getting old without support at a time when he needs it most.

Colin: *“But anyway, basically, the resources aren’t increasing but numbers will and that will just carry on and on ...and now they suggest that we start seeing out GPs and , you know, GPs, they are not specialists, you have one doctor working purely in HIV and even they struggle to keep up with what is going on and don’t know half of the research because they can’t possibly follow it . So, suddenly start seeing your GP who is going to suggest your medication or whatever it is going to be such a poor service...”* (149-155)

In his world, HIV doctors are overwhelmed by the high volume of up to date HIV research. He hopes that the scientific world across the globe is currently working hard on advances in HIV treatment. This fantasy is used to offset the fear of the deterioration of the health service. He is knowledgeable about the proposed outsourcing of HIV service to GPs. Colin is sceptical about that strategy as he sees GPs are lacking specialist knowledge. He is likely to be anxious and fearful of the prospect of losing quality care and uses his knowledge to build on a wider picture of HIV service. Colin’s fantasy about the scale of ongoing HIV research brings him hope that there will be significant improvements in treatment in future. However, he predicts that HIV infection is on the rise and, similarly to George (69-72), feels uneasy and possibly threatened by forthcoming changes in the service which is responsible for his health and well-being. He explains further:

Colin: *“They (HIV consultants) were rushed and overworked it is hard to say why as it is speculative but that kind of thing because we suffer with side effects of medication and that should be dealt quickly, I think it will get worse. And that worries me a little bit obviously. I have*

high blood cholesterol, for instance, due to my medication, I am not sure that that those kind of things will get picked quickly when you are outside the clinic... especially by the GPs.” (164-168)

He predicts a deterioration of HIV care. Colin is concerned that he is already seeing this due to the overworked consultants who are pressured by the workload. He is anxious of losing priority care. He's worried about not being able to access the service at short notice, which he sees as hugely important in HIV care. As a patient, Colin might feel that his needs will no longer be fully considered. That could also mean that he sees his needs as an NHS patient as a matter of priority and is perhaps used to taking it for granted.

Financial cuts invoked old fears that the government cannot be trusted or relied on.

Joseph: “err... but... I think one of the problems is that the government is very slow in making rules and things like that. Also, particularly at the moment, financially for everyone it's a difficult time...” (132-134)

There is an element of scepticism in Joseph's opinion. He has been around long enough to know that the changes in legislation can take time to materialise. He possibly can't see any immediate changes in HIV care in his future.

The comparison with the previous Tory government which was in power during the original epidemic of AIDS, reinforced old feelings of mistrust in politicians. It also underlines a sense of disempowerment as being a part of a minority group. These reflections were echoed in my own views on the current aggressive cuts in public spending by the new Conservative government. As a newly qualified psychologist, I feel that I can relate to the concerns of my participants and understand their vulnerability in the current climate:

Adrian (53): *“I grew, I’ve come through the period where HIV equals AIDS equals death and I never, ever really believed that. Never, never ever believed that. You know, when, it was only in late 1986, early 1987. The Thatcher government realised that it wasn’t about gays or minority groups like Africans, because they didn’t care, they didn’t invest anything, but, it’s, it’s as soon as it started touching the heterosexual community, that’s when the Conservative government, the Thatcher government, did something about it. At that point it was too late, it was just too late for some people. You know, so I have distaste, I have real distaste. Err... and there was a lot of pain attached to that.”* (69-76)

Adrian has felt let down by the government in the past. There are three major assumptions in his account: (a) The government had powers to control the AIDS epidemic at will; (b) The government represents a heterosexual population and will only intervene on behalf of that group; (c) The government is deeply uninterested in the lives of gays and other minorities. These assumptions are likely to be internalised for almost 30 years of living with HIV. Adrian’s knowledge of the past appeared to tell him that he cannot rely on anyone, especially the government.

Drawing from that past, Adrian is concerned that history is being repeated. This knowledge brings a sense of abandonment and betrayal and evokes in him an ideological tension.

Colin looks into the nature of pharmaceutical business and concludes that it cannot be trusted too:

Colin: *“ehm, I also suspect that the drugs companies will see that so much money to be made from keeping all those people on medication which keeps them stable rather than curing it, so that will be an interesting thing, you know, politics, you know, will play part, so sadly I don’t see the day when they got rid of HIV to save the people...”* (120-124)

He is pessimistic about his future as a HIV positive patient. He must feel disillusioned and even disempowered by the long-term prognosis due to profiteering practices in big businesses and the pharmaceutical industry in particular. The notion that no one can be trusted transpired in the remarks of many as the participants were prepared to be left with a minimum of support in times of need. Their prediction of the future of HIV care is grounded in their past experience at times when they felt abandoned.

5.4.2 Split

Participants learned how to put aside anxiety-provoking thoughts and to remove themselves from intense negative emotions. I used the concept of splitting from Melanie Klein's perspective (1948). She describes splitting of the object as a defense mechanism deployed by the ego against anxieties concerning the destructiveness of the death drive. Splitting directed at maintaining the separation between a good object and a bad object to safeguard the security and integrity of the ego (ibid, 1948). The understanding of the meaning of the split in HIV could help to devise appropriate counselling psychology interventions with this particular client group.

Colin: *“Well, I get... ehm, you know, this is probably my way of dealing with life... I tend to, whatever situation I am in, whatever crisis I am in, ehm, at one point I will step outside it and become more objective and I almost find it quite interesting to see how one deals with that situation or not. I see myself as part of a Royal Picture or something and that's a... like stepping in the outside, almost like stepping in to the intellect really.” (51-55)*

Colin shares how he dissociates from the emotional material so he can deal with problems on an intellectual level. Intellect allows him to become a detached observer, so he can separate from his emotional content. This in turn allows him to

function more effectively.

George shares his experience and how he dealt with his HIV diagnosis for the last 16 years:

George: *“I made a conscious decision to carry on working and... so I decided very much that I was going to push it very much to the back of my mind. I think that’s how I dealt with it, really.”* (9-13)

George learned how to put his emotions aside by submerging himself in his work. In his job as a nurse, he deals with other people’s problems which is likely to help him to ignore his own emotional material. George later described himself as “a very logical fatalist person” (George 43, 85). This summarises the way he deals with life: he accepts his life’s drama, so he calls himself a “fatalist”. The nature of that acceptance, however, is intellectual by nature. As George describes further:

George: *“I mean, personally I have never dwelt on the HIV side. That’s been my coping mechanism. So, I never really dwelt on the HIV side. So, I never really accessed HIV services, except the HIV clinic at the hospital, for check-ups, blood, and medication. I work a full-time job. I haven’t got time to access HIV services. I never did.”* (73-76)

George could be seeing his emotions as a sign of weakness. He deals with HIV when it is completely necessary. Ignoring any thoughts of his illness is likely to help George to escape fears and carry on with life as normal.

Relationships with HIV are often emotionally taxing. Joseph, for example, told me, off the record, that he used to refer to HIV as "Betty". Giving HIV a nickname helped him not to feel too overwhelmed. Split helped him to disassociate from the

reality of having HIV. It allowed for improved functioning at the time. Giving HIV a different name was tactically similar to describing oneself as a “logical fatalist”. Joseph perhaps felt too scared to call HIV by its name. By the same token, it was too scary for George to access HIV-related services as he would have had to acknowledge its presence in his life. In both cases, it allowed for disengagement between cognitive and emotional processes.

Elimination

Michael is the oldest participant in the group. He went a long way before coming out as a gay man in his 50s. He now turns away from his gay life and socialises more in the heterosexual community (Michael 93-98, p.79).

Michael: “ *I've had no sexual contact since 2004. I chose to live a life of complete chastity. Ermm... that, so my whole life, my whole life changed dramatic, dramatically once I had that diagnosis and (**short pause**) I'm very happy with that. I have, warm, close relationships with some very good friends err... completely non sexual.*” (21-24)

He reported having vivid sexual dreams:

Michael: “*Sometimes I get peculiar dreams, that's all, but that's all it is, really. Erm, (**short pause**) peculiar in the sense that they are very graphic, that they are very vivid, very. It's like it's really happening.*”

Interviewer: “*Very visual?*”

Michael: *“Yeah, err, very often of a sexual nature. Yeah, well that’s a bit disturbing. This is not all the time. It’s just a medication thing.”*

(31-36)

Michael’s dreams indicate the possibility of elimination of his true feelings onto a subconscious level. He insists that his life has changed for the better since the diagnosis. This forms a part of his split from his sexual needs and fantasies. Michael finds his dreams concerning and attributes them to chemical imbalance caused by antiretroviral drugs. He is therefore removing a sense of his own responsibility in that process. On the other hand, the split helps him to maintain a power balance he needs so he feels that he is still in control of the situation.

5.4.3 Fantasy

Fantasy plays a significant part in adaptation in AHIV, bringing hopes for an ideal and non-toxic medication and satisfactory retirement. They had a clear vision of how they would like to see themselves in advanced years. At the same time, participant’s hopes were cautious as if they didn’t fully believe in such possibilities. Dreams of a better medication played a significant part in participants’ accounts:

Adrian: *“...When something is working and working well(it) helps to enrich the quality of my life, you know and if that means taking a tablet everyday coz I’m nearly off, nearly off my antiretrovirals, but if that means taking a tablet that I have never, never ever had problems with, had a side effect to, that my body, that is okay, everything is okay.”*

(109-112)

Adrian shares his fantasy of an ideal pill which he will be happy to adhere to. The magic pill will cause no side effects, will cause no harm, but will be ultimately

effective. It will allow Adrian to forget about his HIV status, so the impact of the infection will be reduced to minimum.

Colin: *"I think drugs have improved, not that they have announced the improvement and sometimes the name of the drugs are exactly the same but turns out on a background they find out why it gave diarrhea and they removed that thing and you don't even know that it is better, so from that perspective drugs are better... so the drugs have improved and they are working on this."* (113-116)

Colin suggests that pharmaceutical companies are keeping quiet about the improvements in existing treatment. He likes to believe that they are constantly and secretly improving the quality of the old and existing drugs. He doesn't want to think that reduction in the side effects could be attributed to the body's readjustment to ART. If drugs are getting better and improving, it means to Colin that long-term prospects on medication are also improving. The better drugs are likely to promise a better quality of life. If reduced side effects are just a part of compensatory response from the body that could also mean that the body eventually might stop to compensate. This ultimately could become a serious point of concern, so that's possibly why Colin chooses to fantasise about the best case scenario.

David: *"The medication would free me from quite a strict (**deep breath**) regime routine of dealing with my anxiety, yoga meditation and err... eating well all dealing with things promptly. So, medication for me would be a life-changing event, now that I needed it, accepted it, it would change my life. Help me to fulfil myself, return to work, be well err... mix with other people without the fear of the effect they are gonna have on me whilst not on medication."* (101-105)

David's ideal drug will turn his life round and will make him a new person, someone who is more confident, pro-active and independent. He believes that his

readiness to go on ART is an important step in the treatment process. He possibly relates to ART in a similar way to how he relates to yoga and expects a complete holistic transformation, so he become fully functioning of both at a physical and social level.

Adrian, who has lived with HIV for almost 30 years, hopes that the cure will come from nature:

Adrian: "...I think (pause). I absolutely believe that the cure will come from nature, (pause) I don't believe it will come out of mixing chemicals together, I believe it will come from some plant extract or, you know, something that is quite obvious, that's what I choose to believe." (138-140)

The toxic side effects of ART is Adrian's main fear, therefore he fantasises about the cure, his hopes for a natural and non-toxic remedy which has been too evident to be considered before. The meaning of something obvious is profound. If the source is conspicuous, it is likely that the cure will come in abundance and will become available to all. It could also mean to Adrian that science is not looking in the right direction for a treatment solution and reinforces his beliefs in alternative medicine. The most important implication from this, however, is that the cure will come in abundance. It means that it will make HIV redundant. My association with this is based on the discovery of penicillin. Similar to Adrian's vision, it was found in mould and spared humanity from a vast array of bacterial infections. A similar discovery could effortlessly reduce HIV to a mainstream and fully treatable condition. The implication from this is that Adrian will eventually be healed in a more safe and natural way.

A bitter fantasy:

Colin: "I am greatly aware of being 45 and ehm, losing a... later prime years... let's say, and if there is a breakthrough in (a) few years' time... I will be slightly bitter because I know that I lost 10 years of not having (a) sex drive and now I am 45 and I feel like I am not attractive, you know." (69-71)

Colin is conscious of his middle age: he has some unsettling thoughts that he is getting too old for the joy of a private life. He is worried that a “cure” is becoming less relevant for him as time goes by. Aging is a normal process. A loss of sexual drive is a known side effect of antiretroviral drugs (Siegel, Schrimshaw & Lekas, 2006), but also is a part of the aging process. There is no control over this process and the fantasy of healing brings both hope and resentment in Colin. He is anxious that a cure will come at a time when he won’t be able to fully appreciate his new-found health. He is also hopeful that he might still make up for the lost time.

Colin addresses the appeal of youth by saying: “*Age, attractiveness come together (laughs)*” (Colin, 76). This is likely to be representative of the “ageist” and body-focused aspect of gay culture (Bergling, 2007). Therefore, for Colin, as a gay man, age and attractiveness are in tough competition which is accelerated by HIV. Allowing for a fantasy of a cure creates a belief in the temporality of HIV and instigates hopes for new relationships.

Hopes for the future

This theme was clear and apparent in all the interviews. I decide to include it in my analysis not so much from a point of view of the value of the underlying and deeper meanings of that phenomenon, but mainly because of the expressed needs in regards to the future of health care provisions. Participants were concerned about what the future holds and most of them have already thought about how they were going to live in their advanced years.

Peter: “*I just think of people with HIV supporting each other when growing older ehm that might have happened spontaneously anyway but I would like to see not so much gay homes for elderly but HIV gay homes or mixture of both, you know, we don’t have either as far as I am aware of at the moment.*” (182-186)

There is a pressing need for a community environment in Peter’s vision. He

expresses hopes that this will get resolved in time. He is following relevant sources of information with regard to care home developments in the UK. Peter sees the need for HIV care homes as a priority in comparison to gay care homes. This probably reflects on his anxiety of HIV stigma in older years. Adrian elaborates on a similar idea further.

Adrian: "I think in the long term they will need to look at the possibility of having services, you know, if people will be getting really old and they have an old folk's home, you know, is it going to be made an issue again, you know. They may well have to look at investing money in services that like that, for men and women who are quite old and go into geriatric years because some people are still living, I feel alive." (140-144)

He shows concern about the financial future of care homes as he sees in his own example that life expectancy is increasing. He anticipates that he will be living longer and is therefore worrying about his future. Adrian described himself as feeling alive which could also mean that he in fact feels geriatric by being a HIV positive gay man in his 50s. This makes me wonder at what age he will start to consider entering a care home environment.

Peter: "I think that shift (is still) to come and although I don't need that yet, I am sure some HIV positive gay people are suffering from it now, being an older age and being in care homes or whatever, nurses being a bit cautious because they are positive or they are treated a bit different, I don't know. I wouldn't be surprised if that happened, well, I have to find out, he, he." (169-174)

Peter's fantasy of maltreatment in care homes makes him feel uneasy. His chuckle somehow undermines his future hopes. He doesn't operate with facts, but

relies on his imagination. He anticipates forthcoming changes and is fearful of being trapped in a disempowering situation.

Colin: *"I'd like to move into Soho; as you get old you would like everything to be very near to you or otherwise you are not going to do it... so, for me, London is ideal, you have to travel far and the more densely populated the better for elderly... and the idea of (being) stuck in the country somewhere... so, no, London is better."* (195-198)

Colin goes for an alternative and self-empowering vision of retirement in Soho. He wants to feel assured that he is in the centre of town and that all the facilities are within his reach. The fantasy of life in town is seen as the opposite of a secluded retirement in the country. I am wondering what it means to him to retire in the centre of a predominantly young gay community. This somehow contradicts his earlier quote (Colin 71, p. 93) of feeling old and unattractive. The fantasy of Soho might help Colin to reconnect with what is missing in his life these days.

Peter shares his hopes and fears

Peter: *"Living in a place with a shared cooking and/or entertaining each other, or, that would be my hope for being HIV in the future, and my fear would be gradually deteriorating and living on my own and being found in my flat like (laughs) three weeks later! Or cats eaten half of me or sorts (laughs)... But, as I said, I am trying to live in the here and now so..."* (200-205)

Peter's big hope is to move back and reconnect with a community. To him, isolation equals gradual deterioration, while life for other people implies fun and support. There is a stark fear of being left alone and forgotten and not being helped when needed most. His fantasy therefore plays a dual role as it gives hope and it

takes it back. That process is unsettling for him, so that's why Peter tries to ground himself in the present.

5.4.4 Power of Mind and Spirituality

Two of the eight participants mentioned spirituality as an important coping tool in dealing with HIV. The other three have referred to free will and the power of mind in devising effective coping strategies. Spirituality seems to support a positive reconstruction of traumatic experience with HIV. The subsection illustrates how some found an invaluable resource in an alternative outlook on their existential journey.

Adrian: "For me, I didn't, I didn't go along with what they said. For some reason there was something in me, that told me that I would like my life and (pause) how, how, how could they if they didn't know what they were dealing with, what gave them the power to, to tell me that I would be dead in 10 years. ... I chose not to believe it." (27-31)

The exploration of the power of mind started for Adrian in response to the shock of a death sentence. He still feels angry with the medical forecast to his life expectancy. He seem doesn't want to accept the fact that at that time there was very little knowledge of HIV and medical prognoses were often wrong. He found self-empowerment in focusing on his intuition and excluding all other sources of information. This coping is very close to split by its mechanism. The difference is that Adrian appeals to his sixth sense. That intuition helped him with finding sustainable ways to carry on with life and transpired throughout his interview.

George: "Because of what I saw of my best friend, with him not fighting HIV...it was... contributing to his negative mental health and his rapidly deteriorating HIV..." (10-11)

George believes that a positive state of mind is crucial in the process of dealing with HIV. He describes that process in the language of warfare and attributes this to a victory of the power of mind.

Adrian: “**(pause)** *To come through that it was like being given a second chance. It was like being, you know, I knew then that AIDS was not going to take my life. I knew then, you know, I knew, just, something spiritually happened to me. It really opened me up, something, something deep that I can't, I know. There is nothing in human language that I could tell you that happened.*” (59-63)

He describes his spiritual experience as a new lease of life which has helped him to overcome deep fears and despair. He developed a belief that he will survive AIDS and learned how to trust his own intuition. He describes his spiritual experience as a non-verbal phenomenon of personal transformation.

Joseph: “*So, a lot of it is perception, how you perceive things. I mean, that's life, if you perceive things in a positive way you can usually deal with most things.*” (116-117)

He also emphasises the power of mind and power of perception. He believes that the way one thinks about one's condition has a significant impact on the way one deals with life. His account resonates with Peter's experience of using spirituality as an anxiety-reducing technique:

Peter: “*...The life events can be gurus and our teachers but actually what is at the end of the road, you know, it is like, you know, and I think that HIV has been a big teacher and what it teaches me to do, as lots of gurus teach us to live in the here and now, or try to be*

present in the here and now, and not be concerned about what might happen, or what has happened, because all there actually is, is the here and now. And nothing else is actually real, apart from what is happening here and now, he, he... I think that is my biggest gift, I guess, from the illness, which is given to me. Because it has so many variables and possibilities and if I go into the past about infection, you know, it is just... I just feel that it is the safest place to be... now.” (130-140)

Peter thinks that HIV revealed to him the existential secrets of life and death. His new-found ability to live in the present moment he attributes solely to HIV. That ability helps him to master his past fears and future anxieties. He anthropomorphises HIV and attributes positive qualities to it. He describes HIV as caring; helping and insightful. This helps him to connect to and accept the illness. He believes that he has been taught how to keep grounded in a world of uncertainty.

Spiritual explorations have also helped the participants to regain balance and meaning in their life.

*Adrian: “It has (**deep breath**) it has been an awakening (**pause**), it really has, it's been an, it woke me up spiritually. It has been a deep, deep journey, err... into myself because I believe as human beings, I choose to believe that the answer lies within me. Err... (**long pause**) truthfully, for me, it has been a remarkable gift. I didn't see it as a threat. I chose not to see it as a threat. It has opened up my life like (**pause**) like the branches of a tree or the petals of a lotus. It has made me, it has helped me, enabled me to get in touch with parts of myself. I mean that I might never have had the courage to explore because I chose to believe that my journey into, as a gay man with full-blown AIDS now with HIV positive for 28 years... At times, truthfully, it was, it enriched my life. I know, I can only speak for myself I know that, I know that, that might for some individuals can be quite, be very, very different. Err... it has enriched my life. It has opened my life up in the most deepest, spiritual way. At times it was painful but I feel that it was enabled me and given me the ability to become as well informed as I*

need to be for my sense of survival. Even in my darkest dark with this, my darkest dark when I almost died on the 5th of June 1988 (pause) there was something that helped, holding me, I cannot, I do not have the words to explain.” (80-93)

Spiritual discovery helped Adrian to process his fears and it possibly supported him at the time of the initial diagnosis 28 years ago. At that time of his near death experience when he was likely to feel the most disempowered, Adrian finds a solution in the power of his mind. It helped him to survive and enabled his free will in his choice of starting to think positively. He also formed a special relationship with HIV by choosing not to fear it. He then learned how to search for the answers from within. Adrian positively reconstructs his HIV experience as he is convinced that HIV came at the right time so as to enable deeper spiritual explorations. Adrian compares that process with a blossoming of self-development. His experience is very private and profound. He concludes:

Adrian: *“So, it was almost like going through a form of re-birth and (pause) embracing one’s life on life’s terms.” (65-66)*

This is likely to be a learning curve of a lifelong process of searching for contentment. A second lease of life lies in the acceptance of the circumstances one finds oneself in.

5.4.5 Summary

When one is subjected to a traumatic episode, the openness to the world can be difficult to maintain. When fear becomes too disabling the person eventually withdraws. Even years later, some of the memories can be so painful that the participants' consciousness seems to struggle to retain them. They used a vast array of techniques in order to compartmentalise those experiences.

Participants presented specific patterns of adaptation to new life circumstances. Some tried to escape by means of fantasy or denial. In doing that, they were making themselves believe that their HIV experience could be finite and lead to full recovery. Other respondents tried to engage in a sense-making process by looking into a wider picture of the life experience and usually employed knowledge and spirituality as a main resource. Knowledge, for example, demonstrated a two-way effect. It had the potential to decrease, as well as to increase, the negative thoughts such as of depression or low self-esteem. This was happening because the participants were selective in the way they chose to apply their knowledge. Some, for example, used negative past experience as the only point of reference for future predictions and therefore displayed less adaptive coping skills during the interview.

Those who used spiritual resources, on the contrary, displayed what appeared to be a higher level of feelings of contentment and acceptance in comparison to other participants. Their average skills to cope with life challenges seemed to be greater than that of their peers.

Spatial aspects of presented coping mechanisms were informed by the time of the onset of trauma. The shock of the diagnosis induced a split, which was shaped by the necessity of that particular moment in time. The split is robust as it seems to maintain itself throughout the experience and transforms through the prism of employed fantasy or knowledge.

It looks like the aging process with HIV has a potential to lead to revision and re-adjustment of existing coping techniques in older participants. Spirituality, in particular, seems to help AHIV to address a number of existential issues, such as the meaning of life, aging, and the attribution of why one has become ill. The process of

adaptation amongst the participants bears the emphasis on transition and the way one experiences self. It assumes quite specific patterns of coping which can be facilitated in clinical work. Following an existential thought of Jacobsen (2007), suffering can be viewed as an opportunity to enter a dialogue with - and allow to see - one's own journey as an ongoing developmental process on the way to a positive reconciliation between one's beliefs and experiences.

Chapter 6 Discussion Section

6.1 How participants presented themselves in the interviews

General observation

As was mentioned in the methodology section, I received good response rates from the prospective participants in this study. What was common between all of the participants was that everyone wanted to stay and talk off – the - record at the end of the interviews. I asked myself what the underlying need for the participant to want to do this was and even why they wanted to take part in the study in the first place.

On reflection, I think that it could be due to a relatively short interview time (40 minutes) which was originally allocated in advance by the agency. The participants might have also felt that they needed more time to address the topic. They might have even been given their first ever chance to verbalise their thoughts properly and also have been influenced by a perception of stigma of their condition, so they therefore felt at ease when the tape recorder was switched off.

In hindsight, I believe that it was a combination of all of the above. I made some notes in my research diary in order to capture what was said off-the-record and compared these against the content of the actual interviews. It appeared that each of the participants had a main narrative he/she wanted to be sure was delivered, so they subsequently repeated these themes off the record. All this was

taking into account at the interpretative stage, when I was deciding on the emerging themes in this research.

Ultimately, it feels like the participants wanted to talk about their experiences, and I recognised that it was important for them to share these with me. I also suspect that despite the explicit explanation of the main purpose of research, they at times saw me as a representative of authority, someone who was conducting research in an area of their concern; perhaps they also felt like their worries might have a chance of being addressed at a somewhat more official level. I had a feeling that at times they weren't sure where to start or how to go about broaching the topic. This observation is likely to reflect on my own process in research and possibly not even knowing myself where to go with the participants at the initial stage. I tried to keep my mind open and see where the interview data was going to take me and possibly didn't give enough prompts to the participants at that time. I chose just to stay with the general experiential frame of life transition with HIV and see what would eventually be revealed. I was asking myself how I could make sense out of my own experience of aging and how that could be used in my own way of conducting this research. Participants, in turn, might have mirrored my own uncertainty about the scale of the topic at this initial stage.

The use of language

The language used by the participants was specific and distinctive in two major areas of expression:

(a) It appears that HIV discourse is extremely medicalised. Participants demonstrated familiarity with HIV pharmacology, as well as with the biochemical language of specific blood tests, such as CD4 count and viroload levels. It seems to me that they were using these figures as the point of reference for the state of their own health and well-being. This can be partially explained as being due to the fact that HIV can be asymptomatic at certain stages of infection (BHIVA, 2010) and the figures of T-cells count and the number of viral copies in blood may often be the only indicators of HIV presence in the body.

On another level, familiarity and accustomisation with a medical discourse could potentially allow participants to communicate differently with a medical team. It is likely to make them feel more equal and in control in what can often seem like a fragile power balance between patient and medical professional. The use of language might impose question of definition of one's health and own identity as a HIV positive person. It is possible to assume that numbers within a CD4 count or a viroload level can be manipulated into one's own understanding of one's safety and even recovery.

The language potentially supports further dissociation and removal of self from the emotional context of illness and may also advocate an additional sense of control. It supports a further split and use of knowledge when seeking reassurance from an ongoing anxiety.

The discourse that transpired in the interviews may also have influenced the participants' understanding of the dynamic of their condition. For example, the meaning of terms such as 'non-detectable viroload' or being a 'non-progressor' might carry a different personal meaning for a HIV positive person. One of the participants admitted his frustration of being labelled as a 'non-progressor' as he subsequently found it difficult to place himself into any specific group. He didn't feel like he was HIV positive, but he also could not relate himself as HIV negative. The understanding of the term 'non-detectable' viroload could also mean different things to participants and may not necessarily be the same as the medical understanding of HIV. For example, what does it mean when it is said that it is 'non-detectable' and does it therefore imply that the virus is no longer in the system?

Medical discourse might not be exclusive to the AHIV group, however, as it has the potential to add to the complexity of terminology for elderly patients who might eventually struggle to grasp the meanings of a newer and increasingly more advanced HIV vocabulary, potentially pitted against ever-diminishing cognitive functions. It would be interesting to explore the use of medical language in chronic illness further in order to understand this process better. The results of such research may serve to bring additional insight, to the extent that HIV terminology, discourse, and linguistic expressions might be linked to re-adjustment to the

condition and originate in the experience of stigma and confusion over one's own identity within this specific group.

(b) The use of evocative language and metaphoric expressions was another form of communication, which I decided to include as an illustration to my introduction to the participants. Metaphors seem to be preferable for the sharing of emotional experiences as participants struggled at times to find the right words to express deeper meanings. I see the metaphoric language used in interviews as serving two different, but complementary, functions: it allowed participants to express something which was difficult to verbalise or things which were previously unexpressed or unexplored. On the other hand, it also allowed them to distance and detach themselves, so as to avoid revealing themselves completely. Some of the expressions used also contained a footprint of social clichés and subconscious fears and expectations. If life experience of HIV for some of the participants is associated with not being heard or understood by either relatives or a wider community, the use of such metaphors potentially allows them to raise their voice in their own unique way in order to express their pain around stigma and disclosure.

6.2 Stigma and its role in AHIV

Stigma was mentioned consistently in all interviews. It was presented in two different ways: as stigma in a community and self-directing stigma. Participants were wary and expected stigma to increase with age. The prejudices were also associated with sexuality and age and weren't attributed solely to HIV alone.

Stigma in HIV is well researched. Most of the previous studies in this area consistently emphasise the need to enhance a social network of support in AHIV as an attempt to increase the quality of an extended life (Shippy & Karpiak, 2005). They recognised the need to address both stigma and loneliness in this group (Grov et al., 2010). Some authors conclude that finding strategies to make disclosure of HIV status easier for older adults may be an important component of decreasing isolation and depression. They also believe that facilitation of disclosure will increase medication adherence and improve general health (Vance & Burrage, 2006; Vance et al., 2008).

Although these are hugely relevant interventions, my view is that loneliness is a somewhat universal experience amongst the various aging groups; especially the elderly who live alone and, in fact, it might not be particularly unique to HIV. On the other hand, HIV stigma requires a wider psychosocial and psychoeducational input from community psychology and therefore should primarily target mainstream society. Psychoeducation and media can be more effective in addressing HIV and age-related stigma than merely a facilitation of disclosure. It can therefore impact positively on the availability of social choices and eventually increase a likelihood of disclosure in future.

Ultimately, the experience of HIV can be very isolating as people tend to hide their status from their close circle of family and friends. In addition, the effort of maintaining the secret of the diagnosis may create additional stress beyond the challenges on a physical level. The uniformity of stigma makes HIV quite a unique group in comparison to aging healthy adults and those with other chronic illnesses. Stigma become a part of participants' lives and negatively impacts on re-adjustment and re-integration with the community.

The unanswered question is how serious its impact on the future retirement might be and whether there should be provisions put in place in order to support this vulnerable group.

6.3 Observation of time, age and HIV

The most prominent philosophical observation in the study was a sense of the interconnectedness between the *Past*, *Present* and *Future*. My own association of that process was with a ripple effect. Like a pebble which is thrown into water and subsequently creates circular reciprocal waves, lifetime events seem to create a similar resonance across the lifespan of our experience. That circle seems to expand with age and the waves are simultaneously fading away into the *Past* and into the *Future*. The participant's *Present* experience echoes with the *Past* and allows for the meaning-making for the *Future*.

The understanding of HIV itself, the medical support, and the associated governmental policies are all seen and are understood from the prism of the participant's own life experience. Spatial cross-referencing is understandable as most of the participants were traumatised by what they have witnessed and experienced in the pre-HAART era. Therefore, they were trying to make an effort to protect themselves from a repetition of the similar experience in the *Future*. Those who were dependent on others for physical or financial support are now making an extra effort to provide for their future retirement. Those who draw the main resources from community living are contemplating their future arrangements within a friendly and accepting nursing home. It's almost as if, on some level, the participants were expecting their *Future* to mirror their *Past*, the time when they were very ill, frail and dependent. For many of them, this experience was based on stigma, isolation, loneliness and fear that subsequently brings an extra dimension of understanding of how participants are expecting their future to be.

The important question for me in this research was to differentiate what was specific to AHIV and what the relations were like between age, ART and HIV. Although all three were mentioned in the interviews, each was given a different priority in relation to its time and space in participants' lives.

The role of HIV

Interestingly enough, although HIV was a main topic of *Past* recollections, it didn't transpire strongly in the *Present* experience. The participants recognised the physical presence of the virus in their bodies and its impact on their physical health; they were anticipating long-term effects from ongoing exposure to the virus in their system, and showed concerns about diminishing availability of their physical resources. However, in the *Present* moment, HIV seemed to give way to the other more prominent and pressing issues, like age-related illnesses and long-term use of ART. It feels like that at this point, and on some level, all the participants had accepted their HIV status; this acceptance was expressed on a cognitive level of a medical understanding of the nature of the problem. In psychological terms, however, most of the participants were in different stages of denial, struggling to associate themselves with the HIV positive community and seeing their own

experience as exceptional. Growing older with HIV was causing the most concern in regard to the uncertainty of what the future may hold, accelerated aging, and increasing stigma.

The role of ART

Antiretroviral therapy and its long-term side effects was another primary concern in the group. There is an element of paradox in the way people were experiencing ART. Participants were referring to drugs which were once designed to save their lives. Over the years, the very same drugs have become perceived as a health risk, a hazard which was seen by many to be as great, if not greater, than HIV. This creates quite a unique conflict in the HIV community. In the aging cohort, ART was seen as the main contributor to a shortened life span and accelerated aging. Participants, especially those who were in their 40's and 50's, were planning for the future, but were highly anxious that they might lose a quality of life in that journey. They were confused with what would cause the most damage at this stage of their lives: the virus itself or the antiretroviral drugs.

Age

Their physical age seemed to play a part in the way the participants were experiencing a life transition and also revealed that different age groups expressed different needs and priorities. This observation represents the author's own observation of a small research sample and by no means it can be generalised to a wider population.

What appeared somehow paradoxical at first was that the oldest participant was the least likely to report poor medical adherence. A 70-year-old, Michael, expressed no concerns with antiretroviral medication. His outlook on being on treatment was, overall, positive and in line with findings by Sherr et al., (2009), showing higher levels of compliance to medication in the elderly group. From a delayed gratification perspective, this can be seen as contradictory, as elderly participants chose to take potentially toxic drugs and were prepared to deal with the side effects in order to keep the HIV under control, which may indeed be a condition to which they might not have any or minimal immediate symptoms.

The possible answer to such phenomenon might lie in the perspective of a death anxiety which entails dread, apprehension, or solicitude when one thinks of the process of dying, or ceasing to be, or to what happens after death (Yalom, 1980), together with the consequent desire to survive, which therefore makes adherence an obvious choice. This phenomenon could be, however, seen from the perspective of stages of psychosocial development by Erikson (1968) when the final developmental task is retrospection - assuming Michael has developed feelings of contentment and integrity if he believes that he has led a happy and productive life. I am aware that not enough data has been generated by this research in order to explore these more generalised trends and themes in greater detail. However, I believe that it is sufficient to instigate some thoughts of how a particular group might be experiencing aging with HIV.

The individuals who were in their 50's appeared more settled and accepting of their age and their HIV status. Participants from this age group expressed in-depth reflection on the experiential process of living with HIV. They praised spirituality as a crucial experience in their sense-making and life adjustment process. This resonates with recent studies (Brenan, 2008; Kremer, Ironson & Kaplan, 2009) which indicate that spirituality can become an invaluable resource to individuals with HIV in advancing age.

The main practical concern in this age group was the availability of specialised care homes. They seemed wary of stigma amongst peers and care home staff and also expected stigma to increase with age and affect their retirement. The theme of specialised gay HIV care homes was emerging across all of the age groups, but was a more prominent one with those in their 50's. Participants were concerned with their forthcoming age and saw not only HIV, but also their age and sexuality, as a major contributor to an increase in prejudices and isolation. The triple effect of stigma was previously researched by Lyons et al., (2010). It has been noted that homophobic and HIV phobic attitudes are more dominant in those who were born before the 1960's and who are more likely to be peers to the AHIV group. As participants mentioned moving to a care home as anxiety-provoking, it will be useful to explore to what extent such moves were associated with fear of unwanted disclosure.

The participants in their 50's were less likely to adhere to antiretroviral treatment and seemingly substantially relied on their previous experience with the condition. They justified their poor medical adherence from a position of expertise and knowledge of the alternative models of HIV management.

Participants in their 40's seemed predominately concerned with existential questions with regard to youth, health, age, and life transition. I am aware that the majority of the participants were from the white, middle-class, gay male community and that therefore responses from wider socio-economic groups can be different. Saying that, the studies on mid-life crisis indicate that this age group is more sensitive to the problem of life transition (Wethington, 2000). Gay men expressed particular worries about losing their looks and consequentially reduced chances of finding a partner. Transition for gay men could be compared to the studies on middle-aged heterosexual women where the end-of-shelf-life paradigm is associated with reduced physical attractiveness, the 'empty nest' syndrome and increasing loneliness (Degges-White, 2001). This, however, was not unique to those in their 40's, as all single participants were sceptical about the possibility of entering new relationships on the grounds of both HIV and age.

They expressed regret of the loss and of losing their prime years to the disease, longing for relationships and trying to grasp the meaning of their life experience. Psychological underpinnings of the experience of aging amongst the participants seem to be quite broad, but they had one thing in common: the experience of transition and an increased awareness of the limitation of one's life span. They were exploring and transcending their life changes or indeed fighting them.

The majority seemed to accept their life with HIV and expressed no issues with adherence to ART. The participants in this age group showed high political awareness and were very concerned about the future of HIV health care. They were sceptical about changes on the NHS. This theme has also found a resonance with me as both a researcher and a psychologist who is familiar with some of the challenges to the National Health Service. On a different level, however, I also see their concerns as a sign of unwillingness to transcend a wider social dimension of their lives, and to accept and explore those changes.

6.4 Coping mechanisms

Dissociations

I was surprised to encounter indications of split and fantasy amongst all the participants in this study. They presented a clear tendency to separate good objects from bad objects and perceived their experiences as either optimistic or disadvantageous. They were often ambivalent and presented polarising attitudes in relation to the same object and used interchangeably two conflicting meanings (e.g. yes and no; yes, but; I fear, but I don't; I predict it will happen, but I predict it will not, etc.). For example, they will rate stigma as hurtful and as irrelevant in the same sentence. When they had difficulties in compartmentalising a negative experience, the participants were removing themselves into imaginary situations where they were fantasising about future and favourable outcomes in their lives.

Dissociation appears on one level to serve as an adaptive function to life-challenging events and assists with effective coping strategies. It helps participants to disconnect from strong negative emotions, therefore protecting them from deep fear and anxiety of the unknown. Participants chose not to think about certain areas of their lives in relation to stigma, health and relationships. They preferred to fantasise about a future cure and recovery and in doing this to ultimately escape their fear and anxiety.

Many participants also made jokes or laughed at inappropriate moments. I noticed that this always happened at times when they touched on emotionally demanding subjects. My understanding of this phenomenon is that participants wanted to safeguard themselves from the vulnerability of disclosure during the interview. Laughter and chuckles helped them to disconnect from difficult material.

I don't see split as being a maladaptive response in participants' *Present* experience. It seems that the split has become second nature and allows them to function and face daily challenges. One might be tempted to argue toward such a conclusion, but a wider biopsychosocial perspective begs the question of how one can effectively deal with a chronic stigma, rejection and threat to one's own health. The split seems provide most of the participants with reassurance, as it allows them

to contradict their own knowledge in regard to the medical and social outcomes of HIV.

Spirituality

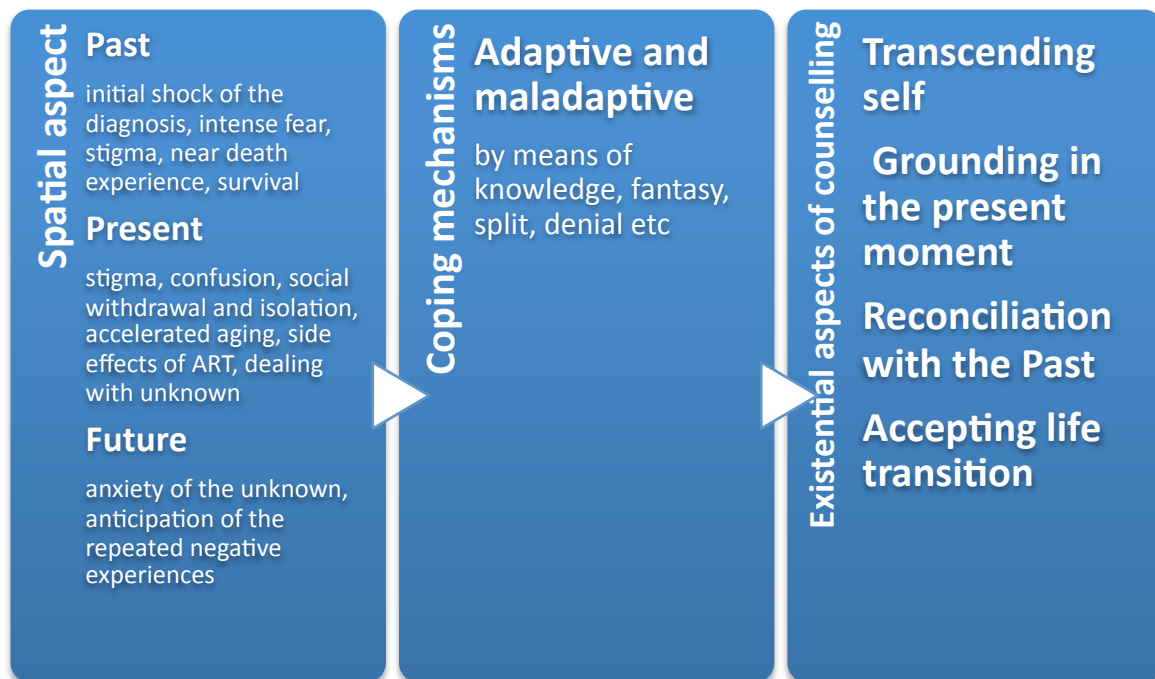
What stands out for me in the research is the observed effectiveness of the use of spirituality by some of the participants. Spirituality has been reported to improve psychological well-being and enhance a meaning-making process; positive reconstruction of traumatic events; and even increase social engagement of the participants. Spirituality was offering a particular model of self which can be understood within a wider social context and allowed for exploration of meanings.

The uniqueness of the group was in the fact that some of the participants have reported a near death experience when they were first diagnosed with HIV in the pre-HAART era. The consequent survival was likely to impact on the changes in the perception and meanings of the world around them. Death, in its own right, has become a part of their *Past* experience to those participants and was likely to affect their spiritual development. No wonder participants have never reported death in their fears of the unknown, as on some level their main anxieties were about the novel and unpredictable *Future* which did not include death *per se*. This, in turn, could be seen close to the notion of self by Spinelli (1994), where spirituality seemingly assists with the existential process of life transcendence and a call for congruence between one's beliefs and the way one is experiencing self. Therefore, it is possible to conclude that spirituality has helped the participants to embrace their *Present* and reconcile with the *Past* experiences.

6.5 Counselling knowledge

The author believes that this research contributes to the understanding of the meaning making process in AHIV. Table 3 expands on the experiential process; coping skills, and suggests appropriate psychological stances when working with this particular group.

Table 3. Spatial & experiential reconciliation using existential framework



The author thinks that appropriate psychological models in working with this group should expand on spiritual and dynamic aspects of psychology. Inclusion of existentialist or psychodynamic perspectives offers an understanding of a model of self and can be seen as relevant for this group. The central themes of midlife and HIV are linked to the phenomenological search for the meaning of life, death, isolation, and freedom. Psychological intervention with a wider philosophical angle can help AHIV clients to reconcile the past and can assist in further acceptance by embracing a wider concept of life transitions. This can eventually be linked with the present moment of the individual experience and subsequently used as a point of reference for any future plans.

An effective therapy can offer support over a wider perspective over life transitory experiences, but can also maintain the focus on the value of living in the present moment. What has not been clearly stated is that Heideggers' philosophical perspective of Time (Dasein) could also offer value, especially to those who might not have a spiritual resource to deal with life changes. This is because similar to a spiritual quest, Dasein embraces an ontological concept of '*thrownness*' into the circumstances (or given circumstances) and returns the client back into

'*everydayness*', but with an ever-expanding understanding of the meaning of a human experience. Heidegger's phenomenological approach might become a good starting point for the counselling method which aims towards an understanding of self and asks the question 'what does it mean to be human and existing with others in the world?' (Copperstone, 2009, p.339). This is particularly true for AHIV counselling in all aspects of promoting and supporting quality of life; psychological well-being, and working with stigma.

Familiarity of the counsellor with the spiritual aspects of clients' lives may also significantly enhance the process of age- and HIV-related re-adjustment. The subject could be seen as delicate because it might be closely linked to sensitive religious narratives. However, addressing spirituality with a client could enhance a process of positive reconstruction and self-empowerment which seems highly relevant within this group.

A further study is needed in which the experience of growing older with other chronic and life-threatening conditions, for example, in oncology, cardiology and diabetes, in order that these experiences could be more comprehensively explored. It would also be very interesting to interview a healthy aging population, so as to understand and compare this group's process of life transition with those of the group experiencing chronic illness, to better understand the processes involved.

6.6 Reflective summary

On a personal level, I was asking myself what was different and what was similar to my own personal experience of life transition to those of my participants. I realised that the participants were all very practical about the changing needs of aging. Even the youngest participants, those of my own age group, were very thorough in thinking through the arrangements with future retirement, care homes, etc. I felt that participants saw the process of growing older as an applied challenge which needed to be addressed, and not something which just can be observed. I am aware that practical thoughts about financial arrangements, for example, are not unique to HIV groups in our society. My own friends are often also realistic about their views and plans for retirement. What I see as being unique to the AHIV group

was a duality of the life transitory process. On one hand, AHIV had an extended quality of life on ART. On the other hand, they felt like that quality of life might be taken away from them and/or progressively diminish with the use of antiretrovirals.

I realised that the process of life transition is universal and therefore is not exclusive to any physiological or health problem. That process - when each individual must learn how to hold, understand and accept specific life-stage challenges as both required and useful - can be found in various discourses of philosophical thought (e.g. Jung, Erikson, Heidegger) and ultimately links to the resolution of internal conflict and dissatisfaction with one's own place in the world. Undoubtedly, HIV brings a specific context to that experience. The personal crisis faced by the participants was exacerbated by the rigidity of societal attitudes and perceived norms which perhaps has made the participants feel more vulnerable than their peers. What was clearly shown in the current study is that stigma has an additional and specific impact on the experience with life threatening illness. It not only affects one's own sense of identity, but in combination with the initial shock of the diagnosis, stigma facilitates further split and is likely to affect the way AHIV feel about themselves in the future.

6.7 Personal reflexivity

In this section, I want to reflect on how I have been implicated into the research process; how I influenced the research; and how the research process has influenced some of my material. I have already positioned myself in terms of my interest in the research topic, which was explained earlier in the text. I would like to reflect further on how this has changed the assumptions that I might had had at the beginning of the process and how they have later been transformed into a more personally engaging experience. The most interesting question is how such understandings raised my own awareness of the issues concerning and surrounding the intersubjectivity of the world and how that intersubjectivity contributes to my interpretation and understanding of existence as a part of Dasein.

Social aspect

The existential concept conveys self-estrangement and alienation which has become ever-increasing in our society, where reduced self-awareness seems to have almost become the norm and promoted on a mass media scale. This sustains what was coined by Loewenthal (2010) as an 'escape motivation', which reduces awareness of life, death, and meaning in wider society. I noticed in my social life as well as my client work that the themes of transience are often avoided, as if it almost intrudes or even threatens a sense of stability and permanence. So, I found that by taking on the project - which maintains a primary focus on the transience of life - was quite refreshing, as I guess it quenched my thirst for this type of exploration.

I didn't expect the research process to be such a life-absorbing experience, however. In some odd way, my own motivation was consciously escaping all the distractions of my 'other' life. Like my participants, I found myself splitting in an attempt to separate this work from the rest of my life by prioritising the project over the demands of my outside world. Unlike my participants, I was aware of this process and discussed it at length in my personal therapy. The split has created an odd, but nevertheless, healthy paradox which helped me to maintain progress and meet the required deadlines of this research.

Duality

In the final stages of the project, I recognised the extent of the duality of my role as a researcher and a clinician. For example, I caught myself gravitating towards a biomedical conception of HIV and unintentionally trying to impose a pre-existing knowledge. I therefore had to pay extra attention in order to recognise the individual and unique experiences of my participants and to prevent those experiences from becoming affected by my own preconceived ideas. I learned to step back and observe the psychological phenomenon as a pure and context-free experience.

In a similar way, as a counselling psychologist, I learned to recognise my dual role in MDT. I tried to sustain a balance between the confidentiality of my professional role and the requirements and obligations to disseminate important

information about the client to a wider medical team. This has been further discussed in the clinical practice section of this portfolio.

Keeping existentialism as a focal point was essential for me as it allowed me to address dualism, such as that found in subject vs. object; mind vs. body; and fact vs. value; and so on. In such a context, the analysis falls within the three key underlying principles of existential phenomenology of relatedness, uncertainty and anxiety (Bazzano, 2009). This resonates with the way I felt and understood the participants' experience and subsequently translated into my own experiences in life and the interpretation of the research material.

Portfolio process

When reflecting on the portfolio as a whole, I understood that my therapeutic approach cannot be defined as overtly positivistic. The portfolio helped me to recognise that my own professional style requires a degree of freedom to allow an assumption that things don't necessarily always get better for the client, and that the essential focus of successful therapy and research lies in an attempt to transcend a wider meaning behind each unique life experience and circumstance.

The research process was mirrored in my clinical work and, at times, I felt like my clients and my participants were sharing a rather universal experience relevant to many of us.

The philosophical implications of the research were concerned with fundamental questions of the nature of life, death, and survival and, ultimately, existence *per se* and these themes captured my imagination throughout the project. During the last stages of this work, I was supporting one of my HIV positive clients in a hospice during his final farewell to life. The meaning of Dasein as the basic constitution of human existence has been somehow intensified by this experience and influenced my own personal philosophy. The client was a man with broad philosophical views and his Buddhist beliefs allowed him to contemplate beyond the conventional framework of our physical existence. Irrespective to this, when his time came to its final stages, I could see the pain and empathised with his struggle when he was faced with the inevitability of the end. That, to my mind, was relevant to the

research material, too. It highlighted the experience of my participants: their anxieties of the unknown and a fear of accelerated aging, which is ultimately designed to bring one to the final stages of life at a time that is perhaps a step or two ahead of one's peers.

A framework and the basic conceptual structure of existentialism in such a context allowed me to make a better sense by embracing the concept of Being in Time in a broader systemic perspective. Various individual life stories have ultimately become one human tale of the hopes and struggles of those who are affected by HIV, themes which I have tried to capture in a separate sub-section (4.5). This perspective helped me to get a better overview of those experiences. The project brought to my awareness the notion of time and its limitation in its continuum. My philosophical stance evolved and benefited from a further degree of understanding, an understanding which was inspired by Camus, in that the best way of living is to aim for being in harmony with your own life and to love it in all manifestation: *Past, Present and Future*.

Section B: Clinical practice

Combined Case Study

Adherence and the uncertainty of the unknown: cognition and experience.

Introduction

I have chosen this case because it represents a particular complexity and also highlights certain challenges that I faced while working with this client who suffered from depression and had poor adherence to antiretroviral medication (ART). As his life story is exceptionally rich with traumatic material and experiences, it took me some time to establish the best therapeutic plan to undertake. The focus of our work together over these past months has shifted from CBT to the exploration of existential problems and eventually reverted back to CBT. My dilemma was that the vested interests of the referring agency were based on a promotion of adherence in order to achieve a long-term physiological effect. I found myself trying to find a balance between the requirements of the medical model and my own role as a psychologist trying to grasp the underlying issues behind my client's maladaptive behaviour.

Theoretical framework

In cognitive behavioural therapy, maladaptive thinking originates in dysfunctional beliefs and assumptions about the self and the world (Padesky & Greenberg, 1995). CBT interventions are designed to understand how life challenges are perceived, interpreted, categorised and responded to (Datilio, Beck & Freeman, 2007).

CBT for chronic health problems helps clients to understand their own needs and assists them to put their priorities into perspective within a wider social and medical context of treatment. There are two ways of approaching this, one of which is a problem-level formulation, meaning interventions generally derive from a concrete, health-related issue and help to improve the immediate quality of life

(White, 2001). Case-level formulation, on the other hand, attempts to follow the client's life path and their life story - with all of its ups and downs - by validating the story of both the client's distress and the client's competency and is a methodology which can also be approached in a relatively short number of sessions (Bor & McCann, 1999).

A life-long adherence to medical drugs can become an issue for effective HIV treatment as it relies on regular intake of medication to reduce viral load. A long-term use of antiretroviral therapy, however, can be associated with a number of serious side-effects, including neurological, gastro-intestinal and psychiatric symptoms and these can also affect body shape and body image due to changes in the way that the body metabolises fats (BHIVA, 2001). Non-adherence is therefore quite common and frequently leads to treatment failure and the development of viral resistance (Kalichman et al., 2010). Taking all of the above points into consideration, complex HIV issues are usually most effectively addressed within a multidisciplinary team, where various professionals can utilise their individual and particular skills and therefore work towards realistic and achievable goals for treatment (Bor, Evans & Levitt, 2007). In this particular case, the close involvement of MDT has possibly added to the sense of helplessness for the client and ultimately fed into his self-defeating behaviour. High expectations from the professionals involved in the referral process has been addressed in Palazzoli, Boscolo, Cecchin & Prata (1980), where the authors have reflected on the complicity of such a dynamic and its subsequent impact on therapeutic relationship.

CBT was selected initially as the therapeutic method of choice because it is evidence-based model and the National Institute for Health and Clinical Excellence (NICE) guidelines recommend it as the treatment of choice for depression (NICE, 2009); it also corresponds with the agency's expectations in regards to non-adherence (BHIVA, 2001). As the case was in progress, I maintain that the goal of the therapy is to help the client to create a contextual meaning, whilst also accepting the pain that inevitably goes with such an acceptance and understanding.

The referral

Brian* was referred by his medical consultant to the HIV Psychology Unit at one of London's hospitals. According to the referral, he was feeling perpetually sad; overwhelmed and admitted to being unable to adhere to antiretroviral drugs (ART). His level of CD4 cells** had become a serious concern for his consultant.

Initial assessment and presenting problem

Brian is a 48 year old, HIV positive, Caucasian gay man. He stopped taking HIV medication over 3 months ago and found it difficult to explain why. Brian came to the first session and placed himself clumsily onto a chair. He looked somewhat embarrassed and tried to take up as little space in the room as possible. That to me was at odds with his rather chubby appearance. He was dressed casually in sports clothes, talked very little, and looked away for most of the session. I could only assume his emotional state by the fact that he was constantly adjusting the jacket he was holding on his lap all the way through the session. His answers were very short and basic and I sensed some inner struggle in him. It was difficult to say whether this was as a result of a lack of trust in our new relationship, or whether he was trying to protect his own emotions by not saying much. On reflection, I suspect it was more than likely both of these things.

Risk assessment

On the initial assessment, I was mainly concerned with the risk assessment and tried to place his non-adherence into the context of his depression and his own life story. It appeared that despite stopping ART, Brian was still taking Fluoxetine (40mg daily), a medication which he had been taking for the past 3 years for his depression. He was also adhering to Amitriptyline for his neuropathy.

*all names has been changed in order to preserve anonymity and confidentiality

** The CD4 count is like a snapshot of how well your immune system is functioning. These are the cells that HIV kills.

As HIV infection progresses, the number of these cells declines. When the CD4 count drops below 200 due to advanced HIV disease, a person is diagnosed with AIDS. A normal range for CD4 cells is between 600 and 1,500. The requirements to start an ART with HIV positive population in the UK is based on CD4 count below 200; in the US CD4 >350 (i-base, 2009). In Brian's case in the time of referral CD4 was 40.

On self-reported measures for anxiety and depression, he scored moderately severe on depression scale (PHQ 9=16) and he scored 7 on anxiety scale (GAD 7) which is indicative of mild anxiety. Brian had no suicidal thoughts. He had had a suicidal ideation once in the past when he was initially diagnosed with HIV almost 30 years ago, but actually never tried to act on this thought. Although he didn't appear to be suicidal, he seemed to have very little concern with regard to his antiretroviral therapy and to the possible outcomes of non-adherence, and this obviously required a thorough exploration. There is a possibility that poor adherence to ART can also be seen as an act of self-harm (Grassi et al., 2001), and may equally be a result of poor emotional regulation (Johnson et al., 2006).

Negotiating contract and therapeutic aims

I was aware of the likelihood of PTSD in Brian's case. I used a few extended assessments and supervisions to establish the safety and the priorities of psychological interventions for him. On initial supervision, it was decided to refer Brian to specialised psychological agencies if PTSD needed to be prioritised. This was because the service does not provide PTSD treatment on site and therefore cannot guarantee an adequate supervision for the type of interventions. On extended assessment, it appeared that there was likelihood of Type III chronic PTSD as described and according to DSMIV criteria (DSMIV-TR, 2000). It did not cause immediate concerns, as there were not enough symptoms in each diagnostic criterion of PTSD present in order for Brian to qualify for specialist trauma referral. For Brian himself, the main issue was in his low mood and the loss of direction in his life. After an extended assessment, we agreed on an initial 12 sessions of CBT to see if we could work through the depression and find the possible triggers for non-adherence. I felt from the start that Brian might benefit from case level formulation as it would help to explore a view of the world within a wider social context of his life story and may help to access and explore his beliefs about self, others and the world (Bor & McCann, 1999).

Summary bibliography of the client

Early experiences

Brian was diagnosed with HIV in the early 90's when it was regarded as a death sentence and, according to him, it took him almost 10 years to re-build his life. He was born in Australia and started living separately from his divorced parents from the age of 13.

When he was 15, he started his first long term relationship with a forty year old man. A year into the relationship, Brian was subjected to S&M without consent. He was chained to the bed for 3 consecutive days and spent most of that time alone in the house. Brian said he felt hurt, scared, but also angry as he felt let down by someone he had trusted. This incident is seen by me as one of the early vulnerability factors (Appendix I). During that period of time, Brian had no family to go to as his new step-mother did not want any children from Brian's father's previous marriage in her house. His own mother was also involved in a new relationship at this time and was unavailable to him.

He worked hard to support himself and worked his way up to attending and completing a university degree. After university, Brian got himself a job in the banking sector and subsequently had a number of years within a successful career in an industry which he actually talks very little about. When he was diagnosed with HIV, he disclosed this information to family and only a couple of very close friends. Brian's mother - who has a history of perpetual depression - had denounced him shortly after his diagnosis, wishing him dead for bringing shame onto the family. She subsequently put these thoughts and feelings into a letter and they have never been in touch since.

One of his closest female friends was so upset that she unintentionally disclosed Brian's status during a board meeting at his work place without his prior consent. He was subsequently fired the next month, ostensibly for poor job performance, and used his pay out to travel the world. According to Brian, he was convinced that he would be dead within a year after the diagnosis, so he decided to see as much of the world as he could before his death. When he realised that he

was still alive and feeling physically good a year later, he decided to settle abroad and start a new life in a place where no one knows him and his past.

He consequently settled in the UK 18 years ago. Brian went through various low paid jobs and, in 2000, he trained himself as paramedic. He took a lot of pride in this job and talked about it in much more detail than he had ever mentioned his previous career in finance. According to Brian, he felt like a professional and also felt wanted. He told me that he used to be sent to the most difficult calls as his team had trust in him and his professionalism. During his time in the UK, he had two long-term relationships, one of which had evolved into a life-long friendship.

Precipitants

In 2003, Brian went on a date with someone he met online. He has a limited memory of what followed later that night, but remembered walking back home 3 days later. It appeared that he was drugged and repeatedly gang raped during this time. He ended up in the hospital as a consequence of the sustained physical abuse. His memories of this time seem displaced and fragmented with abrupt recalls of forced intravenous injections and humiliating acts of physical abuse.

Following discharge from the hospital, Brian found it difficult to carry on with work, he felt profoundly ashamed, and believed that the incident was self-inflicted. He didn't want to report the case to the police for the fear of homophobic attitudes and stigma. He was seeing a counsellor through the occupational health service of his employer for almost a year following the incident, but eventually sabotaged the therapy. During this time, he got involved in recreational drug use and fell into the 'wrong crowd'. Brian kept it secret from the therapist and has gradually become less and less open about himself on the sessions and eventually stopped attending therapy altogether. He was eventually arrested for possession of large amounts of recreational drugs which, according to him, belonged to his various friends who used to stay at his home. He was subsequently sent to prison in 2008. Brian was released in 2009 and spent a year on probation.

During his time in jail, he was treated for Hepatitis C which he believes he contracted during the previous sexual assault he had suffered. The treatment process was physically and psychologically challenging. Brian suffered from a high fever and used to be taken handcuffed for his hospital check-ups. This made him feel ashamed and humiliated. During the same time, he stopped taking the antiretroviral medication he had first started in 2003. According to Brian, the supply of HIV drugs in prison was irregular and he was worried that he would subsequently develop a drug resistant strain.

When his physical condition improved, Brian accepted a role as a “listener” provided by Samaritans on the prison’s wards. His hope was that he could arrange an earlier release and in the meantime secure better prison living conditions by doing this job. He had to visit and listen to his fellow prisoners who were perceived by the authorities to be a high suicide risk. He told me that he worked with mentally disturbed people, many of whom were convicted murderers, paedophiles, and rapists who were keen to share their pride in the finer details of the offences they had committed. He was not provided with any form of psychological debriefing. He describes his time in prison as scary, he was fearful for his own life and well-being.

Resource

Brian had received ongoing support from his father who flew from Australia for the trial and was always available to him over the phone. He was also visited regularly by his ex-boyfriend, Paul.

Lead in to referral

On his release from prison, Brian realised that he had lost most of his possessions and also lost his home. He had no friends left, apart from Paul, who offered Brian the opportunity to stay at his flat and to sleep on a sofa.

A year on, he still lives at the flat and seems very close to Paul and his mother who apparently visits them both often. They share a one bedroom flat and sleep in separate rooms. They have a cat, Daisy, who they both seem to adore. Their life style arrangements seem to be pretty much as that of a couple, but with no sexual contact. Last summer, Brian started feeling more depressed. He felt like he has lost the meaning and purpose in life. He thought of himself as “waste of space’ and tried

to ease the 'burden' on Paul by running away and sleeping rough for couple of nights on a beach in Brighton. During the same period of time, he stopped taking ART, but remained adherent to his SSRI medication.

The development of therapy and therapeutic pattern

Brian was compliant with the referral decision from start. He also told me that he wanted to keep his depression at bay. He talked little. He seemed to feel uncomfortable in the client's chair and he appeared as if he was looking for my approval. Brian required a lot of prompts and, if not for his commitment to therapy, this work would not have been possible. Half way into the contract, as the therapeutic relationships progressed, he became more open, he started to elaborate on his main concern, that of losing his purpose and possessing a lack of motivation in his life. From past counselling sessions, he had already learned about the nature of his negative automatic thoughts about being useless and a "waste of space", but seemed reluctant to address these thoughts.

I have seen Brian for 24 sessions, out of which he has missed two appointments due to HIV-related health problems and one appointment when their cat Daisy had an operation. He was always on time for his sessions and, according to him, he was always contemplating on our work after the sessions. He talked little and seemed that he was undergoing some emotional battles. The sessions used to require lots of prompts. Originally, it felt that he struggled with silence, showing non-verbally lots of discomfort as if he was expecting to be told what to do next. Introducing silence and two-way conversations with a sharing of ideas seem to facilitate his therapeutic process further. Brian has become more confident in taking a leading role on the sessions. It looks like he felt safer operating on an intellectual, rather than an emotional level, which often happens with traumatised clients (Bryant et al, 1998). I was aware of not opening up Brian emotionally until it felt appropriate and we were both ready for this to occur.

He was responding well to behavioural activations and used creativity in finding things he might enjoy in his Activity Plan. He was doing most of his homework on time and showed reliability and commitment. Over the course of his

therapy, Brian built up his confidence gradually. By session 14, he was searching online for voluntary placements and jobs and had signed himself up to an Open University course for the coming academic year. All these activities were done at his discretion and were not part of his CBT homework.

He went back on antiretroviral medication just 3 weeks into the contract. This response did, however, raise my suspicions. I was concerned that either Brian was not telling me something or that he might be trying to please me and/or the health services. His progress felt a little 'too easy' for me and I wanted to explore more of his cognitive patterns, especially as his negative assumptions about himself seemed to remain unchanged.

I have noticed a cyclic nature of these patterns when Brian gave up ART for a second time through the contract. There were no clear previous patterns of poor adherence, however. He started antiretrovirals in 2003 and was adherent until his time in prison. It is possible to assume that during time in jail Brian developed new belief system which helped him to survive. In that Brian had possibly convinced himself that ART had no impact on his well-being.

By session 18, Brian told me that he had stopped his HIV medication again. He was visibly upset, if not overwhelmed. We tried to look at the cost and benefits of ART in more detail, as suggested in CBT literature by (Padesky & Greenberg, 1995). After completing the table of pros and cons, Brian told me that in his head he understands the importance of ART and would probably say exactly the same to anyone else who was in a similar position. In his heart, however, he doesn't believe that his life expectancy is any different without it. That he had lived for 30 years without HIV treatment and sees no reasons to make these pills a part of his life now.

The therapeutic plan and main technique used

Behavioural activation for depression was considered to be safe as Brian presented no suicidal ideation and his depression scores were moderate. It was used at the very start by the introduction of an Activity log diary and an exploration of pleasurable activities. A recent review of behavioral activation studies for depression found that it has a robust effect and that policy makers should consider it an effective

treatment (Spates et al., 2006). Behavioral activation has also been proven to be especially effective in altering negative thought process (Jacobson et al., 1996).

Cognitive restructuring was introduced soon after the client developed familiarity with the model. Interventions for poor adherence as well as depression are based on the idea that there is a negative assumption behind depressive cognition and that that can be allocated and challenged (Rupke et al., 2006). Some refer to this general technique as “reframing”. In depression, the triggers for the feelings of hopelessness and helplessness are often concealed. Communicating in words about what the causes of the feelings can make it possible to identify triggers. I used a Socratic dialogue as the main tool in order to help Brian to recognise and reflect on erroneous thinking patterns.

As a former paramedic, Brian had a good understanding of the consequences of poor adherence, but he still needed help to put it into a context of meaning for him personally. We originally explored the “costs and benefits” of non-adherence together.

The shift happened when we used his metaphors and his dreams material to help transform therapeutic information into a form that was easy to remember. Such work provides useful guidance and can be applied to relevant moments in a patient's life (Otto, 2000). CBT allows the incorporation of stories, metaphors and analogies within the daily practice, challenging unhelpful styles of thinking and addressing maintaining behaviours.

As his verbal presentations at this time were quite minimal, I suggested we started with interpreting Brian’s dreams, in that the aim of dream work was to explore the various images and emotions that a dream presents and evokes, whilst not attempting to come up with a single, unique dream meaning (Kolsched,1996).

The collaborative development of his stories enhanced the consequent CBT rapport as interpretative work enable clients to gain a new perspective upon their problems, increases personal impact and gives clarity of meaning (Blenkiron, 2005). Brian was not obliged to agree with what was said about his dreams and was using his own judgment in deciding which comments appeared valid or provided insight.

I also chose to include the method within a CBT-framed contract because I thought it would help him to reconcile himself with his experiences and emotions and allow for a creative interpretation. Brian showed significant interest in this work and has become more connected, reflective, and open about his experiences since.

This, in turn, led us to explore his notion of an ideal future which I adopted from Leahy (2003), called the “time-machine” technique. For me, at this time it was important to understand if it was going to be possible to re-engage Brian with life, or at least with some aspects of it. It appeared that his future contained the same layout as his present life and that he was living with Paul and Daisy in his dream house too. This subsequently took us on an exploration of Brian’s values and meanings which ultimately stands behind the acceptance work (Hayes et al., 2003). At this time, I was starting to look at ACT - as it is a therapy based on functional contextualism, meaning that if Brian’s life experience as it stands from his past contains little of so-called ‘healthy normality’. The role of ACT becomes one that conceptualises psychological events as a set of ongoing actions within a situationally and historically defined context (Hayes, 2011, in press). This meant to me that by helping Brian to get rid of his ‘symptoms’ by means of conventional CBT, it would ultimately only increase his experiential avoidance behaviour and also increase his need for emotional control. The aim was not about removal of his surface behaviour (non-adherence), but to help him to transcend self so to accept the pain, which was inevitably linked to both his past and his present. To me this meant to take a new and therapeutically different direction to ground-sweeping changes of cognitive restructuring.

Key content issues

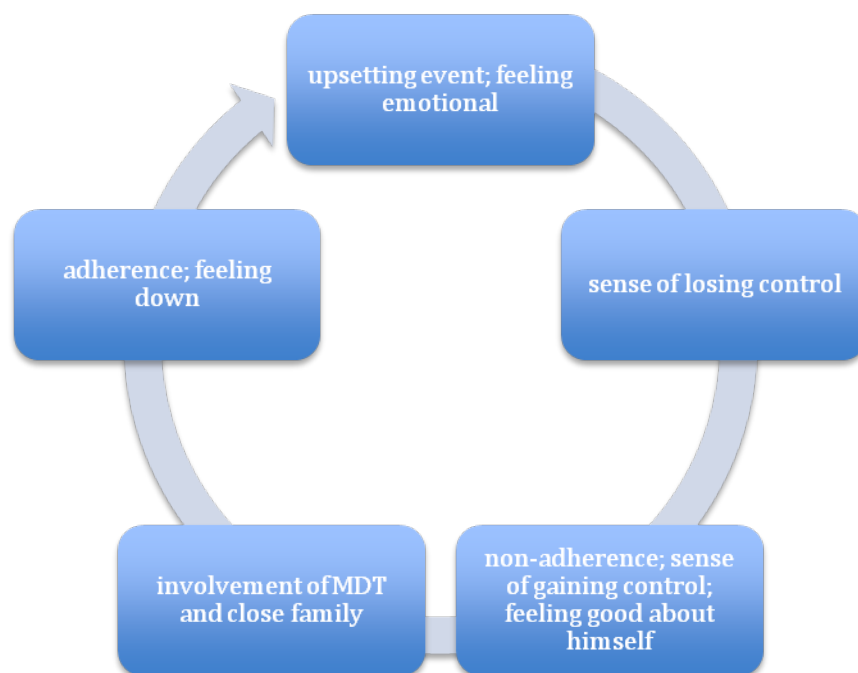
Agency

The vested interest of the agency based on the promotion of adherence so to become more effective in achievement and maintenance of long-term virologic suppression and, more importantly, the long-term health for their patient. This, in turn, determines and defines specific goals in a given clinical setting (Conway, 2007). For me, such a context created a dual role as therapist as Brian defined his interests differently to the interests of the agency.

Maladaptive cycle

Despite the fact that Brian was recognising his own erroneous thinking (e.g. being a waste of space, etc.), his core beliefs understandably remained unchanged. He believed that he had no control over his life and had tried to offset this feeling by introducing control by means of non-adherence as the only available option. He understood the self-defeating cycle, but was not interested in challenging it mainly because his own main issue was elsewhere.

Table 1. Self-defeating cycle.



My own dilemma

My own recent interest in existential psychology has led me think outside CBT framework. According to Janoff-Buman (1992), most people base their life on three basic assumptions: 1) that the world is benevolent (meaning other people are positive or neutral towards me); 2) that the world is meaningful and predictable; and 3) that I am worthy (as in competent, decent and sufficiently good). When faced with trauma, those basic assumptions of one's life become disrupted. Brian seemed to

have lost his faith in his life and the meaning of the world and was finding it difficult not to judge himself for the way it had all turned out for him.

On the other level, I found Brian's story very touching and a parallel process on supervision showed a strong sense of helplessness about his life circumstances. Just as Brian worked as a "listener" in prison, At certain point in this process I have become his "listener", whilst my supervisor has turned into my own listener too. The stories were vivid and grim and I felt that I need to address that by taking a wider philosophical approach and move beyond CBT. I was drawn to explore the meaning of life with him so to understand what can be seen differently in his particular case.

On the presented session, I started to move away from CBT to his experiential accounts and reflections.

Transcript

The twelve-minute extract was recorded during session twenty-four and was taken from 28:00 minutes into the session. I have included an extra two minutes, as I feel that it added a relevant context to the segment.

Leading into the session

We were discovering a self-defeating cycle of Brian's behaviour and we were looking at the costs and benefits of taking antiretrovirals (ART). This is a CBT intervention to help the client to get a fresh perspective on erroneous thinking patterns (White, 2001). On the session I had written a long list of the costs of taking antiretrovirals, but not many of the benefits. That obvious lack of benefits seemed to prompt Brian to elaborate upon his views regarding the medication.

CL.1: That's what I was saying before, you know, I don't particularly think that my life expectancy would be different...I think that what was going to be, it would have been...well before all that had happened

CP.1: (writing down and reading out what I do) life expectancy...ehm....Non-depending on ART, you know...

Comm.1: Brian presented me with another belief of his which I noted in the session. He started to talk more and it felt like he needed to explain himself further. I was keen to complete our task to ensure that the structure and continuity of the session was maintained. In fact, my actions in writing in a log has also provided more space for Brian to pull together some of his thinking.

CL.2: Actually I don't believe in the whole ART, but I believe in myself

CP.2: Uhm

CL.3: If that's make sense

CIP.3: Yeah, yeah (agreeing in the same pace)

Comm.2: The pace has changed, he has something important to say which I hear in his voice and respond quickly, almost in the same manner, I probably want to encourage him to say it. What would be more appropriate is to chase his idea of being separate to everyone else and why he thinks he cannot do anything about his life expectancy (as he was already doing something about it by non-adhering).

CL.4: Because you know I can say, I worked in Africa and things like that and also it must be here (showing up where the wards are) people because the death rates are certainly gone down, but still...I was here for 20 years, I did get sick, but I don't know, I told you about that

CP.4: ...20 years without ART (writing in a log)...(loud noise outside the counselling room, one of the consultants walking into her room in heavy boots)...yep

Comm.3 He raises his voice, it is important to him and in hindsight it would be better to switch from my task and give full face to face attention to Brian. He is conveying more than just pros and cons, he shares his experience and the understanding he is making from that experience. Out of all the reach material he has just given me, I stayed with 20 years of life without ART, he did get sick, but he survived.

My 'yep' is a way of appreciating his view, but also to amplify and to reflect back to the client without making any interpretations (Beck, et al., 1979). I sound as if I am agreeing that 20 years without medication is a good predictor of not needing it now. By agreeing, I am hoping to plant some doubts in his mind. I believe Brian says what he says out of doubt and portrays conviction only on the surface. I sense that there is a different reason to that rather than beliefs that he is fine, his memories of Africa where he saw AIDS related deaths, his close friends who died young back home, he knows what he is talking about, but he chooses to believe differently. People are dying out there, but it is not him. My own thought process being interrupted by the consultant next door was also a reminder how busy the HIV services still are.

CL.5: And, you know, the reason I got sick ...I got some thinning of blood; diarrhoea thing is going on, couple of...and the reason I take it (ART-CP.) coz my dad was upset...so, but I know alongside I had a new lease of life, didn't I?

CP.5: Uhm (in a funny voice), do you think it will make any difference to you if instead of 20 you would have to take 1 pill instead, or a few?

Comm.4: This intervention was instigated by him reminding me about opportunistic infections he had had quite a few times lately. It was informed by the previous week's supervision and aimed at recognising the reasons behind poor adherence as often "therapy for human HIV/AIDS and related opportunistic infections involves polytherapy and complex regimens, both of which are risk factors for non-adherence" (Mansoor & Dowse, 2006). In such cases, alternative options are available and contain fewer pills. I recognise that intervention came as disruptive. This happened as Brian activated my own schema as a saviour and partly because I often struggle to introduce an outside agenda to the immediate content of the session. This difficulty transpired in my own voice. Brian in turn gave me a good chance to revise his beliefs about the causes and consequences of HIV and touched on his need to please others. The latter is also important because it helps him to reattribute responsibility for his own actions onto others and supports a poor adherence cycle (see Table.1 above). What is interesting is that Brian is asking for my reassurance or my opinion and I am getting sucked into that process and almost

supporting his magical thinking. The better course of action could be to pause and to comment on the new lease of life.

CL 6: I wouldn't see any issues with that

CP.7: Would you find it easier?

CL.8: Oh yeah, the combination is such a...you know, taking far too many tablets ...

Comm.5: He says he is interested, but I can see in his body language and changed voice tone that the main issue is not in the quantity of pills. My own role here changes and I am no longer a counsellor for him, but a part of MDT, therefore his replies are short and rather compliant. He was interrupted from the previous message he tried to convey of not believing in ART. He is posing a real, non-rational issue. A process comment would be more appropriate in this situation. "I find myself getting into suggesting to revise the quantity of pills, when what you are really saying is that there is something that makes you feel that your life expectancy is out of control. Something that makes you feel different from other people".

CP.8: You see that could be another reason to talk to Dr Smith* (more open) in more detail and ask if she could possibly revise your drug cocktail?

CI .9: That would be helpful

Comm.6 I am carrying out a psycho-educational component of my role and also trying to make an attempt to link it with the importance of being open in communication. We talked earlier in the session on how Brian had failed to inform his consultant that he had stopped taking antiretrovirals again. The reason he gave was that he didn't want to upset her as she was very happy with his blood results.

The way he responds to my intervention shows that the 'MDT' barrier is still there and I need to focus on him and not on other people in his life. He removes himself from taking any decision, leaving me to decide what to do next. He attributes

power to MDT, but also suffers from that power and rebels against it. The effect on me here is that I am taking a leading role by becoming the face of the institution.

CP.9: Coz you know what is interesting about your beliefs, some of them can be challenged and some of them are quite existential by nature, you know, and some...like your 'life expectancy is not depending on antiretrovirals' ...you know..

CL.10: So what are you saying?

Comm.7 I lost Brian here. I don't like the language I'm using by inviting conversation about 'his beliefs', this might come across as patronising and medical-model driven. My own process also moved far. I was still thinking of him not wanting to believe in medication, questioning life expectancy, thinking about his life in its context of struggle. Some of it made perfect sense to me on a human level and some of it didn't. I am not clear with my own intervention because I am exploring the theme for myself in that very moment. I also believe that life is transient and not predictable. He, on the other hand, seems to believe that his own life is somehow different to other people. He backs that up with 20 years of life without ART and potentially might grow to believe in his infallibility. An alternative interpretation would be that it would be of benefit to initiate a longer silence on my part leaving Brian to decide where to go next.

CP.10:...Hmm, it depends on the context given ...you can die in a car accident...

CL.11: Yeah, yeah totally about this HIV, so...you know, we could all perish at any time, as you know

CP.11: That's where Japan comes from?

CL .12: Yeah yeah that this is it...I haven't got any ideas that humans are sort of strong and that...but what I do is based on experiences I have, you know, try to change the basis of our health, but you know...

CP.12: Uhm

Comm.8: My intervention was based on Brian's earlier remarks on the recent tragedy in Japan. I put his statement that life expectancy is not depending on ART into perspective. Some of it was my personal material and my interest in existential views. I was looking for a way to engage on a deeper level. He engages immediately saying that his life experience is based on a real life trauma. He talks about the strength of human beings and I need more time to see where he is heading with this. It would be a good idea to make a simple connection between Japan and one of his own traumas as Brian tries to convey the idea that when bad thing happen, nothing can be done. This, in turn, might justify to him that his own life is somehow different and he could possibly can have control over it.

CL.12: I had such a long time and I waited for as long as possible before I did take the tablets

CP.12: Uhm

CL.13: And it did change my life, so I am positive again...(mumbles)...and then I found myself in a different age, anyway so....(he stops)

CP.13: Are you saying that you hadn't had time to readjust to it all?

Comm.9: Brian opens up and shares his experience on how resistant he was from the start in regard to medication. By giving a noncommittal remark, I show that I listen and stay with him in the moment. I would like to explore further what he meant by 'being positive again". My understanding at that time was that he found it difficult to accept changes, so I offered an interpretation of readjustment as an alternative way of looking at things.

CL.14: Everything, all my life, in all aspects...

CP.14: (repeating after him) all life, in all aspects...

Comm.10: I am engaged in the process and just following the emotional emphasis in his voice.

CL.15:...changed for me and I can say it, and I can see it, and I don't like it, and I can't really fight it because that is what has happened with your life and that, you know...so I feel... disappointed with myself, not being...(not) making more contribution myself and anything else really...

And now all that circumstances and all that doesn't meet my expectations ...of...my last (mumbles)

It just feels like waste, waste of space...

Comm.11: Brian says he is disappointed with himself and that his life doesn't meet his expectations, which in turn reinforces his negative beliefs about himself as a waste of space. To me that was a powerful allegory of how his reality is different to his own image of himself and the life he should have. The words are coming across as quite unusual and potentially might be linked to the traumas of previous rape, S&M or even life in prison.

CP.15: Is it a waste of space do you think or is it a difficulty of fitting into a new environment? It is just like you were saying about losing the weight, some people do and some people don't and to me it sounds more like wanting to get in touch with yourself from the past, the way you used to look like...

CL .16:Yeah, I think about that and I think I don't expect (to be) like I was even 10 years ago, people change quite dramatically, you know, and I know that and understand from the times when I was a paramedic, you know, and I can see it in parents, I can see it in other people, I compare myself to other people my age, you know, I could probably be quite in comparison, except I have bit too much weight

Comm.12: I am offering an alternative interpretation to his negative thoughts while slightly normalising his experience. I am referring to the material from one of the previous sessions when he told me that he has nice shirts in his wardrobe from the time before prison and how he tries hard to lose weight so he can start wearing them again. To me, he tries hard to lose both his physical and psychological weight, so he can fit once again into those old ideas of how life should be and how he should

be in this life. What is happening instead is that he is not losing weight, but gaining more. Brian joins in immediately confirming that he was thinking about it too. Brian shares his concern with age and growing older. There is a sense of loss on many levels, loss of youth, aging parents, etc. I can relate to what he is saying. He simultaneously denies those fears by saying that he can be compared favourably to his peers, just with some extra weight.

CP.16: How old are you now?

CL .17: Forty-eight

Comm.13: *I knew his age, but on some level I probably wanted to verify that we are almost from the same age group. To me, in that moment, he sounded much older than his 48 years and I wanted to put it somehow into perspective for him.*

CP.17: Being 48 and living almost 30 years with HIV...

CL.18: It is nearly 28 years, 28 years

CP.18: What does it mean for you to be 48 and to be HIV positive?

CL.19: I don't know, ask me that 20 years ago and I wouldn't have expected to be here, you know, and I supposed I said to anyone...more and more people of my age living with it, I don't know if I had it for such a long period of time...

Certainly a group of people of my age who have had it since the early days are a very big group

I don't know, but I try to read up on things on HIV and ageing *per se*, I am at the age where I understand my body and my energy changes and my metabolism, anyway, you need to deal with that as you deal with that I suppose...Sometimes I don't know what's going on really, I went and saw that person yesterday, a consultant, is it to do with my age or all those drugs I've been taking for the HIV and Hepatitis C and things like that. I need to know those things ...and there is no experience there, it is only just all happening now, isn't?...so, not really

Comm.14: My intervention was informed by my recent research interviews about the process of life transition with HIV. What Brian has said or not said has evoked the research material for me. I took a risk of bringing stuff to the session in order to understand Brian better. His voice softens which tells me that he is sharing something private, he's conveying a great deal of uncertainty with his life, health and future. There is no one who can give him the answers simply because there are no answers there and, like everyone else, I don't have the answers for him either. Possibly because of this uncertainty, he craves a control which is only available to him by means of poor adherence.

CP.19: And what does it feel like just to be 48 without a HIV context...just getting to this age?

(Long pause)

CL.20: Hmm, it is really, really, just as you know, I remember 20 years ago, I was talking to my dad and he was quite depressed, his second marriage had broken up and things weren't good for him ...and I think I am the same sort of way...His life turned out pretty well, he met someone else, you know, they have a good life together...He was around my age when I think about it and look back on it... he was in a terrible spot, as well in terms of, I suppose...(Pauses. Loud noise outside the room)

Hhm (he's about to resume and the noise also comes back) you know, and how things transgressed I think, you are not old and not young.

CP.20: So are you somewhere in between?

CL.21: Oh I don't know, it is a limbo time really...you know, it's ehm...

Comm.15: An alternative intervention could have been in feeding back to Brian his uncertainty about his life and putting it back to him. However, I took a further risk by attending my own countertransference in regards to my own mid age. I was asking Brian to separate the experiences of ageing from HIV, as I am still not sure to what extent his HIV experience is important to him. The intervention unravelled another layer of his experience, the depth of his crisis of midlife, which

sounds bigger than HIV itself. He took a long pause to think. He compared his experience with those of his father, does he see a transition in his comparison, his father's tough times seem resolved in the context of a new family. I was wondering about his identification with the father. He now feels in a limbo which is a journey in between the transition and transgression. This, in turn, impacts on his work with me where he could also feel that he is in a position of not knowing and why he is doing it for.

It's also important to acknowledge the loud noise outside the counselling room which is part of the hospital environment, but Brian seems to want to say more and was interrupted twice in his attempts to do so. On some level this is significant as he tries to out speak the environment to which he has become institutionalised within.

CP.21: What sort of emotions comes with it?

CL .22:I don't know really (his voice raises)... I am not ...I had no physical contact with anyone...(pause)... for 3 or 4 years, you know, had anything like that ...and I feel quite worthless, not worthless, but you know...I don't know how to explain it, but besides all that has happened to me, that's happened to me and that's that...I am very lucky to have Paul, but we don't have any sort of physical relationship at all...you know.

It's just been time...it feels ages and on a top of that I don't have a drive or sexual function, not that I want sex or whatever, it is the last thing that I want....

That's one other thing that is not working and it's up to me try to find out, they can't deal with it here (at the clinic CP.), so I go to the GP, the GP just looks at me like an idiot-what would you expect.....this and this, take your tablets, that sort of stuff and I get the same kinda thing back and I don't know what to draw from that, I can read about it, but it doesn't help me.

And I am just walking through my life and it is not, I don't know which way to turn, I don't know and it is difficult....

(pause)

that's it really.

Comm.16: Brian raises his voice after I asked about his feelings. Brian has shown in previous sessions that he finds it difficult to express his emotional context. His raised voice could indicate irritation, however I feel that it is still important for him to try to express his feelings now. He underlines the isolation of his experience and shares those things in his life that are "just not working", I am not sure if I have any moral right to label those thoughts as malfunctioning. He also shares his feelings of not being understood by others and also by professionals. He is alone and his basic needs are denied to him, his GP seems not to understand why a HIV positive man with chronic trauma is interested in getting back his sexual drive. On one level he takes his frustration with a GP surgery and the fact that the only thing he can get from that source is yet another prescription. He is effectively institutionalised and rightfully asking me why would I want to bring him to those emotions when no one actually understands him; why should he open up to me, as I am also struggling to grasp the depth of his pain. The counselling room in the hospital looks like any other medical room with a couch and extra lights for detailed observation. I have wondered if Brian also experiences me as he does his GP, someone who doesn't understand him. I also wondered if his raised voice could indicate this frustration. Analytically what Brian might be saying is that he used to be force fed (e.g. when sodomised or raped). Refusing ART to him might be associated with refusing this aspect of his life. I did not say anything and provided Brian with space which I think enabled him to express difficult thoughts. I felt taken by his experience. Unlike his GP, I am not offering a magic pill to him. My own schema of not being able to help resonates with Brian's schema that there is no help available. This, in turn, is quite difficult for both of us. He concluded his line and put a full stop to it so not to be left with silence.

CP.22: So, it is very difficult and it's feeling quite frustrating...

CL.23: Well, I am at a loss, really, it is almost like a grief...

CP.23: Grief or...

CL.24: ...whole grief and I don't know which way to turn with it, you know, I have got no job to give me any structure. I think a lot of people can meander through

some transition times in their lives with work or relationships or something and, you know, it is not happening...

I can't achieve anything ...that I try, like little things, like losing weight, I can't achieve it (his voice changes), you know, I just don't see the point half the time...and it probably leads to a lot of this as well.

What point is there? I have just the rest of my life with nothing. And you know, I am the one who has to change it and I just can't get my foot up on any sort of level whether it's to do with that or my medication, or my energy, or going to the gym , or trying get a job, and all that stuff is my own fault (mumbles), and it's no one's fault, and I need to resolve that sometimes I can't drag my ass out of the flat, it is too scary sometimes, you know, I just feel grief and I don't enjoy anything, really.

Comm. 17: I reflected back those feelings to Brian. I stayed with his feelings and he trusted me and shared his grief. This was a powerful and emotionally charged moment. I don't recognise the old Brian from the previous sessions, the Brian who was emotionally unavailable, who used to hide every sign of sadness, who used to talk very little as if he had nothing to say. He presented with a lot of self-blame, but what is important to me is that he tries, that he doesn't give up, irrespective of his grief and isolation. His negative thoughts and core beliefs are irrelevant to the message he conveys as he seeks connections on a human level, it doesn't feel like he needs to analyse his cognitions any further, but to see that someone can accompany him through that pain before he allocates another resource.

The process and challenges of work

The main question was to what extent I could help Brian and to what extent his expectations about the process were his and what were mine. As his therapist, I am also a part of wider MDT and this is made clear from my interventions as they are informed by the agency's agenda and this is subsequently transparent on the tape.

My personal philosophy was moving me away from CBT to less directive approaches, so to connect on a different level in search for another resource. This was informed by my late interest in existential works of Jacobsen and Yalom. This process of mine has not been settled yet and still in progress. In order to prioritise psychological interventions, I needed to understand what was causing the main distress; he had multiple trauma and I was going layer by layer trying to understand what was the surface presentation and what was hidden and what was informing the whole context.

Use of supervision and reflection on MDT

Supervision was an invaluable tool in the context of my work with Brian. It wouldn't be possible at this stage of my professional development to work on this case without fully comprehensive support. Supervision has helped me to verify the safety boundaries and explore a psychological view beyond one particular model and also to explore the wider contextual issues and resources that might be available to Brian. It has also directed me towards ethical signposts of my profession and introduced me to the concept of a virtuous therapist as described in Cohen & Cohen (1999). The context of the work of the HIV unit has also become more transparent. I understood the extent with which HIV psychology is linked with MDT. I have got an insight into a complex chain of relationships in the effective management of chronic illness, where consultants and nurses have months - if not years - of established relationships with a patient and that this can occur well before their patient has become my client. Such close involvement may feed an expectation from a medical team regarding the commitment to therapy and treatment outcomes. It is important to recognise that the remit of HIV psychology lies in supporting adherence as clearly indicated in QIPP performance targets (CDC, 2010), but that it also, importantly, can have a dramatic effect on HIV funding (Appendix II). My dual role caused some of my own dilemmas and impacted on some of my interventions with Brian. As Brian was torn between his roles of being a victim and being a survivor, so I feel split between my role as a psychologist and being accountable to MDT with his adherence issues.

The ultimate aim is collaborative work where doctors and psychologists are working together with a shared view that is respectful of the patient's ability to contribute to his own self-healing. In the case of Brian, however, health professionals have eventually become his only social network of support and on-going care and therefore becomes a part of self-sustainable cycle of poor adherence.

Discussion

Brian's case is challenging and multidimensional and because of that it was seen by me - to a large extent - from a phenomenological lens of '*thrownness*', an idea which was introduced by Martin Heidegger to describe a state at which each human has his own facility and cannot live someone else's life. It means that we are all thrown into existence, but we are all thrown into our own existential situations. And each of us comes here with a particular race, background, appearance and a life story (Heidegger, 1962). To exist means to immerse oneself fully in one's situation and to accept one's facility and to act on that basis (Jacobsen, 2007).

Brian happened to find himself in a life which he would never envisaged happening to him. He used as an example the recent events in Japan earlier on in this session; I translated the meaning of non-adherence as an existential contemplation on the transience of our own lives. Thinking of it later, I felt that Brian had tried to convey a different message comparing himself with a savaged island that had survived against all odds and possibly irrespective of ongoing support of humanitarian foreign aid.

Unexpectedly, CBT gelled into my new perspective as a good preventive and psycho educational tool. Brian ultimately wanted to share and express his experience, but he also wanted to know what to do next and slowly began looking for solutions.. His real life choices are very limited and his social prospects are likely to downgrade irreversibly. In the current climate he might need to learn to prepare himself to carry on with the basic job and slowly build on a wider social circle. Paradoxically to my original view, CBT could become very useful at this new stage in Brian's life. It can help to readjust to a novel and rather less ambitious life. Saying that, the same could also be achieved with existential work. This is because once the

internal freedom has been found, the external reality could be perceived in a different light too. It is important to maintain a certain pace for Brian's adjustment, a little too slow or a little too fast, and he can get confused or overwhelmed.

My own path of on-going discovery helped me to see his case from various perspectives. What is more important is that I kept Brian and his human needs at the core of our work. The discovery showed me that small steps, no matter how small they are, could support Brian on his own journey of re-adjustment and self-containment.

His case touched me on a personal, emotional, professional and philosophical level. How sad was his hopelessness and how my own old schemas of being a 'saviour' transpired in many interventions. How that was reinforced by demands from the agency which want to be sure that he is complying with his prescriptions. He had existential questions to which I didn't have the answers.

Appendix I

CBT Formulation

Vulnerability factors/Early experiences

Parents divorced when Brian was 12 years old
Mother in low wouldn't want him in the house when he had nowhere to live
Non-consented S&M age 15 with the first b/f
Diagnosed HIV 28 years ago

Mother denounced him when learned about his diagnosis

Core Beliefs/Attitudes

- I am worthless
- I am waste of space
- I am a big blob
- I am pathetic
- I have no control
- No one understands me
- People who love me should be able to read my mind

Precipitants (critical incidents)

- Rape -3 years ago
- Recreational drug abuse
- Imprisonment and loss of a social circle
- Erectile dysfunction*

The problem

Depressed; emotional distress
Thoughts- This is just pathetic! No one understands me or my life priorities; I am 48 and feel like in a loop
Feelings- sad, down, isolated, ashamed; forced to adhere; worries for Paul's health
Behaviours- adhering to medication
Physical- tired, bad night sleep, nightmares

Protective factors/Strength

- Has support from a close friend with whom he shares the flat
- Daisy the cat
- Counselling
- GYM
- resourceful- has a long history of survival

Current triggers

Not being able to find a voluntary job-enhances belief of being useless to everyone

CRB check requirements to the jobs he is interested in

Manipulated by Paul to start taking ART

Process 1:
adherence in order to "save" Paul

Process 2: non-adherence:

I feel vulnerable and useless
I don't believe that HIV has anything to do with that or "my life expectancy"

Process 3:
Relationships issues, struggle to place relationships with Paul or to form relationships with others

Process 4; pleasing others:

I will go to GYM so my counsellor feels good

I can't tell my doctor that I stopped medication because she will get upset

If I tell Paul what I think it will kill him

Process 5: feeling institutionalised and alienated; surrounded by "well wishers" who don't fully understand him; everyone insists on ART as "this is the main problem"

The treatment targets

- The meaning of midlife
- Finding means to connect to and accept the problem
- The impact of non adherence on future plans/ important people in his life
- The deeper meaning of relationships with Paul

Appendix II

Organisational Formulation



Section C: Critical literature review

Sexual Risk Behaviour in Gay Men: A Literature Review

Key words: sexual risk behaviour; UAI; MSM; HIV prevalence: sexual cognitions

Abstract

The aim of the review is to look at the current understanding of the causes of unsafe sexual practices amongst gay men; to explore what research says about the trends in risk behaviour (RB); and to look at the ways that the normative construction of sexual practice can be further challenged or understood from a Western cultural paradigm.

This resonates with the NHS agenda and its search for high quality and sustainable HIV service models (UK PH Commissioner report, 2010).

Introduction

There is a wealth of research literature on sexual risk behaviour (RB) in gay and bisexual men. This is hardly surprising, as the World Health Organisation (WTO) puts HIV prevention, treatment and care high on its agenda (WTO, 2009). Risk behaviours, such as unsafe sex, alcohol and recreational drug usage, are one of the main contributors to HIV transmission and are widespread in the general population (HPA, 2009). According to the statistics, 3.7 percent of adults used Class A drugs in 2008/09, compared with 3.0 percent in 2007/08 (Health Protection Agency (HPA), 2009). In the UK, the level of sexually transmitted infections (STI) has remained high over the last five years, with higher HIV prevalence for men having sex with men (MSM) and also for heterosexual women. This is due to the spread of infection caused by unprotected genital intercourse in most cases (HPA, 2009; Baker et al., 2009).as well as decrease in attendance of sexual health clinics (Gainsbury, 2009).

Relevance to Counselling Psychology

The role of counselling psychologists, apart from working therapeutically with those infected and affected by HIV, is to help to prevent further transmission through psychoeducation and by supporting informed decision-making around sexual risk behaviour (Bor et al., 2007; Bangsberg, 2008; Flowers, 2001). Psychology helps HIV-infected people to deal with dramatic accounts of lifechanging experiences and lifestyle adjustments they may encounter (Vanable, et al., 2006). Members of HIV positive families might also need support in regard to understanding their own needs following the diagnosis of a close relative. According to the National Institute for Health & Clinical Excellence (NICE) Guidance, the key task for local sexual health services is to identify and address the risk factors in attendees and, where appropriate, implement psychological approaches in order to reduce unsafe sex (NICE, 2010). British HIV Association (BHIVA), in this year's consultation paper, also emphasises the importance of professionally trained counsellors to be available on demand at local Genitourinary Medicine (GUM) clinics (BHIVA consultation draft, 2011).

Current understanding of Risk Behaviour

Risk Behaviour, which is also referred to in various texts as Future Discounting behaviour and Impulse Response, will be used in this review synonymously. By definition, risk-taking behaviour is a 'lifestyle activity that places a person at a higher risk of suffering a particular condition' (Free Medical Dictionary). Literature searches do not consistently differentiate between RB, Future Discounting behaviour and other forms of potential self-harm. In the broader sense, RB can encompass a wide range of activities such as smoking, recreational drug use and unprotected sex with casual partners, crossing a road on a red light and even irresponsible borrowing.

The current understanding of risk-taking behaviour is that it constitutes an inability to inhibit responses or delay gratification where the behaviour has a deleterious impact on health and wellbeing (Yates, 1992), and this is accounted for by a range of models. The clinical model suggests the limbic region of the midbrain becomes hyperactive, while executive functions of prefrontal cortex become suppressed or hypoactive. This removes some control mechanisms and prompts responses based on impulse (McClure et al., 2004).

An alternative account is provided by the ABC model of behavioural approach according to Skinner (1971) and implies that behavioural response (B) contains five types of consequences (C). These are: attention-seeking, avoidance, escapism, stimulation of senses and gain of desired object. All of the behavioural consequences are triggered by antecedents (A). Antecedents are not limited in time or in quantity. Spatial relationships in risk behaviour is rather complex. Some studies indicate that future outcomes are discounted hyperbolically and not in a linear fashion as artificial intelligence studies have suggested (Schweighofer et al., 2006). This means that the degree of discounting decreases as the magnitude of reward increases. If a spatial dynamic of RB is closely linked to the hyperbolic model, that might indicate that there is a temporal window that extends symmetrically from *Now* into the *Future* and into the *Past*. This, in turn, might suggest that the *Future* and *Past* are casually linked (Bickel et al., 2008). Studies showed that smokers, for example, tend to discount the future more than non-smokers. More interestingly, some data suggests that smokers tend to discount the past to a greater extent, too (Bickel et al., 2008).

Discounting is also closely linked with the availability of choices in the present moment. The classic example of a choice is described in behaviourist text by Schweighofer et al. (2006) where individuals were given a choice between having one apple now (immediate reward) or two apples in the near future (delayed reward), with the majority opting for an immediate reward. This happens not because we assign a larger value for larger reward but the study outlines that, depending on the task at hand, humans can flexibly choose the type of reward discounting (Green & Myerson, 2004). The reviewer is interested in gaining an insight into what might seem on the surface to be counterintuitive choices and what

research says about people and what they feel or think when engaging in sexual risk behaviour, and what constitutes a consequential reward in unprotected sex.

Overview

There is inequality in the way different types of RB are seen by society, with some treated as more acceptable than others. Sexual RB is stigmatised by many people and unwillingness to talk about it is common (Cunningham et al., 2002), which on its own offers challenges to the unbiased research.

Historically, the gay community, especially men who have sex with men, (MSM) were at the forefront of related research due to higher risk of HIV acquisition via unprotected sex, in particular, unprotected anal intercourse (UAI) (BHIVA, 2011). The definition of what entails sexual intercourse is important as it can vary substantially where some consider manual or oral stimulation or the use of sex toys as sexual acts. As it was pointed out by Hill et al. (2010), such variability in understandings is not purely a matter of discourse but it reflects on the accuracy of the relevant research questionnaires. For the purpose of clarity, the primary focus of this review will be on UAI as the major risk for HIV transmission (BHIVA, 2011).

The paradox of the post-AIDS era is that since 1996 there has been a steady resurgence in STIs among MSM in Western Europe. This has coincided with decreased HIV-related mortality (Dougan et al., 2007) and the corresponding consequence is that the prevalence of HIV positive gay men has increased and there are now more people living with HIV in the West than at any other time during the epidemic (Trussler & Marchand, 2005). The level of RB has also increased during the same time, and in both the UK and USA, studies have shown that gay and bisexual men put themselves at risk of HIV infection through unprotected intercourse and there has been a persistent shift towards more risky sexual behaviour over the last decade (Osmond et al., 2007). This new phenomenon in itself presents a set of challenges for health and social service providers (Lyons, 2010).

Current research

The majority of quantitative research looked into various measures of unsafe sex and has usually taken demographics, social and psychological factors, as well as sexual risk cognition, into account. The usual variable for sexual RB in gay men populations also includes relationship status; sexual identity; understanding of HIV; and measures for anxiety and depression. For HIV positive men it also includes recent CD4 count; viroload and antiretroviral medication (Elford et al., 2007).

According to Fendrich et al. (2007), the current approach to risk measurement in quantitative research has become fairly rudimentary. The researchers examining correlates of RB on a number of typical count measures, but that doesn't explain the reality and the underlying logic of MSM who seem to be consistently moving up from less to more and more risky behaviour. To improve on our understanding the authors examined psychometric properties of data against the HIV Transmission Risk Scale. They introduced a refined measure of sexual risk for HIV by classifying individuals on their full range of reported sexual activity and demonstrated the feasibility of Rasch scaling of RB. They reported significant difference among levels of RB, with such markers as HIV status and presence or absence of a primary partner. This was consistent with previous works of Bolding et al. (2005), who have also noted a weak to non-existent correlation between RB and demographic figures.

To explore contributory factors to HIV further, Menza et al. (2009) devised a Prediction Model in a similar way as is used in other clinical specialties such as oncology and cardiology. They found that methamphetamine and inhaled nitrates usage was another strong predictor of HIV acquisition, especially when it comes alongside a previous history of bacterial STD. Taking this into account, the researchers advised to ask routinely MSM during sexual screenings about their recreational drug usage, especially those men with repeated STD. Interestingly enough, non-concordant² UAI has typically been seen as the strongest factor for HIV acquisition, but it was a weaker predictor in the model of Menza et al. (2009).

² Seroconcordant - partners of the same HIV status; non-concordant or serodiscordant - when one partner is HIV positive and the other is negative.

A partial explanation can be taken from a recent National AIDS Manual (NAM), which reports of lower risk for UAI, in comparison with protected intercourse with the usage of certain water lubricants (NAM, 2010). This raises a whole new set of questions of what might constitute safe sexual practices in MSM and what might entail an effective prevention (e.g. type of lubricant used).

Recreational drugs

Albeit the wealth of research regarding the role of recreational drugs, alcohol and Viagra in RB, the current review is not going to report in depth on the use of stimulants in gay sex. I would like to acknowledge that widespread use of recreational drugs, such as cocaine or inhaled nitrates, seems clearly linked with sexual RB and the consequent increase in the level of sexually transmitted diseases (STD) (Cavazos-Rehg et al., 2009). Another example is the popularity of crystal meth, where research showed that 1 in 10 gay men used it to enhance and prolong sexual experiences and frequently used it in group sex which is often reported to be unprotected (Bolding et al., 2006).

The author's view, however, is that substance misuse can contribute significantly to the decision-making process and therefore can initiate sexual risk behaviour in otherwise risk mindful groups. Therefore, substance-related UPS can be seen as consequential but not representative for the purpose of the review. Furthermore, volatility of subjective experience in the context of drug consumption might well be disproportionate to a relatively small number of men who more frequently engage in drug-enhanced UPS and therefore cannot be generalised to a wider social sample (Hurley & Prestage, 2009).

What happens and how people might feel about unprotected sex with a partner of unknown HIV status is the main focus of this review.

Myth and truth of promiscuity

An important aspect of risk of infection is strongly associated between sexual desires and enactments, which was moderated by avoidance of condom usage, STI contraction, and relationship status in Moskowitz's and Roloff's study, and seems consistent across the range of similar research where HIV serostatus did not exclusively moderate the association (2009).

A sample of UK gay men showed a higher number of casual sexual partners than in heterosexual samples. The participants seemed knowledgeable, well-intentioned men but a core group was engaging in unsafe sex and had cognitive processes which minimised their perception of the risk of sexual infection (Tacconelli et al., 2009). Researchers looked at the practices of so-called Safe and Unsafe sex groups of gay men. These two groups did not differ in Mood (anxiety and depression) but were different in Cognitions. The Unsafe group had clear preference for higher sexual risk cognitions which were based around pleasure and the need for relationships. This is not to say that sex without a condom is different, but that condoms represent 'mechanical' difficulties, interrupt the flow of sex and restrain intimacy (McInnes et al., 2009). Apart from seeing condoms as an intimacy barrier, the emotional regulation plays also a big part in RB. Higher prevalence of depression in mostly young gay men is a known contributor to RB (Savin-Williams et al., 2010).

The studies refer to correlation between different types of cognition and emotional regulation and can be relevant to Counselling Psychology.

Social stigma and cliché

Moskowitz and Wrubel (2005) found that gay men consistently experience difficulties in maintaining safe sex and have a higher number of partners than heterosexual couples. Gay men tend to be portrayed as individuals lacking in self-determination and agency and control (Worth & Rowstone, 2005), while the reality is that relatively few gay men engage regularly in such activities and the majority

live far more mundane lives than suggested by literature of sexual risk (Prestage et al., 2007). On the other hand, the promiscuity of gay men becomes some sort of cliché and Braun et al. (2007) argued that increased sexualisation of gay culture leads to the introduction of highly sexualised norms of sexual behaviour which, in turn, leads to unwanted sex or even sexual coercion amongst gay men as gay identity itself is almost expected to be sexual.

There is an alternative way to see and understand the meaning of RB in the gay population, which was introduced by Patton (1996) in a concept of 'psychological deficit'. Patton advocates the view that once a healthy sexual desire becomes pathologised and re-interpreted as a desire for dangerous sex in the context of the post-AIDS era, it taps into representations by a wider community of what might be seen as sexual norms behaviours and safe sexual practices amongst gay men.

Worth and Rawstone (2005) argued against the deficit model and want to see it abandoned. According to them, this implies that if gay men were socially 'normal' they would not use drugs and engage in unsafe sex. It is not clear how the authors decided to link three specific variables such as methamphetamine usage, UPS and 'cultural milieu' with the definition of social normality. It seems more likely that the argument of Worth and Rawstone (2007) is an attempt to define gay behaviour as socially abnormal. Their conclusion was based on the assumption that gay men are confronted with a paradox: on the one hand, they have 'freedom with chosen lifestyle and identity', while on the other hand, feel obliged to mould their desires with wider cultural norms of society (Worth & Rawstone, 2005). The question of societal norms, unsafe sexual practices and drug-taking behaviour was largely attributed to the gay community repertoire. Such representation of a gay lifestyle is consistent with Worth's earlier views on gay lifestyle. She sees a sexual liberation and multiple partnering as the keystones of gay culture where gay relationships are marked by infidelity anxiety and reluctance to disclose polygamy (Worth et al., 2002).

Sexual functioning of gay men can be, in fact, informed by the various intrinsic and extrinsic sources (Imrie et al., 2007). An interesting psychological observation came from Hurley & Prestage (2009), reflecting on changes in attitudes toward sexual behaviours. They concluded that gay men were confronted with the AIDS epidemic that claimed many lives and now they must come to terms with the knowledge that blood and sperm, two perceived life-giving fluids, have become representations of death. HIV risk awareness now constitutes an environment in which not only sexual identity, but also practices of intimacy, may represent a gay man as a high-risk individual (Hurley & Prestage, 2009).

Promiscuity, on the other hand, has become, in a way, a vehicle by which some men improve their self-image and the fleeting connections formed during sexual encounters provide some gay men with the sense that they are desirable and wanted (Parsons et al., 2008; Bergling, 2007). The debates about gay promiscuity come in two different contexts in relation to those infected and uninfected by HIV. These two groups seem now more merged with the introduction of new technologies. The internet, for example, has dramatically changed the way gay people date and also allows HIV positive men to avoid abuse, discrimination and sexual rejection by advanced negotiating of online identity (Davis et al., 2006). The study showed that serostatus identity was linked to various assumptions and expectations about safe sex. HIV positive men, in particular, expect their partners to take responsibility for themselves. On the other hand, online behaviour is rather similar to offline behaviour in this respect and is not affected by willingness to take risks (Bolding et al., 2005).

Relationships

Risk-taking behaviour appears historically to be associated with a subjective assessment of a sexual partner's HIV status based on moral and social grounds rather than any medical knowledge, such as HIV test results (Dodds et al., 2002). This contributes to further risk, as in the UK, for example, an uptake of HIV testing is relatively poor in comparison to the rest of the West and varies between 50 percent and 75 percent in high-risk groups such as MSM (Hart, 2010).

Gay men's relationships are often overlooked in HIV prevention efforts and little research combines sexual agreements with relational characteristics and serostatus of the couple. As per Hoff et al. (2010), the majority of couples interviewed reported explicit agreements of the nature of their relationships, e.g. monogamous or negotiated degrees of freedom. This was nearly equal in monogamous as well as in open relationships. However, only concordant negative couples endorsed HIV/STD prevention amongst their top motivations for making an agreement. UAI with the primary partner, however, poses a significant risk of HIV infection in gay relationships (Hoff et al., 2010) and for many couples, discarding condoms symbolises their commitment to each other and UAI can be seen as not just the way of increasing sensual pleasure, but also ensuring fidelity within the relationships (Worth et al., 2002).

The data from US National HIV Behavioural Surveillance System (CDCP) showed that two-thirds of gay men who acquire HIV do so from their regular partners. Men were not good at guessing their own or their partner's HIV status but used condoms 43% of the time with the regular partner vs. 72% with the casual (CDCP, 2005). Sullivan et al., (2009) suggest that around 68% of HIV transmission in the US came from gay male partners (UCLP conference, 2010). Men with diagnosed HIV, on the other hand, were least likely to be responsible for HIV transmission within relationships, as such couples were more likely to use condoms with the main partner, unlike seroconcordant couples (Sullivan et al., 2009). All these findings, in my opinion, require some further exploration, especially in the area of HIV-related responsibility amongst positive and negative men and their understanding of the meaning of UPS within and outside of their relationships.

Serosorting

The studies show some differences in sexual practices of HIV positive, negative and men with unknown status. Comparison of prevalence of high RB amongst HIV positive men in the US showed a substantial reduction in such behaviours after people become aware they are HIV positive. HIV positive men, in

return, were increasingly using the internet to filter partners of the same status for most risky sexual practices such as UAI (Marks et al., 2004). These findings were consistent with other studies which reported an increase in sexual RB amongst gay men, as well as reporting an increase in the cases of UAI amongst MSM in industrialised countries (Carter, 2010). Elford & Hart (2003) showed that HIV positive men were more likely to report UAI if it was with another HIV positive casual partner. This phenomenon has been termed serosorting and implies that men chose UAI with someone of the same HIV status.

In a longitudinal study, between 1998 and 2008, Lattimore et al., (2010) surveyed gay men visiting London gyms. They found that the percentage of men reporting UAI had increased from 24.3% to 36.6%; however, the behavioural pattern had changed with gay men showing a tendency to increasingly use serosorting (Lattimore et al., 2010). This trend, alongside strategic positioning (where the HIV positive partner takes the riskiest sexual role) and increased usage of Viagra and crystal meth as sexual enhancers, appears to significantly contribute to an increase in STI's, inclusive of HIV diagnosis (Elford, 2006).

Serosorting is discussed widely in recent literature (Hart & Elford, 2010) and is often looked at from the point of view of risk of HIV infection. Wilson et al. (2010) have estimated that the proportion of the HIV infected but undiagnosed population is crucial to determine effectiveness of serosorting and estimating that risk of acquiring new infection in the UK, for example, is over 30%. On the other hand, it seems that serosorting is also widely popular within the HIV positive population (Elford & Hart, 2010) but not much is said about the direct risk from HIV super-infection for that group through the development of new resistant strains of the virus (Poudel et al., 2007).

Some qualitative research has looked at sexual risk cognition and assimilation of HIV related 'optimism' as described in Flowers (2001) when HIV was no longer seen as a 'death sentence' by gay men due to availability of antiretroviral drugs. Brennan et al., (2010) devised three separate scales, addressing beliefs about the transmission of HIV while on treatment (susceptibility); the quality of life while on HIV treatment (severity); motivation to use condoms consistently while on treatment (condom motivation); and found that all three were

better markers for assessing HIV treatment optimism among HIV positive MSM. White men, however, showed less motivation in condom use than any other group (Brennan et al., 2010). This data is different to the studies on HIV negative men where Fendrich et al., (2009) found no correlation between RB and demographic factors.

Flowers et al., (1998) explored HIV risk-related behaviour in a qualitative study, finding a specific identity-related temporal context in which gay men engage in unprotected sex on the spur of the moment. The experience of loneliness, desperation, homelessness and redundancy were all seen as key antecedents of UAI. This finding appears to be consistent with the behavioural and psychosocial assessment by Reisner et al., (2009), who concluded that gay men who had problems with disclosure of their sexual orientation; those who had been previously treated for STI; those who were attending public cruising areas or actively using the internet for dating were less likely to be engaged in sexual risk-reducing practices (Reisner et al., 2009). Self-reported depression was also consistent in that group.

High- and emerging-risk groups

Young people

To determine whether the increase in HIV infection reflects a rise of HIV incidence or is as a result of an increase of HIV testing, Dougan et al., (2007) looked into data from UK HIV surveillance system and found that although HIV diagnosis among MSM in the UK rose by 54% between 1997 and 2004, the number of MSM under 35 years of age in London showed no increase, although it had increased in all other age groups (Dougan et al., 2007). Her indirect estimates suggest that the rise in HIV incidence was influenced by an increased uptake of HIV testing. However, this stipulation does not cover various sub-groups e.g. Asian and Black British gay men, who are often reported to have increased difficulties in coming out (McKeown et al., 2010) and, hence, are less likely to be covered by health protection campaigns. Also, some research shows that HIV stigma is highly prominent among young MSM, which potentially prevents them from overcoming social and healthcare barriers (Dowshen et al., 2009).

Over 40's and over 50's

As the US estimates suggest that one in two gay men will become HIV positive by the age of 50+, such a demographic shift can be partially attributed to new HIV acquisition which, according to Marks, Cepaz and Janssen (2006) comprises 15% of all new cases.

Current data on older gay men tends mainly to compare sexual behaviours with STD prevalence. Baker et al., (2009), for example, suggested that there is an increase in RB in this particular group as they also observed an increase of other STIs in the group of gay men age of 50 years old and over. RB trends show no difference across all age groups in terms of consistency of condom use and number of sexual partners (Dougan, et al., 2007). If sexual activity declines with age, it is not clear why an increased incidence in HIV diagnosis among older MSM has been reported. It has been suggested that HIV positive status, along with recreational drug usage, a large number of sexual partners and low scores on internalised homonegativity, are strong predictors of UAI in that particular group (Jacobs et al., 2010). Saying that, the study was looking at men age 40 or over, leaving no clear indication of what constitutes an older age. To clarify the matter, Elford et al. (2008) made two distinct groups of older HIV positive men: (1) those who were diagnosed with HIV under the age of 50 and just belong to the ageing cohort and (2) those diagnosed with HIV over the age of 50.

The second group also included people who were infected with HIV in their 30s and 40s (so-called 'late diagnosis') and people who were infected late in life ('late seroconverters'). To back up his viewpoint, Elford refers to National HIV Surveillance data for England, Wales and Northern Ireland for 2000-2007, which suggests that 44% of newly diagnosed older gay men were infected with HIV when aged 50 or over. This somewhat corresponds to BBC reports on the heterosexual population aged over 50 getting involved in more risky SB, including casual sex and the growth in popularity of swingers' clubs (BBC, 2010). This also shows that the ageing cohort appears to be getting less attention from the relevant services and STD/HIV identification across all age groups needs more effective secondary prevention efforts (Onen et al., 2010).

In order to understand better the effects of ageing on RB and, consequently, HIV, it is important to understand the socio-cultural context of this particular group. Some MSM, for example, report that they have only embraced their sexuality by the time they reached their midlife. This group often includes people who come out late in life and display RB typical of adolescents (Beard & Hissam, 2004). Eighty percent of them report no condom use and those who were over 60 were more likely to come from an oppressive homophobic culture (Jacobs et al., 2010). This is particularly disconcerting as the sample represents the higher rate of HIV infection. Men of that age often reported multiple partners and HIV acquisition in over 40s is also common (Jacobs et al., 2010). This can be partially attributed to the fact that during their midlife men shift from seeing 'future' in terms of its potential to seeing it in terms of its limitations (Dittmann-Kohli, 2005).

On the other hand, many older gay men continue old patterns of behaviours and struggle to adapt scripts rooted in their adolescence, while others see signs of ageing and possibly developing chronic conditions which bring awareness of limited time (Dittmann-Kohli, 2005). Making a successful midlife transition and adjustment to life changes requires both internal and external resources. Social and community support is not always available for these men as they have grown up in a mainstream heterosexual culture and are unlikely to use LGBT support. Their alienation from the gay community can be even more prominent due to internalised homophobia (Beard & Hissam, 2004). The current gay culture can be also seen by these men as less accessible because it fortifies youth, beauty and sexuality as key components of gay identity (Jacobs et al., 2010).

Conclusions

It seems that the behavioural focus of sexual risk research has found a good grounding in a number of correlates and the most researched variables in STI infection rates are based on correlations between stress, mood and cognitions (Marks et al., 2004). For counselling psychologists, it is good to remember that 'no feelings...have ever been unambiguously identified or defined without referring to its antecedents or consequences'(Skinner in Malone, 1975, p.140).

The behavioural model of losses and gains seems to be a good predictor for RB; however, if human beings were just rational agents and able to calculate future rewards against future losses accurately, we, as a society, would be less likely to experience issues with sexually transmitted infections, alcohol and drug-related problems on the current scale.

Acceptance of gay culture, in particular in Western society, and the consequent sexualisation of that same culture seems to contribute to behavioural expectations amongst the younger generation of gay men, as well as those who came out later in life. Both groups have the highest HIV infection rates. Similar trends were also observed in the heterosexual community and are likely to reflect on wider social changes in a society.

Issues of identity and acceptance and of close relationships appear somewhat overlooked by the majority of studies. The deeper meaning of intimacy, fidelity and age in MSM could also benefit from further research. What needs to be examined in greater detail is a link between the value of intimacy and the meaning of commitment in relationship, and desirability of UPS amongst the committed partners and single gay men.

Unprejudiced and confidential sexual health counselling can help to recognise and improve the risk in order to keep HIV negative MSM negative, preventing acquisition, and to support and strengthen HIV positive men's resolve not to pass on HIV infection and, in doing so, minimise further transmission (McDaid & Hart, 2010). Research informed psychological work can allow for a deeper insight into the various individual meanings of sexually risky behaviour. The understanding of underlying reasons and contextual underpinnings of such behaviour will allow for a more focused therapeutic sessions. It might also increase a likelihood of effective and brief psychological interventions with this client group.

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Appendix A

Ethical Approval Form

Ethics Release Form for Psychology Research Projects

All trainees planning to undertake any research activity in the Department of Psychology are required to complete this Ethics Release Form and to submit it to their Research Supervisor, **together with their research proposal**, prior to commencing their research work. If you are proposing multiple studies within your research project, you are required to submit a separate ethical release form for each study.

This form should be completed in the context of the following information:

- An understanding of ethical considerations is central to planning and conducting research.
- Approval to carry out research by the Department of Psychology does not exempt you from Ethics Committee approval from institutions within which you may be planning to conduct the research, e.g.: Hospitals, NHS Trusts, HM Prisons Service, etc.
- The published ethical guidelines of the British Psychological Society (2004) Guidelines for minimum standards of ethical approval in psychological research (BPS: Leicester) should be referred to when planning your research.
- **Trainees are not permitted to begin their research work until approval has been received and this form has been signed by 2 members of Department of Psychology staff.**

Section A: To be completed by the student

Please indicate the degree that the proposed research project pertains to:

BSc MPhil MSc PhD DPsych X N/a

Please answer all of the following questions, circling yes or no where appropriate:

1. Title of project

Growing older with HIV: a phenomenological perspective.

2. Name of student researcher (please include contact address and telephone number)

Sacha Lawrence, 93 Ham Park Road, Straford, London, E15 4AD. Tel.07724449972

3. Name of research supervisor

Dr. Paul Holland

4. Is a research proposal appended to this ethics release form? **Yes**

5. Does the research involve the use of human subjects/participants? **Yes**

If yes,

a. Approximately how many are planned to be involved? 8-10 participants

b. How will you recruit them? Via London HIV charities

c. What are your recruitment criteria?

HIV positive men and women aged 40 or over with over 5 years of experience of living with HIV

(Please append your recruitment material/advertisement/flyer)

d. Will the research involve the participation of minors (under 16 years of age) or those unable to give informed consent? **No**

e. If yes, will signed parental/carers consent be obtained? N/A

6. What will be required of each subject/participant (e.g. time commitment, task/activity)? *(If psychometric instruments are to be employed, please state who will be supervising their use and their relevant qualification).*

Each participant will be asked to complete a 30-40 minute semi-structured interview, which will be tape recorded.

7. Is there any risk of physical or psychological harm to the subjects/participants? **Yes**

a. If yes, Please detail the possible harm:

There is a possibility that patients may discuss difficult HIV related past or present experiences which could leave them feeling emotionally heightened or distressed. The researcher has extensive experience in working with this clinical area and able to manage any emotional distress that can possibly occurs during or after the interview. The participant will also be informed, prior to giving consent, that they can withdraw from the study at any point.

b. How can this be justified:

Although the HIV epidemic has been established for over then 20 years, it is still perceived as a young person's condition. This does not reflect the reality of ageing population in the UK. It is therefore of clinical value to ascertain the perspectives of HIV positive clients' on issues regarding ageing. It will add to the current research knowledge and as specified by the HIV Public Health and Commissioning Overview, London (Ruf & Foreman, 2010), it will assist in establishing strategies to improve health outcomes for this often neglected population.

8. Will all subjects/participants and/or their parents/carers receive an information sheet describing the aims, procedure and possible risks of the research, as well as providing researcher and supervisor contact details?

Yes

(Please append the information sheet which should be written in terms which are accessible to your subjects/participants and/or their parents/carers). Please see Appendix B

9. Will any person's treatment/care be in any way compromised if they choose not to participate in the research?

No

10. Will all subjects/participants be required to sign a consent form, stating that they fully understand the purpose, procedure and possible risks of the research?

Yes.

(Please append the informed consent form which should be written in terms which are accessible to your subjects/participants and/or their parents/carers). Please see Appendix C

11. What records will you be keeping of your subjects/participants? (e.g. research notes, computer records, tape/video recordings):

Digital recordings of the interviews and hard copies of the transcripts.

12. What provision will there be for the safe-keeping of these records:

Digital data will be encrypted and kept on a password protected computer. Hard copies will be coded to preserve anonymity and kept in a locked filing cabinet, in accordance with the Data Protection Act (1998). All audio material will be erased on a completion of the project.

13. What will happen to the records at the end of the project:

Hard copy data will be destroyed within 6 months of completing the study.

14. How will you protect the anonymity of the subjects/participants:

All names will be coded in transcripts to preserve anonymity; there will be no access to tapes to anyone apart from the researcher and his supervisor.

15. What provision for post research de-brief or psychological support will be available should subjects/participants require?

All the participants will be debriefed at the end of the interview and names and contact details of charity based counsellors will be given to every participant.

*(Please append any de-brief information sheets or resource lists detailing possible support options)*Please see Appendix D.

If you have circled an item in bold print, please provide further explanation here:

Signature of student researcher ----- Date -----

Section B: To be completed by the research supervisor

Please mark the appropriate box below:

- Ethical approval granted
- Refer to the Department of Psychology Research Committee
- Refer to the University Senate Research Committee

Signature ----- Date -----

Section C: To be completed by the 2nd Department of Psychology staff member*(Please read this ethics release form fully and pay particular attention to any answers on the form where bold items have been circled and any relevant appendices.)*

- I agree with the decision of the research supervisor as indicated above

Signature ----- Date -----

Appendix B

PARTICIPANT INFORMATION SHEET



Dear Participant

I would like to invite you to take part in my doctoral research study

Growing older with HIV: a phenomenological perspective.

Before you decide to take part I would like you to understand why the research is being conducted and what it will involve for you if you decide to take part. Should you decide to take part, your participation is entirely voluntary and you are free to withdraw at any time without giving any reason. This will not affect the standard of care you receive in any way.

INTRODUCTION

You are being asked to take part in a research study. Before you decide it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with anyone important to you. If there is anything not clear, or if you would like further

information, please ask to speak to Sacha Lawrence on the number provided. Take your time to decide whether or not to take part.

PURPOSE OF THE STUDY

The study is interested in how HIV positive people experience their lives in the era of advanced medical treatment. The dynamic of the condition has changed and HIV is no longer perceived as a death sentence but it is seeing more as a chronic and manageable condition. One consequence is that the prevalence of the HIV positive population has increased and there are now more people living with HIV in the West than at any other time during the epidemic (Trussler and Marchand, 2005). The research is interested in how that new dynamic impacts on individual experiences of living with HIV.

We would like to hear about your experience. We plan to invite a total of eight to ten people to participate in the research.

PROCEDURE

You will be asked to participate in a confidential, private, one to one interview, which will be held in a counselling room at Helios. The researcher will ask you to describe your experiences. The interview will take between 30 to 40 minutes and will be recorded. Later, the tapes will be transcribed into text, which will then be analysed in order to look for distinct themes that accurately describe the phenomenon of life with HIV.

If you are interested in viewing the final results of the study I will be happy to provide you with that information.

RISKS AND BENEFITS

I cannot guarantee that participation in this study may assist you directly in any way but it may offer you additional insight in your own life. Your help is important in order to gain further psychological knowledge of the evolved condition.

There might be a chance that after the interview you might feel you have a need to talk more about, or explore in depth your life experiences. You will be provided with the contact details of appropriate counselling services wish you decided to do that.

CONFIDENTIALITY

It is entirely up to you whether or not to take part. If you decide to participate you will be given this information sheet to keep and be asked to sign a Consent Form.

All the information collected about you during the course of the study will be kept strictly confidential and will not be traceable to you as an individual. The tapes and transcripts will be destroyed at the end of the study. If you withdraw from the study, all your identifiable records will be destroyed according to Data Protection Act and we will not use the data collected up to your withdrawal.

In the written report of the study, quotes from individuals may be used to illustrate the themes found, these will not be attributed to any individual by name. The information you share with me maybe be also looked at by my supervisor Dr. Paul Holland or academic staff at Psychology Department at City University. This may be done in order to verify that the study is being carried out correctly. You will not be asked to identify yourself on this tape.

RESULTS OF THE STUDY

The results of the final analysis may not be available until up to 6 month after your interview. The final report and findings are likely to be made available to

relevant professionals and maybe be submitted for publication so that insight related to possible improvements in patient care can be shared with colleagues.

Thank you for taking time to read this information and showing interest in this study.

If you have any questions regarding this information sheet or remain unclear about any point of the research study please feel free to contact me on 07876660087 or email me on sacha.lawrence.1@city.ac.uk

you can also contact my academic supervisor Dr. Paul Holland on 07710621852 or email him on drpaulholland@hotmail.co.uk

Appendix C

CONSENT FORM



Client Identification Number:

Title of Project: **Growing Older with HIV: a phenomenological perspective.**

Name of Researcher: Sacha Lawrence

1. I confirm that I have read and understand the information sheet dated.....

for the above study. I have had the opportunity to consider the information, ask

questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw

at any time without giving any reason, without my medical care or legal rights

being affected.
3. I understand that relevant sections of data collected during the study,

may be looked at by academic staff at City university. I give permission for these individuals to have access to my data.

4. I am aware that the research might be published at a later stage. I understand that I

have the right to access the above information and the results of the research

5. I agree to take part in the above study.

Name of Participant _____Date _____

Signature _____

Researcher _____ Sacha Lawrence _____Date _____

Signature _____

Appendix D

The Leaflet



CITY UNIVERSITY
LONDON

Growing older with HIV

Are you age of over 40 years? Have you been diagnosed with HIV for a minimum of 5 years?

WOULD YOU LIKE TO CONTRIBUTE TO
RESEARCH IN HIV HEALTH?

Please contact Sacha on sacha.lawrence.1@city.ac.uk

or call me on 07876660087. Alternatively you can contact Kim at reception to arrange an appointment

Appendix E

Debriefing Note



Dear participant,

Thank you for taking part in the research of the Ageing with HIV: a phenomenological study. If you feel in the following days after your interview you have some issues you what to talk about, or explore in more depth, please do not hesitate to contact your

🚦 One of the counsellour's at Helios.

You can always call the main number (02077137122) and book an appointment with Kim at reception.

Alternatively you can

🚦 contact myself or my supervisor on the numbers below:

Sacha Lawrence

Trainee Counselling Psychologist at City University

07876660087 sacha.lawrence.1@city.ac.uk

Dr.Paul Holland, City University

doctorpaulholland@hotmail.com

Thank you again for your participation,

Sacha Lawrence

Appendix F Sample of analysis

Experience vs. Cognition

Q. Now you are over 45 now, what does it mean to you to be 45 and HIV positive these days?

The Experience of the person:

What's implication for his experience

Relief? Concern
 Concern
 Worry
 Thinking of future possibility
 Anticipation
 Re-assessment
 Thinking of future possibility
 bitter face etc
 age + attractiveness
 Experience
 Worries
 Knowledge
 Re-assessing himself
 through the knowledge
 perception is to accept life style
 that is to accept life style

- 81. K.: Ehm other than say like from being 45 normally, what bearing an HIV
- 82. have ...ehm I feel like that the drugs you take suppress your sexual drive
- 83. and...on a good side I tend to be a bit of a sex addict so it means I have less of
- 84. a negative life style and, you know, on the other hand, it means you can't be
- 85. in a relationships and enjoying relationships and enjoying sex. It is greatly
- 86. diminished and I am greatly aware of being a 45 and ehm losing a later
- 87. primer years lets say, and if there is a breakthrough in few years of time I
- 88. think they just found out, that certain percentage of the population, like 1 in a
- 89. 1000 actually is ...immune to HIV and they have cured somebody recently
- 90. by using the gene not the actual therapy but by using that cells and injecting
- 91. them in the actual person and they have got rid of HIV
- 92. Lets pretend there is a cure in the next 5 years time, I will be slightly bitter
- 93. because I know I lost 10 years of not having sex drive and now I am 50 and I
- 94. feel like I am not attractive you know, being that idea, you know, age,
- 95. attractiveness come together (laughs)so that's that one thing about
- 96. being 45 and HIV
- 97. Coz I am not worried about my health too much as I've got a feeling that you
- 98. ve got to get life as much as anyone else, ehm but I know that there are side
- 99. effects, side effects to the drugs but I personally feel that they are improving
- 100. and I think if you leading a reasonably healthy life style then pretty

Positive Recombination
 loss / Control
 Cure
 age is a no control
 towards with control
 implies control
 bargaining

Appendix G

Example of Table of Themes for Colin

Main Theme	Sub-Theme	Quote	Line
Adapting self	Use of knowledge	<i>"I think the future of people with HIV and age is that they are going to have their benefits removed if they are on them . I think it is going to be tough for quite a lot of them and fortunately I am not in that situation so it is not such way for me personally..."</i>	169-170
			149-153
			120-124
			114-117
		<i>"I also suspect that the drugs companies will see that so much money to be made from keep all those people on medication which keeps them stable rather than curing it so that will be an interesting thing you know, politics , you know, will play part, so sadly I don't see the day when they got rid of HIV to save the people..."</i>	
		<i>"I know I can see from a distant observation it looks like really depressing but I see it like I witness it and being there properly, so I know it is not (depressing) , it is all perception so I think being HIV, the biggest thing with ageing and HIV for me is really about taking care for myself and providing for myself which I don't think I have done in the same way if I haven't been HIV ..."</i>	
		<i>"Yeah I think I know what it is like to be a very frail old person when it takes all day just to go to the post office and do shopping that's how it used to be and just before I went on medication ...and I also know that this is not particularly depressing because actually it takes quite a lot of your energy "</i>	

	Split	<p><i>"... I was like someone from Auschwitz almost eh in terms of weight...shocking for everyone else. I was actually fine with it, I knew I was all right time-wise and it will work out...blind...blind faith in fact that it is all going to be ok really."</i></p> <p><i>"I tend to, whatever situation I am in, whatever crisis I am in...ehm...at one point I will step outside it and become more objective and I almost find it quite interesting to see how one deals with that situation or not. I see myself as part of a Royal Picture or something and that's a...like stepping in the outside, almost like stepping into the intellect really</i></p> <p><i>possibly seeing myself as an art project and getting healthier, I thought as a part of objectivity really ...hmm "</i></p>	51-55 65-69 76-77
	Fantasy	<p><i>"I think London is ideal for old people, I read recently lots of (old) people want to move in. I'd like to move in to Soho as you get old you would like everything to be very near to you or otherwise you are not going to do it so for me London is ideal, you don't have to travel far and the more densely populated, the better for elderly...and the idea of stuck in a country somewhere...so no London is better..."</i></p> <p><i>"...but on the other hand medication may improve so much so you start not to feel that you are HIV anymore"</i></p> <p><i>"Let's pretend there is a cure in the next 5 years' time, I will be slightly bitter because I know I lost 10 years of not having sex drive and now I am 50 and I feel like I am not attractive, you know..."</i></p> <p><i>"I think drugs has improved not that they have announced the improvement and sometimes the name of the drugs are exactly the same but turns out on a background they find out why it gave diarrhoea and they removed that thing and you don't even know that it is better, so from that perspective drugs are better ..."</i></p>	243-248 170-174 92-94 149-133

	Control & power	<p><i>"I think being HIV, the biggest thing with ageing and HIV for me is really about taking care for myself and providing for myself, which I don't think I have done in the same way if I haven't been HIV... and I don't just mean security, I also (mean) listening to yourself; if you don't want to go out, if you don't want to go drinking and if you don't want to go clubbing – don't do it. If you don't want to hang around with those people – don't do it."</i></p> <p><i>"you are forced by HIV because you are actually frailer and you just need to address those things as you can't keep going like everyone else and I think that is very positive point that is because it gives you rights to be more like you rather than following the pack . I am sure you realise that in gay culture there is a big pack mentality, everyone is trying to sort of keep up with each other . It is great to step out of that lot earlier than everyone else "</i></p>	<p>99-104</p> <p>107-112</p>
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Appendix H

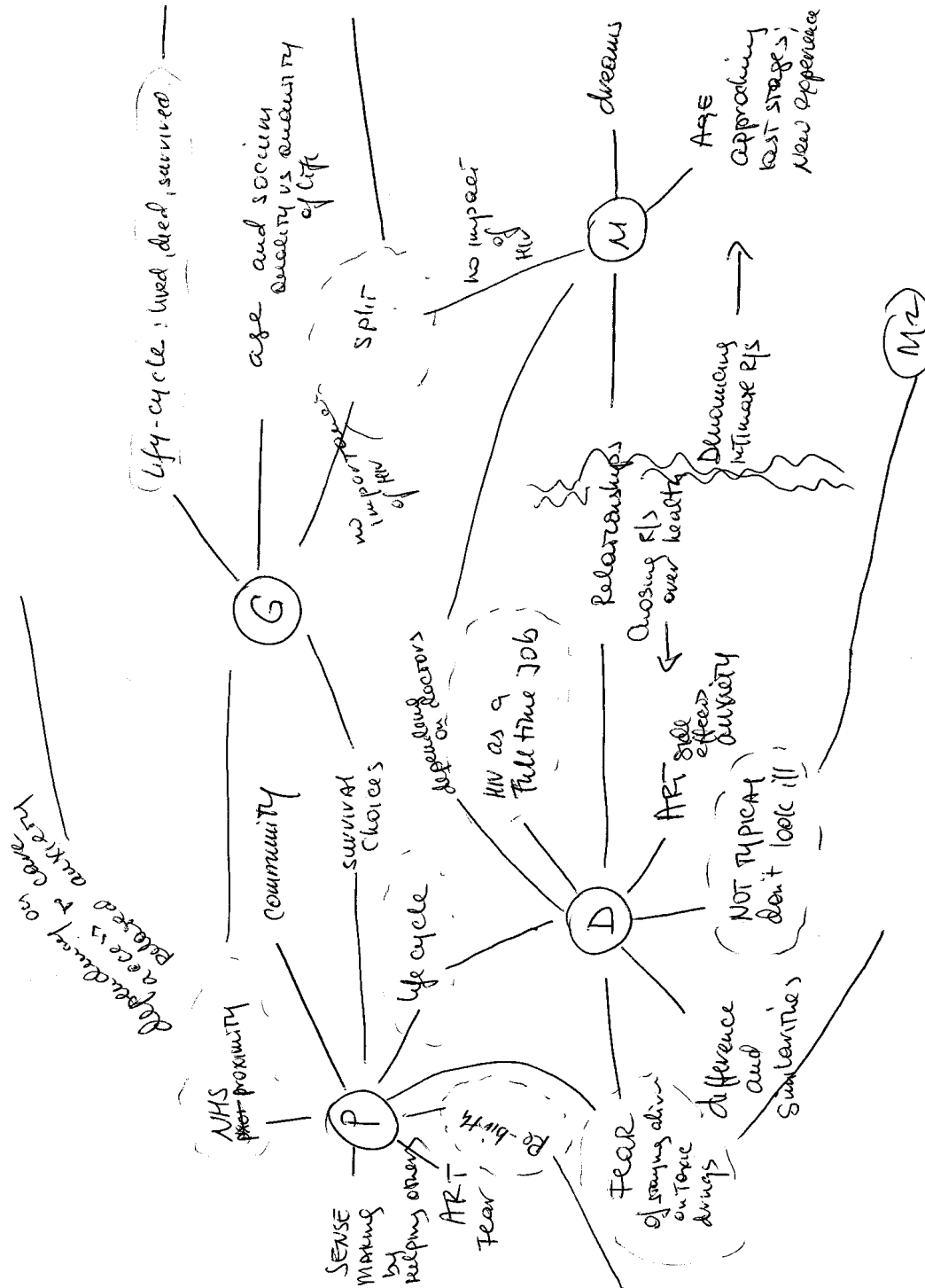
Example of Master Table with Quotes

MainTheme	Sub-Theme	Quote	Line
Adapting self and accommodating changes	Knowledge	<p><i>“there will be various needs err..but.. I think one of the problems is is that the government is very slow in making rules and things like that. Also, particularly at the moment, financially for everyone it's a difficult time” J</i></p> <p><i>“age and I think my family have smoked. I mean I have taken lots of drugs. I've taken a lot of alcohol. I've abused my body hugely. I don't realistically see myself being old age. My father died in his early 60's and also my grandparents had cancer. So the reality is that even with HIV or without HIV I can't see myself an old old person. It just doesn't equate with my family. So I see myself being a medium tail person and I see myself have to work till the day die. I find that very depressing.” G</i></p> <p><i>“Bearing in mind that I know for a fact that I was always safe with any anal type sex that I's had so there was never any unprotected sex done under any circumstances so I'm pretty certain that I must have got infected through oral sex. Which was always considered low risk so err.. (short pause). One of the other reasons also err was, I really didn't want to risk getting re infected err.. so, I know for a fact that the virus that I was infected with is, that is completely, has no resistance to any of the available therapies they have. That's why I wanted to keep it. Keep me infected perhaps other mutations of that can build up resistance to other therapies. So I didn't want to take that chance.” M</i></p>	<p>120-124 C; 169-176 C; 98-108 A; 51-60 M; 154-156 A; 140-146 C; 146-152 A; 125-139 C; 149-159 C 132-134 J; 56-61 G; 69-72 G; 54-60 M</p>
	Split	<p><i>“...finding out that I was HIV positive was not easy coz at the time it was a death sentence and you saw it as that. I saw it as that but I think I made a conscious decision to carry on and carry on working and because of what I saw of my best friend, with him not fighting HIV...”G</i></p> <p><i>“Well, since 2004 I have been totally, err completely, I've had no genital sexual contact since 2004. I chose to live a life of complete chastity. Ermm.. that, so my whole life, my whole life changed dramatic, dramatically once I had that diagnosis and (short pause) I'm very happy with that.” M</i></p> <p><i>“Well I get...hm...you know...this is probably my way of dealing with life...I tend to, whatever situation I am in, whatever crisis I am in...ehm...at one point I will step outside it and become more objective and I almost fid it quite interesting to see how one deals with that situation or not . I see myself as part of a Royal Picture or something and that's a...like stepping in the outside, almost like stepping into the intellect really , so ...” C</i></p>	<p>9-13 G; 73-76 G; 21-24 M; 31-36 M; 51-55 C:</p>

	Fantasy	<p><i>"Absolutely I think that shift to come and although I don't need that yet I am sure some HIV positive gay people are suffering from it now being an older age and being in care homes or whatever, nurses being a bit cautious because they are positive or they be treated a bit different I don't know. I wouldn't be surprised if that happened, well I have to find out he he" P</i></p> <p><i>"The medication would free me from quite a strict (deep breath) regiment routine of dealing with my anxiety, yoga meditation and err.. eating well all dealing with things promptly. So medication for me would be a life changing event, now that I needed it, accepted it, it would change my life. Help me to fulfill myself, return to work, be well err...mix with other people without the fear" D</i></p> <p><i>" I think it's not something that's going to go away, I think (pause) I absolutely the cure will come from nature, (pause) I don't believe it will come out of mixing chemical together, I believe it will come from some plant extract or you know, something that is quite obvious." A</i></p>	<p>189-186 P; 169-174 P; 200-205 P; 109-112 A; 138-140 A; 140-144 A; 101-105 D; 113-116 C; 69-76 C; 195-198 C</p>
	Spirituality and Mind	<p><i>"The thing I learned about HIV most of all is to be more present in the now that is the biggest teacher because I think because the life events can be gurus and our teachers but actually what is at the end of the road you know it is like you know and I think that HIV has been a big teacher and what it teaches me to do as lots of gurus teaches us to live in here and now or try to be present in here and now and not be concerned about of what might happened or what has happened because all there actually is in here and now and nothing else is actually is real apart from what is happening here and now he he</i></p> <p><i>I think that is my biggest gift, I guess, from the illness which is given to me". P</i></p> <p><i>"It has (deep breath) it has been an awakening (pause) it really has, it's been an, it woke me up spiritually. It has been a deep, deep journey. Err..into myself because I believe as human beings, I choose to believe that the answer lies within me. Err.. (long pause) truthfully, for me, it has been a remarkable gift. I didn't see it as a threat. I chose not to see it as a threat. It has opened up my life like (pause) like the branches of a tree or the petals of a lotus. It has made me, it has helped me, enabled me to get in touch with parts of myself. I mean that I might never have had the courage to explore because I chose to believe that my journey into, as a gay man with full blown AIDs now with HIV positive for 28 years. At times, truthfully, it was it enriched my life. I know, I can only speak for myself I know that, I know that, that might for some individuals can be quite, be very, very different. Err..it had enriched my life. It has opened my life up in the most deepest, spiritual way. At times it was painful but I feel that it was enabled me and given me the ability to become as well informed as I need to be for my sense of survival. Even in my darkest dark with this, my darkest dark when I almost died on the 5th of June 1988 (pause) there was something helped holding me, I cannot, I do not have the words to explain the darkest, the darkest ever period of my life became the light that pierced through and that this is through going through the most distressing time of my life...the light has been piercing, absolutely surrendering to it. It has enriched my life" A</i></p> <p><i>"So, a lot of it is perception, how you perceive things. I mean that's life, if you perceive things in a positive way you can usually deal with most things" J</i></p> <p><i>"contributing to his his negative mental health and his rapidly deteriorating HIV" G</i></p>	<p>130-140 P; 116-117 J; 27-33 A; 59-63 A; 80-93 A; 65-66 A; 10-11 G; 93-99 C</p>

Appendix I

Initial Handwritten Diagram



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