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An Existential-Phenomenological Investigation Into The Experience Of People Living Long-Term With The Human Immunodeficiency Virus (HIV)

Counselling Psychology Doctoral Thesis

Alan Palamountain

This dissertation was written by Alan Palamountain and gained ethical approval from the New School of Psychotherapy and Counselling and the Psychology Department of Middlesex University. It is submitted in partial fulfilment of the requirements of these institutions for the Degree of Doctor of Counselling Psychology and Psychotherapy. The author reports no conflicts of interest, and is alone responsible for the content.

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Abstract

This was an idiographic investigation capturing the first-hand experiential accounts of six participants living with HIV. The purpose of this research was to identify how, in the current economic, the scarce resources available to service providers in the field of HIV might be best allocated to their service users. Further, this research was conducted at time when we are seeing an increasing homogenisation of counselling psychology, a profession characterised by an embrace of pluralism. As such, the research aim was to further our knowledge of the lived experience of individuals living with HIV and to understand what, if anything, it can contribute to the wider counselling psychology discipline. I conducted semi-structured interviews with six participants. After I had analysed each transcript I asked each participant to look at my analysis of their respective interview and provide me with comments or suggestions to ensure I had captured their experiential accounts accurately. The data was analysed using Colaizzi's Descriptive approach (1978), a method which facilitates a descriptive phenomenological inquiry into the unique individual experience as well as commonalities. Main themes reflected how living with HIV was actually experienced by individuals. The participants approached reported feelings of isolation, anxiety about disclosing their HIV-positive status and the stigma of having HIV. Stigma was further broken down into self-stigma, stigma by health care professionals and stigma by association.

Key words: Lived experience of HIV; counselling psychology; Colaizzi's Descriptive Phenomenological approach; pluralism.

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1. Introduction

This research project is an investigation of the unique experiences of, and commonalities between, six people living with the long-term with the human immunodeficiency virus (HIV). Despite an increase in qualitative research over the past decades, reflecting the embrace of postmodernism (Landridge, 2007; Manafi, 2010; Smith, 2008), there is now more of an homogenisation within the discipline of counselling psychology (CoP) which runs counter to its core principles of plurality and subjectivity. For some this constitutes a challenge to the profession's identity and survival as a distinct discipline (van Duerzen, 2010; Woolfe, 2012). An explanation for this, at least, in part can be explained by the prevailing economic climate of austerity and the scarcity of financial resources since health services are far from immune from the demands to justify their existence in terms of effectiveness and value for money. For example, the former point of proof effectiveness is an explicit criteria set by the National Institute for Health and Clinical Excellence (NICE) for determining which psychological therapies should be provided by the National Health Service in the United Kingdom (Guy et al., 2012). By adopting a medical model to understand the issues faced by people living long-term with chronic conditions such as HIV, any approach that does not concur with this position, for example, existential challenges faced by individuals, have been by and large excluded from the recommendations for service provision (Mollon, 2010).

A further consequence of this socio-political and economic environment is that the vast majority of service providers are needing to be increasing mindful of resource constraints. Therefore, conducting research into the experience of living long-term with HIV from an existential-phenomenological vantage point and which reflects upon the philosophical roots and values of counselling psychology would seem apposite and timely.

At the time of commencing this research, I had been working in the field of HIV for over two decades. I had been responsible for setting up and facilitating a Men's group for heterosexual men living with HIV. I also ran counselling services for two London based HIV Charities. During that time two of the most significant changes that have occurred have been firstly, the introduction of effective anti-retroviral medication and, secondly, the reclassification of HIV from being a life-threatening terminal illness to a chronic disease where one's life expectation is now similar to that of a normal healthy person. Therefore, I began to question whether the support services being provided for people living with HIV were still focussed on the most important areas of living with HIV or whether those areas of importance had changed. In other words, what were some of the assumptions being relied upon to inform the choices of service providers and, in particular, what areas to focus their limited resources on?

To conduct my research I choose to contact other HIV charities providing support and counselling to men and women living with HIV because I did not want to interview people who attended the counselling service I worked for as it could be argued that any prior knowledge I might have of these individuals could contaminate my research findings because they might not be open about some aspects of their experience in case I judged them or reported their concerns to whoever was running the charity. This might also be a concern for the individuals I interviewed for my research, but I considered that it was less likely that they would be concerned as I would not have any background information about them and there would be written assurances that the information contained in the interviews would be used for the sole purpose of providing me with data for my research project. This is an example of the awareness I had of how my biases and assumptions could prejudice both the gathering and analysing of my research data and it was something I needed to remain vigilant of throughout the research process. All the individuals I interviewed came from a counselling service for adults living with HIV and who resided in East London. I provided a brief outline of my research question and the reason for my research to the head of the counselling service and asked them if they would in turn ask their counsellors to enquire if any of their clients would be interested in participating in my research project. I was provided with the contact details of several clients who requested I contact them with more information. After contacting all the clients on the list I was able to recruit six individuals who were willing to be interviewed by me for my research project. As part of the counselling service they attended were asked to fill out Core 5-OM (Evans et al., 2000) questionnaires and the beginning and end of therapy contracts. The Core 5-OM has thirty-four statements about current moods or feelings. Scores for each of the items on the questionnaire can be tallied and the averaged both within and between clients. The extent to which the client's responses differ between the initial assessment and the final session are considered as a measure of the efficacy of the therapy provided. Any positive changes in the outcome measurement are interpreted as being indicative of a successful therapeutic encounter. The data from these questionnaires are then collated and reported to funding bodies as supporting evidence for the efficacy and viability of the service provision. A problem with this form of evidence gathering can be, as Stilies et al. (2006) argued, that clients typically score themselves as having improved, or at least feeling *'less distressed'* at the end of the conclusion of therapy, compared to when they first started. This is not conclude that something positive may have been experienced by the client or to infer a wider point that such diagnostic measurement tools do not have any value. However, I suggest that we cannot rely on these forms of standardised data alone to make sense of a person's whole lived experience. Furthermore, from quantitative measurements alone one cannot claim to have an understanding of the unique experience of an individual, which as counselling psychologists in a profession defined by its' embrace of subjectivity, is what concerns us the most.

Therefore, as well as identifying a gap in the exploration of the lived experience of people living with HIV from an existential perspective. My research seeks to explore what are the most important concerns for people living with HIV.

Epistemologically, I approached this investigation from the same vantage point that informs my own work as a counselling psychologist and therapist, namely existential phenomenology. I would argue that to understand and attempt to make sense of an experience, and a person's uniquely subjective engagement with it, can be best achieved by a process of description and clarification as defined by Husserl ([1913] 1931, [1931] 1967). In so doing, I agree with the hermeneutic position, proposed by Heidegger ([1927] 1962) and Gadamer ([1975] 1996); that one inevitably and unavoidably engages in an interpretative, meaning-making process informed by one's own subjective experience. As a researcher I approach this investigation with the awareness of having my own preconceived world views which have been derived from my own experiences. This means that I am equally and inevitably involved in an associated interpretative process of my research participant's interpretative process which Giddens (1976) referred to as the 'double hermeneutic'.

I conducted the research in the following way:
Each participant attended a semi-structured interview in which they asked to reflect on their experience of living with the Human Immunodeficiency Virus (HIV). Each interview lasted 60 minutes. After I had transcribed and analysed the interviews each participant was given the opportunity to read the analysis of their interview. They were asked if they had any feedback they wanted to give me. None of the participants had any concerns with how I had transcribed and analysed their interviews. To analyse the data I used Colaizzi's (1978) descriptive phenomenological method. It will not possible to make any generalisations from my findings to the wider population, however this idiographic investigation report is intended to contribute to our greater understanding of the lived experience of people living with HIV.

In the following chapters I start with an overview of the associated literature by way of further explaining the rationale for my research project. I go on to provide a comprehensive review of the research methodology I employed, in terms of definition and epistemological grounding. Then I explain why I choose Colaizzi's (1978) descriptive phenomenological method as well as a detailed rationale for my decision to contact each participant and why I asked them to review my analysis of their interview. Next, I present the pivotal Findings chapter and subsequent Discussion. I conclude with a summary of the clinical relevance and implications of my research. Finally, I give an appraisal of the strengths and libations of my research and give some suggestions for future research.

2. Literature Review

Before conducting my current research study, I researched the existing literature in the field to see if there was any value in further exploring my area of interest. More specifically, if a worthwhile contribution could be made to the current knowledge base. Most of my information was sourced from Google Scholar, the National AIDS Manual, Researchgate.net.

Scope of the existing literature review.

I was aware of the both the breadth of the relevant literature and the word-count limitations, therefore, it was necessary to decide what should be included and what was outside the scope of my literate review. However, this constraint need not be considered as problematic, but instead it has helped me become more focussed in my search for relevant literature. It has also enabled me to analyse the existing knowledge to find what is most relevant to my current research study. As outlined in the introduction, this research is based upon someone's self-report of their experience of living with HIV. Therefore, for the purpose of explaining my rationale for how this research study developed and emerged, the Literature Review will focus on several key areas. I will begin with a discussion about counselling psychology and I will present a brief history of HIV/AIDS.

2.1 Contextualising Counselling Psychology (CoP)

Counselling Psychology (CoP) has been defined as consisting of six characteristics (Cooper, 2009): an emphasis on subjectivity; an acknowledgement of the uniqueness of the individual; a collaborative and egalitarian understanding of the therapeutic relationship; understanding the client and ourselves as always relationally embedded; an intention of client empowerment; and a focus on wellbeing and the realisation of potential. I will explore in the following sections these attributes in more detail and contextualise what is still, relatively speaking, a young profession in the United Kingdom.

Although it was formally recognised by the British Psychological Society (BPS) as distinct discipline in 1989, it was not until 1994 that CoP was granted full divisional status. At the same time clinical psychology, for example, had been established in 1966. Indeed, the five year delay between recognition and membership was because of resistance from the 'mainstream' BPS divisions, most importantly clinical, who challenged the CoP's emphasis on continuing personal development and reflective practice, as well as the importance of personal therapy (Woolfe, 2012). It is for these very reasons for that resistance that both define and distinguish CoP - and with fundamental implications for both practice and research. More importantly, by embracing subjectivity (Duffy, 1990) and a collaborative relational approach to the work of understanding clients' lived experience of problems with welling and living (Milton, 2010), the unique and holistic experience of the individual is granted precedence and so finally afforded due recognition. Mindful of this, in recent years the appetite for qualitative research and first-hand experiential accounts has gained momentum (Smith, 2008).

Several influential commentators from within the profession (for example, van Deurzen, 2010; Cooper, 2011; Woolfe, 2012) have argued that the CoP in the United Kingdom faces what essentially amounts to an existential crisis. To understand these arguments in more detail, a review of the historical and philosophical foundations of CoP as well as these associated tensions will be explored in the following sections, including an exploration of what the research 'evidence' can show us. However, I will start by expanding upon the attributes that characterise CoP as a profession.

2.1.1 An Inherently pluralistic discipline

CoP is unequivocally pluralistic in nature and resists any meta-narrative which means that no singular orientation within the discipline should be considered superior to the alternatives. This plurality is evidenced by both the BPS and the Health and Care Professions Council (HCPC) recognising the three main traditions of psychoanalytic-psychodynamic, cognitive-behavioural and existential-phenomenological (including humanistic) approaches (Orlans and Scoyoc, 2008; Strawbridge and Woolfe, 2010). Kasket (2012: p.65), when describing how these orientations should be able to co-exist in a spirit of learning and mutual respect argues that:

'a particularly honest, realistic, pluralistically orientated member of the family of applied psychologies, in that it is willing to expand its horizons to accommodate a plurality of viewpoints, a multitude of possibilities, and an infinite variety of potential 'truths'. Our world is unimaginably diverse, our experience is full of paradoxes, and our selves are multifaceted ...Much is unknown and never will be known. Very little can be reduced to bare fact or absolute certainty...I would argue that counselling psychology is the applied psychology that most fully embraces working with these complexities.'

An important point to be made here is that counselling psychologists, informed by existential and social constructionist ideas, maintain the position that there is no unitary or immutable truth in the experience of living and instead accept there can be as many possibilities as there are perspectives. This also means that we must resist assuming that we can know with utter conviction the answers in a world replete with a multitude of experiences and viewpoints. Rather, as professionals engaged in research and practice, the aim is ‘to maintain open and enquiring minds and a degree of humility in the face of complexity’ (Strawbridge and Woolfe, 2010:p.19).

Within this pluralism, there is an existential-phenomenological and humanistic philosophical underpinning which informs the CoP’s holistic understanding of what it means to be human and what a well lived life might look like. In other words, the intention is to attempt to understand a person in a way that acknowledges them in all their contexts - personal, social, political, historical - that together constitute their lived experience. To do so requires contemplating the person and their experiences from the position that all that they do is fundamentally relational, both in being with others and with the environment (Milton, 2010). this is an important idea which will be explored more fully in the next section.

2.1.2 A relational approach to problems with living

As previously mentioned, at the heart of CoP practice is the endeavour to understand a person’s holistic experience of being in the world and how their current way of being might be impeding a well lived life. A fundamental aspect to this notion is a view of humans as being imbedded in the world we inhabit and as being always in-relation to others (Merleau-Ponty, 1962; Spinelli, 2005; Milton, 2010).

In recognition that we are all relational beings and that we are affected by how we respond to and engage in our everyday lives, by definition this will include our experience of our encounters with others. As such we do not function detached from the world since we irrevocably embedded in it the world and so how our environment is can have a direct impact on our health and wellbeing. An obvious biological reality to this claim is that we cannot physically exist without resources derived from our natural environment given that we all need to breathe, eat and drink (van Deurzen, 2010). Furthermore, there is a significant psychological aspect supported by research on the correlation between proximity to the natural environment and wellbeing that have shown that how readily available contact with the natural world can substantively reduce levels of stress and associated physiological indicators (Sustainable Development Commission, 2008).

However, despite the weight of supporting research evidence, Milton (2010: p.298) argues that there is a persistent refusal to acknowledge such a relationship in mainstream psychology. He states that *'an anthropocentric bias remains in much much psychological thinking. Many psychologists have 'stopped' at the boundary of the human body/personality'* (Higley and Milton, 2008). In fact, the propensity of many in psychology to continue to 'stop at the boundary' as argued by Higley and Milton can in part be explained by a persisting adherence to a philosophical position tradition often referred to as the Cartesian paradigm. This paradigm is characterised by an assumed dichotomy between mind and body. Furthermore, there is an assumption that each of us stands alone distinct from the world and others as rational autonomous entities (Dilman, 1993). This tendency to further dichotomise and limit the parameters of the lived experience of human beings creates a philosophical tension which underpins the crisis CoP faces at the present time (Deurzen, 2010; Woolfe, 2012). This tension reflects the continuing and expanding dominance in the Western world of an objectivist paradigm which has shaped not only the advances in the natural sciences, but also dictates how many researchers and theorists work to explain both human behaviour and our lived experience. The difficulty facing the CoP is that this paradigm runs counter to our philosophical underpinnings and values which puts the profession in an uncomfortable and vulnerable position. In the next section I will explore this philosophical grounding and how it fundamentally contrasts with that of the mainstream before making explicit the most important implications this has for research and practice.

2.1.3 The philosophical context and tensions

As well as being grounded in the counselling profession, counselling psychology is also embedded in psychology and so effectively forms a fusion of two distinct disciplines. The former is first and foremost interested in engaging with the subjective experience, values and beliefs, with an emphasis on the free will of individuals. It is largely informed by humanistic, existential-phenomenological, systemic, narrative and social constructionist ideas (Spinelli, 2005; Orlans and Von Soyoc, 2009; Shorrock, 2011). Psychology is predominantly an applied and experimental science, and has positivist philosophical roots aligned with the natural sciences (Strawbridge and Woolfe, 2010). The philosophical roots of counselling can be traced back to the European Romantic Movement of the late eighteenth century (Orlans and Von Soyoc, 2009), however, it was in the post-war United States that it merged as a discipline. The term 'Counselling' was used by Carl Rogers (1951), who was the founder of the person-centred approach and his core conditions of empathy, unconditional positive regard and congruence still persist as defining features of most counselling approaches. Other influences driven from the humanistic tradition include Maslow (1968), who developed the notion of the self-actualising principle, and Perls' Gestalt therapy (1973) which focused on the holistic experience of an individual at a particular moment in time. All these counselling approaches are grounded in a subjectivist stance which emphasises the importance of the unique experience of the individual.

The origins of this subjectivity can be found in the writings of Kierkegaard ([1884] 1944) who was a nineteenth century Danish philosopher, theologian, social critic and regarded by many as being the founder of existentialism (Langdridge, 2007). Kierkegaard, argues that there can be no singular truth to explain the lived experience and to try to attempt to uncover one as a means to securing a meaningful life is ultimately an act of futility. His stance is endorsed by Nietzsche ([1883 1962: p.83), who was another existential philosopher, who argued that in describing our experience, there are no absolute facts since words 'are but symbols for the relations of things to one another and to us; nowhere do they touch upon absolute truth'. What we have is the unique potential of human beings to create meaning - a meaning which never be objective or value-free. It is only in subjectivity that the potential to explore purposeful living exists.This is not an easy option because it requires us to confront fundamental existential concepts, for example the harshness of freedom, responsibility and choice. It also requires us to stand apart from the collective and lose ourselves in the seductive comfort of the masses and conformity. The fundamental issue here is that truth is subjective because it is shaped by context and the unique perspective of the individual and so truth can be unitary.

This stance is known as postmodernism and challenges conventional assumptions of how we reach our understanding. Postmodernism posits that a person's unique perspective is formed and expressed within a relational matrix which is shaped by the social, historical, political, technological and economic contexts within which their lived experience happens (Fox et al, 2009; Kvale, 1992). Manafi (2010: p. 27) argues that truth 'cannot be disconnected from the interests, intentions and desires of the speaker. It is an anti-representationalist and anti-essentialist stance which glorifies subjectivity without eradicating respect for the other and the relational systems that sustain us'. CoP is rooted in this philosophical position which reflected by the veneration of the of the first person experiential account of being in the world. Furthermore, it rejects any objectification of the human condition which predicates separateness.

The embrace of postmodernism is especially notable in the philosophical challenge it presents to a positivist paradigm and more specifically in how its influence has grow which is evidenced by the 'explosion of interest' (Smith, 2008: p.1) which has been seen in qualitative research during the past decade. Nevertheless, one needs to shown caution against any false dawn for the celebrants of subjectivism since, as explored above and as a major underpinning for the rationale for this research project, influential commentators have referred to a crisis at the present time for the profession (van Deurzen, 2010; Woofle, 2012. This crisis can be described as the philosophical tension from being at once firmly in opposition to but at the same time shaped and constrained by the positivist paradigm.

A french philosopher named Rene Descartes (1596-1650) shaped western thought and attitudes to the way knowledge is generated ever since. The Cartesian paradigm has dominated all research in the natural sciences and also in applied psychology in terms of both research and practice (Heath, 2002). The epistemological aim for research is to achieve an objective and replicable methodology that enables us to uncover verifiable facts and universal truths about ourselves and the world we inhabit (Papineau, 2002). This paradigm is of immeasurable value specifically in the advancement of medicine and technology, however, when adopting this stance when attempting to make sense of human behaviour from a relational and subjective vantage point, as counselling psychologists do, it is challenged as being fundamentally incongruent (Bohart, 2005; Elkins, 2007; Corrie, 2010; Rapley, Moncrieff and Dillon, 2011).

Difficulties with living can be understood as being synonymous with physical illness, and so the associated epistemology is often referred to as the medical model (Szasz, 1974; Boyle, 1990; Wampold, 2001; Bentall, 2004). The medical model assumes that emotional distress and suffering is symptomatic of abnormality or disorder and as such should be treated as one would a physical disease. There is also the explicit intention of eradicating the symptoms in order for the person to be ‘cured’. Thomas Szasz was one of the most vehement critics of the medical model. In his seminal critique of psychiatry, *The Myth of Mental Illness*, he argued that so-called ‘mental illnesses’ were no more than names or labels assigned to behaviours that were deemed inappropriate or unwanted by society. Szasz, however, considered them as problems with living dressed-up to be synonymous with physical disease despite there being no ethology to support it (Szasz, 1974).

The World Health Organization's International Classification of Diseases manual, which is now in its tenth edition (ICD-10) and the American Psychiatric Association's Diagnostic and Statistical Manual (DSM) series, as evidence of the dominance of this stance (Manafi, 2010; Kinderman, 2013). For example, in new edition of the DSM-V (2013), even more problems have categorised as requiring psychiatric intervention including grief becoming associated with 'major depressive disorder' and the criteria for 'generalised anxiety disorder' has been significantly widened. Furthermore, some of the inevitable struggles which most of us are likely to experience are now deemed for psychiatric intervention. In other words, we can lose sight of the most important aspects of an individual's lived experience as Kinderman (*'Grief and anxiety are not mental illnesses'*, 2013), who was also a past chair of the British Psychological Society (BPS) Division of Clinical Psychology states that 'diagnosis and the language of biological illness obscure the causal role of factors such as abuse, poverty and social deprivation. The result is often further stigma, discrimination and social exclusion'.

Nevertheless, it is a paradigm which shapes the parameters for that which constitute mainstream opinion along with influential research and in due course service provision. However, from the perspective of the CoP, the dominance of the medical model is has been made equally apparent by our inclusion on the register of the Health Care Professions Council. Therefore, the CoP is presented to the public as being involved in general health care, the alleviation of pain and cures.

The Cartesian paradigm's influence is also reflected in the dichotomy which persists within a profession which is defined by relational practice, but at the same time is required to produce rigorous scientific research. The BPS makes this explicit by saying 'the scientific demand for rigorous empirical enquiry' (Division of Counselling Psychology, 2005, p.1) has to be satisfied. As a consequence, this has meant counselling psychologists have become classified as scientist-practitioners (Strawbridge and Woolfe, 2010) to highlight the dual functions of their role. However, Lane and Corrie (2006) argue that this demand for scientific rigour is being used to also incorporate the emboldened position of qualitative research. Furthermore, Strawbridge and Woolfe (2010) suggest the idea of practitioner-scientist in order to give recognition to the importance of one’s own practice to the contribution to the knowledge base. Moreover, Woolfe (2012) has proposed the term reflective practitioner be used to accentuate the requirement for reflexivity from counselling psychologists who are, like their clients, relationally embedded in the same contextual world and so removing the term of ‘scientist’ completely.

Nevertheless, CoP is situated in a society which remains enamoured with quantifiability and is fundamentally moulded by a Cartesian comprehension of humankind. Manafi (2010: p.25) states that ‘ Despite the pluralistic shift within our field, Descartes’ ghost still haunts us; his unworldly philosophy continues to influence our conceptualisation of the human self and our practice’. There is still an adherence in mainstream psychology and beyond to understanding and conceptualising the human predicament within the perspective of Cartesian dualism: such as the mind/body, self/other, normal/abnormal dichotomies. It would appear that with more and more emphasis being placed on providing justification for the spending of all too meagre resources in today’s economic climate combined with a tendency to look towards that which can be supported by evidence from quantitative research and outcome measurements runs the risk of drowning out the individual’s voice and their lived experience in an ocean of treatment plans and disorder manuals.

Through the acknowledgment and comprehension of these philosophical, socio-political and historical contexts, and the associated tensions; the significant implications for counselling psychology and the ensuing crisis facing the profession can be appreciated. Indeed it is I think also evident that this has particular relevance to the present research rationale. Clearly, there are profound implications for CoP from the drive for standardisation and homogenisation of evidence-based practice.

2.1.4 Implications for counselling psychology research

As I have attempted to highlight in this review, counselling psychologists understand emotional suffering from a holistic, contextual and inter-relational perspective which sees the subject account of the client as being pivotal. Many commentators have suggested an embrace of post-modernism particularly over the past decade, firmly aligning the profession with its' philosophical foundations. Therefore, this positions the nature of CoP as being anti-establishment because it represents a critical, questioning attitude towards the mainstream assumption of it being a scientifically-grounded discipline grounded in objectivist 'evidence-based' research (Miller, 2006; Woolfe, 2012). At the same time, there is an associated increase in interest in qualitative research which acknowledges this relational matrix whilst embracing subjectivity (Smith, 2008).

Some key groups have clearly benefited from this increase in interest, most significantly minority groups in society which have until quite recently been ignored. For example, a growing literature base of qualitative research based around Lesbian, Gay, Bisexual and Transgender (LGBT) psychology (Brandon, 2011; Flowers et al, 2016; Hicks and Milton, 2010; Milton and Coyle, 2007). These non-conformists have often felt excluded and in some cases persecuted by the prevailing attitudes of society, however they have taken the opportunity to make sense of their lived experience and be understood in way that can facilitate a sense of acceptance and empowerment.

Cooper (2011: p.10) interviewed a number of influential policy makers and found that at senior levels where appropriate types of service provision are decided there is 'no postmodern turn just around the corner' and he predicts the demand for evidence-based practice will not diminish. In fact far from it, since he found 'very little evidence of a shift of interest towards qualitative research: indeed, to a greater extent, these colleagues seemed more interested in developing increasingly sophisticated methods of quantitative enquiry'. However, Corrie (2010: p.52) argued that 'gold standard evidence is essentially 'product focussed', whereas practitioners are 'person focussed', less concerned with global statements about effectiveness than how information can inform the subtleties of what they do'. I would argue that this does not mean we should abandon qualitative research methods, nor an unqualified acceptance of quantitative methods. However, it does mean that we need to engage with and produce relevant high quality research that helps to build our knowledge-base and from which future studies can build from that fulfil the criteria of policymakers. Surely, all research that enables us to better understand the impact living with HIV has on people's lives or challenges us to consider and re-evaluate what and how we relate to them should be welcomed.

2.2 A short history of the AIDS epidemic

The AIDS epidemic was first noted in the West on June 5th 1981 when the US Centers for Disease Control and Prevention (CDC) in its Morbidity and Mortality Weekly newsletter reported unusual clusters of Pneumocystis pneumonia (PCP) caused by a type of Pneumocystis carinii (now named Pneumoncystis jirovecii) in five gay men in Los Angeles (CDC, June 1981). Over the next 18 months, more PCP clusters were identified amongst otherwise healthy men in cities throughout the country, along with other previously rare diseases in the West, such as Kaposi's sarcoma, systemic fungal disease and persistent generalised lymphadenopathy (CDC, May 1982; CDC, June 1982), which is common in immunosuppressed patients. In June 1982, a report of a group of cases amongst gay men in Southern California suggested that a sexually transmitted infectious agent might be the etiological agent and the resulting syndrome was initially referred to GRID or gay-related immune deficiency (CDC, June 1982; The New York Times, June 18th 1982). Health authorities soon began to realise that nearly half of the people identified with the syndrome were not gay men. The same opportunistic infections were also being reported amongst haemophiliacs, intravenous drug users and Haitian immigrants (CDC, July 1982a; CDC, July 1982b). This led some researchers to rename the syndrome the '4H' disease (Cohen, 2006). By August 1982, the disease was being referred to by its new CDC title: Acquired Immune Deficiency Syndrome (AIDS) (Marx, 1982). In May 1983 a team of scientists led by Dr. Luc Montagnier at the Pasteur Institute in Paris reported that they had isolated a new retrovirus from lymphoid ganglia that they believed was the cause of AIDS (Barré-Sinoussi et al.,1983). The virus was named lymphadenopathy-associated virus (LAV) and a sample was sent to the CDC which was later passed onto the National Cancer Institutue (NCI) (Kingman & Connor, 1989). In May 1984 a team led by Dr. Robert Gallo of the United States confirmed the discovery of the virus, but they renamed it human T Lymphotropic virus type III (HTLV-III) (Popovic et al., 1984). In January 1985, a number of more detailed reports were published concerning LAV and HTLV-III, and by March it became evident that the viruses were the same, from the same source and were the same etiological agent of AIDS (Marx, 1985; Chang et al., 1993). In May 1986, the International Committee on Taxonomy of Viruses ruled that the both names should be dropped and a new name: Human Immunodeficiency Virus (HIV) be used instead (Coffin et al., 1986). HIV1 and HIV2 found in West Africa are now considered distinct forms of the virus.

HIV is very similar to a virus known as Simian immunodeficiency virus (SIV), which is found in monkeys. There is good evidence to support the view that it crossed the species barrier between monkeys and humans, possibly in the late 19th or early 20th century. The most common theory of how this could have happened suggests that it occurred during hunting and butchering chimpanzees and primates. HIV belongs to a group of viruses known as retroviruses. The ability of the virus to change means it can, at times, evade suppression by antiretroviral therapy. The genetic material of a virus can contain either DNA or RNA. Chickenpox, herpes simplex and hepatitis B are all DNA viruses. RNA viruses use the enzyme reverse transcriptase to transcribe the RNA virus into a DNA copy of itself. The retroviral DNA is then capable of integrating into the host chromosomal DNA. HIV and hepatitis C are both RNA viruses. Through mechanisms still not fully understood, HIV prevents the body's immune from functioning properly. Normally, the immune system fights off infection. However, HIV is able to infect CD4 T-cells, which are key cells that coordinate the immune system's fight against infection. Many CD4 T-cells are destroyed by being infected and even uninfected CD4 T-cells may no longer function properly. HIV infection is also thought to drive the immune system into a continuous state of heightened activity.

This chronic immune activation or inflammation has been found to contribute to increased rates of cardiovascular disease and other metabolic complications that are to be found in people infected with HIV.

Acquired immune deficiency syndrome (AIDS) is caused when the virus (HIV) damages the immune system. Once the immune system is damaged it is unable to protect the body against certain specific opportunistic infections and tumours. These infections and tumours are known as opportunistic because they are caused by organisms normally controlled by the immune system, but that take the opportunity to cause disease when the immune system has been compromised and damaged. The timing and types of clinical problems affecting people with AIDS can vary widely and this is why it is referred to as a syndrome. AIDS is a collection of different signs and symptoms which are all part of the same underlying medical condition which is HIV infection. Infection with HIV is the necessary precondition for the development of AIDS. It is possible for a person's immune system to be compromised in other ways apart from HIV infection, leading to some rare infections found in AIDS. A number of rare congenital immunodeficiencies, certain blood diseases, chemotherapy, the drugs given after an organ transplant and idiopathic CD4 lymphocytopenia and radiation can all cause immune suppression. Although it is evident that HIV has a central role in the development of AIDS, questions still remain convening some of the specific mechanisms by which HIV damages the immune system. This system is complex and can be affected in numerous ways by a retrovirus such as HIV. The role that other cofactors play in the development of immune system damage is still under investigation.

HIV/AIDS denialism is the belief contrary to conclusive medical and scientific evidence that the human deficiency virus (HIV) does not cause acquired immune deficiency syndrome (AIDS). Some reject the existence of HIV whereas others are willing to accept the existence of HIV, but argue it is a harmless passenger virus and, therefore, cannot be the cause of AIDS

(Steinberg, 2009). Claims have been made that AIDS is the result of an immoral lifestyle; that an artificial link was created in the interests of profit by scientists and pharmaceutical companies; or that AIDS and/or the drugs developed to treat HIV are part of a racially motivated conspiracy. In East Africa there was a belief that HIV was engineered and introduced to target specific groups within the general population. Whilst there is no evidence or justification to support these denialist claims, they are still used to apportion blame onto certain groups or as a justification for others in power to withhold funding for treatment. Absence of treatment has led to increased transmission, unnecessary morbidity and mortality (Steinberg, 2009).

There are three established criteria known as Koch's postulates, developed in the 19th century, which prove the link between a pathogenic (capable of causing disease) agent and a disease. These postulates have stood the test of time (Haden, 1992; O'Brien and Goedert, 1996).

Firstly, there must be an epidemiological association. In other words, the suspected cause must be strongly associated with the disease. Modern culture techniques and tests such as polymerase chain reaction (PCR) can identify the presence of HIV in patients diagnosed with AIDS.

Secondly, there must be the ability to propagate outside the host. This has been achieved with animal models.

Thirdly, that the transfer of a pathogen from one person to someone previously uninfected can produce the disease, has been obvious in several ways including accidental occupation exposures resulting in AIDS or an AIDS diagnosis in infants born to HIV-infected mothers.

The notion that HIV does not cause AIDS only merits discussion because it is still being used by some to justify the denial of treatment and care to others.

2.2.1 HIV transmission

HIV can be transmitted through the blood (including menstrual blood), semen, breast milk, vaginal fluids and rectal secretions of infected individuals. Transmission to another person can only occur if those fluids enter the other person's body. HIV can be isolated from other bodily fluids, such as sweat, saliva, and tears, but the viral concentration is so low that the transmission risk is negligible. HIV cannot be transmitted through coughing or sneezing, sharing household items or swimming in a pool with someone who is infected with HIV. Transmission is affected by viral fitness (the ability of the virus to replicate and cause disease), amount of exposure and host resistance. There are three main HIV transmission routes:

1. Through unprotected anal or vaginal sex. The presence of another sexually transmitted infection (for example, an active case of herpes or syphilis) can heighten the risk of HIV transmission, as does unprotected sex with someone in the primary (acute) stage of HIV infection or at any stage where there is a high viral load and therefore high levels of viral shedding. HIV is not able to pass through quality latex or polyurethane condoms.
2. Through blood-to-blood contact. This mainly occurs through sharing of injecting equipment amongst drug users. The risk of transmission is high whenever needles and syringes are shared or reused without proper sterilisation. Very rarely, HIV infection can result from an occupational accident amongst healthcare workers. Fortunately, follow-up studies have found that 99.7% of all needle stick or cut exposures do not result in HIV infection. In countries where the blood supply is not screened, transmission has occurred through the use of infected blood and blood products. In the past, infected blood products such as Factor VIII used to treat haemophilia were found to be responsible for causing many HIV infections.
3. Vertical transmission from an HIV-positive mother to her baby while pregnant, giving birth or breast feeding. In the absence of antiretroviral therapy, the average risk of transmission during pregnancy or delivery is in the region of 10 to 15%, although it will be higher if the

mother has primary infection, a high viral load or has developed AIDS. Breastfeeding carries a risk of transmission and should be avoided if alternatives to breastfeeding (including a safe clean water supply) are readily available and affordable.

The United Nations Programme on HIV/AIDS (UNAIDS) reported on global HIV figures in November 2012, ahead of World AIDS Day on 1 December. It said that in 2011, there was an estimated 34 million people living with HIV worldwide. There were an estimated 2.5 million new infections in 2011. It is difficult to know exactly how many people have HIV, as often people do not realise they have been infected and may well live with HIV for some time before they are diagnosed. UNAIDS and the World Health Organisation (WHO) produce figures for the global epidemic and also for individual countries, based on numbers collected by the health services in each country. The Health Protection Agency (HPA) estimated, at the end of 2012, that the total number of people living with HIV in the UK is 96,000.

2.2.2 How has HIV affected the world?

Even before HIV was identified, safer sex and safer drug use had been established as ways of reducing the risk of the illnesses. As the virus spread around the world and deaths began to mount, research into finding a cure or at least a vaccine began in earnest. Drugs were developed, but it became clear that treatment with one drug on its own did work well in the long term. Treatment with two anti-HIV drugs was found to have more benefit, but the real breakthrough came with the development of anti-HIV drugs that worked against the virus in number of different ways. In 1996, triple drug HIV treatment (combination or highly active antiretroviral therapy or HAART) was introduced and this treatment significantly reduced the amount of the virus in the blood and allowed the immune system to strengthen. HARRT reduced the number of AIDS deaths dramatically in countries where the treatment was widely available. However, HIV was still spreading rapidly in some of the world’s poorest countries, especially in southern Africa, and wider access to HIV treatment is only now becoming a reality. The early HIV combinations were difficult to take and many were found to have unpleasant long-term side-effects.

Gradually, more powerful, easier to take and safer drugs became available. As a result of these and other improvements in HIV care, doctors are increasingly hopeful that many people infected with HIV will now be able to live a normal lifespan. Nevertheless, HIV continues to spread and HIV is now firmly established as an important health issue in the 21st century, and one of the most significant causes of illness and death in human history.

Over the past thirty years of the HIV epidemic, many advances have been made in HIV treatment and care, and now HIV is considered as a chronic medical condition rather than the fatal illnesses it once was. People living with HIV are able to live longer, healthier lives. However, stigma remains a significant problem. The stigma associated with living with HIV has to be considered in association with other traits, behaviours and identities that are deemed undesirable. Research has shown that mental health is an important element in HIV and greater attention to this is necessary, at this time of economic uncertainty. HIV requires a multidisciplinary approach, and psychologists from a variety of disciplines have much to contribute.

It may be that many people think that HIV is not a big issue anymore in the UK; that the much talked about and feared plague of death that people were expecting in the very early 1980’s did not happen, and everything is under control. While on the surface this might appear to be the case, this obscures the considerable challenges that many people living with HIV in the UK continue to encounter.

2.2.3 Psychological, social and political challenges

From the early days of the discovery of HIV there have been considerable psychological, social and political challenges associated with living with HIV. From the beginning of the HIV epidemic, the disease has been associated with groups of people who already experienced stigma and felt denigrated by society. Susan Sontag (1991) observed that many of the metaphors associated with HIV and AIDS were often associated with notions of sin and punishment. Before

HIV was identified, it was known as the “gay cancer” or gay-related immune deficiency (GRID). It was constructed as the “gay plague” sent down by God to punish the immorality of “gays” along with prostitutes and drug addicts. Although we have now come a long way since then, there is still prejudice and hostility towards people living with HIV. There have been major advances in understanding how HIV is transmitted and can be prevented. Since the advent of improved medical treatments, HIV has become, for many patients a chronic, manageable illness rather than the death sentence it was once seen to be.

2.2.4 HIV a ‘gay disease’

A controversial view is that HIV is a ‘gay disease'. This view may have come about because transmission is greatest when the carrier of the virus is doing the penetration. This because small tears in the anal epithelium during anal sexual intercourse can occur more easily than is the case with vaginal sexual intercourse. This is based on the assumption that men who have sex with men are more likely to have anal sexual intercourse than men who have sexual intercourse with women and that heterosexuals do not have anal sex. Whilst some people may still believe HIV to be a ‘gay disease’, HIV/AIDS is beginning to lose its association of exclusively affecting men who have sex with men (‘gay AIDS’). However, as the HIV epidemic grew exponentially in poorer regions of the world it became associated with Africa ('African AIDS’). HIV is perhaps the largest public health crisis facing us today. After thirty years of the HIV epidemic and advances in the medical treatment and care of people living with HIV, we might hold the view that everything is under control, at least here in the UK. Whilst, it may be true that the incidence of HIV infection rates in the UK is small, it is still a significant problem, and, unfortunately, has continued to grow. By the end of 2011 there were 96,000 people living with HIV in the UK, of whom an estimated 24 per cent were not aware of being infected (Health Protection Agency, 2012).

2.2.5 HIV testing

HIV testing amongst gay men has become a central issue for research and policy makers because of the benefits offered by the development of anti-retroviral treatments for HIV. For many people, these treatments have transformed HIV from a fatal infection into a chronic disease. In the past, cultural responses to HIV have been characterised by the term 'HIV/AIDS exceptionalism' (Bayer, 1991). This 'exceptionalism' highlighted how political, social and public reactions to HIV infection were often very different to other medical conditions. This 'exceptionalism' comes from both initial state reticence to act upon the emerging AIDS epidemic (Silts, 1978; King, 1993) and, more crucially the initial failure of Western medicine to find a cure or at least effective treatment for HIV. This 'exceptionalism' warranted changes to the way HIV was managed. For example, the design of drug trial, the involvement of affected communities in policy development, the introduction of community-based care for people living and ill with HIV, the promotion of safer sex (Patton, 1990), and AIDS activism (King, 1993). Therefore, public health responses have not followed a traditional infectious disease control model (Shilts, 1987).

However, in recent years there has been a call for a move towards HIV/AIDS normalisation (DeCock and Johnson, 1998). Developments in effective medication, such as highly active retro-viral therapy (HAART) has seen a marked improvement in survival rates compared to previous treatments in the United Kingdom and in North America (CDC update 1997). Furthermore, where new treatments, such as combination therapy or HAART are available they also indicate a change in the management of HIV. However, it is difficult to determine whether there will be a normalisation of HIV distinct from a medicalisation of it as a disease. This medicalisation of HIV infection prevention is apparent in discourses surrounding HIV testing. It is important to note that the literature regarding HIV testing and, in particular, gay men is complex and there are methodological issues to taken into consideration (Beardsell and Coyle, 1996). In North America, HIV testing and counselling services have been seen as 'the cornerstones of US AIDS epidemic prevention strategy' (Mosen et al., 1998). However, in the United

Kingdom HIV testing has not been regarded as central to gay men's HIV prevention work. These international differences are most starkly illustrated in countries where HIV testing is not widely available. These differences are important in relation to HIV testing because they shape the meaning, likelihood and social consequences of HIV diagnosis and the scope of HIV related care. Flowers and Church (2002) reviewed the literature concerning both the levels of HIV testing and gay men's HIV testing decisions. Much of the research literature Flowers and Church (2002) looked at was from before the introduction of new therapies for HIV and also did not take into account the changing face of HIV testing amongst gay men. Other research has tended to focus one the impact that new therapies have had on lives of people living with HIV (Brashers et al., 1998), the influence of being optimistic about treatment outcomes (Kelly et al., 1998) or upon the sexual behaviour of gay men as a whole (Hickson et al., 1998).

Siegel et al. (1989) identified three social constructions of the HIV test which are helpful in understanding current changes in responses to HIV testing. These are described as 'psychosocial', 'public health' and 'medical' constructions. Each construct has its own rationale regarding whether or not to take an HIV test, and this has important implications for how we make sense of the contemporary debate around the policy of HIV testing.

The psychosocial argument surrounding HIV testing relates to the psychological and social consequences of testing and diagnosis. Testing is understood from the perspective of the person being tested and is often conceptualised around a costs and benefit analysis of testing for a given individual at any given time. Flowers (2002) looked at studies conducted before the introduction of HAART and found that for those individuals who tested HIV negative there were positive mental health outcomes (Huggins, 1991; Moulton et al., 1991). However, for those who tested HIV positive they experienced a range of mental health issues (Green et al., 1996). Some of the difficulties experienced by HIV positive gay men were related to the social consequences of having an HIV positive diagnosis, such as, disclosure of their positive status

(Wolitski et al., 1998), having access to social support (Green, 1993) or living with stigma (Charbonneau et al., 1999).

The public health argument affecting HIV testing concerns the epidemiological logic that testing can be beneficial at a population level by identifying and reducing infection. It draws on the collective rather than the individual good (Danziger, 1998). It is further argued that testing on a population level will help reduce risk of becoming infected with HIV (Wenger et al., 1994) and promote safer sex. However, much of the research literature regarding the relationship between HIV testing and sexual behaviour is methodically inadequate and the findings are contradictory (Beardsel, 1994). Other studies seem to suggest that multiple HIV testing is associated with HIV-risk-related behaviour (Dilley et al., 1998; Leaity et al., 2000).
Furthermore, in the United Kingdom, HIV positive test results appear to be linked to periods of celibacy (Beardsell, 1999) or an increase in the frequency of sex with anonymous partners (Keogh et al., 1998).

Since the availability of HAART, the public health argument also promotes the notion that HIV testing will lead to greater numbers of HIV positive individuals seeking access to newer treatments (De Cock and Johnson, 1998). This could potentially lead to an overall decrease in viral load within a population (Goldberg et al., 1998).

Along with the success of newer treatment options, new difficulties have arisen, for example addressing unexpected futures or rebuilding lives based on uncertain foundations (Traenkmann and Ezer, 1998) and also concerns about drug side-effects (Nicholson, 1998). These concerns highlight the complex multiple effects these newer treatments have on HIV positive people. Clinical markers of both individual and public health, may improve with treatment (overall reduction in viral load and population infectivity), but the quality of life for individuals living with HIV may not (Flowers, 2002).

Flowers (2002) states that the salience of the three distinct arguments has changed over the course of the epidemic. In Siegel et al.'s conceptual framework, debates about HIV testing were originally framed around the dialogue between psychosocial and public health discourses, at a time when medical benefits from early HIV diagnoses were somewhat limited and the influence of the medical rationale for HIV testing was minimal. As a consequence, social and personal resistance was framed in terms of the tensions between public health and psychosocial discourses concerning HIV testing. For example, this narrative centred around the politics of testing, the potential for civil rights abuse, the importance of informed consent, breaches of confidentiality and the personal and social consequences of a potential HIV positive diagnosis.

The medical discourse is framed around possible benefits of early detection of HIV. It presents a powerful rationale for the widespread uptake of HIV testing and this medical discourse has also strengthened and changed the public arguments for HIV testing. This shift in relative importance of the medical, public health and psychosocial perspectives presents a challenge for policy makers, HIV organisations and individuals alike wherever HIV testing rates amongst gay men are low. It cannot be denied that the costs and benefits of HIV testing have changed as a consequence of recent medical developments. However, in this era of medical optimism, the psychosocial arguments both for and against HIV testing must not be forgotten. HIV testing occurs within a variety of social contexts. Each of these contexts bring with them the same benefits where treatments are available, but potentially distinct psychological, social and legislative costs. Furthermore, research is needed which examines the prevalence and consequences of HIV-related stigma. Discrimination also needs to be challenged, for example, in terms of employment, health care or further education. In this way, working with organisations and addressing equal opportunities policies relating to HIV testing and HIV positive status, offers a further possibility of reducing the psychosocial costs of HIV testing and HIV positive. Furthermore, the discrimination that affects all people who are thinking about being tested for HIV needs to challenged along with the stigmatising side effects and the impact of taking medication has upon daily life. The decision to take treatment drugs for HIV is often thought of as an individual's choice to made in consultation with their HIV specialist physician's recommendations and expertise. Therefore, attention should be paid to facilitating informed choice around HIV testing focusing upon the medical benefits of early diagnosis in the context of a clear understanding of the possible psychosocial costs involved in the HIV testing process. At the same time, gay specific organisations need to continue to work at challenging the stigmatisation of HIV status both with and beyond the gay community. These organisations should continue to prioritise issues around sexual health for all gay men including those who have not taken the HIV test, those who have tested HIV positive and those who have tested HIV negative.

Managing the complexity of HIV testing decision-making in the context of the new treatments has seen a shift from HIV 'exceptionalism' to HIV 'normalisation'. However, the legitimacy of the term 'normalisation' in this context requires examination. Crucially, what may be central within the current cultural shift may not be a process of HIV 'normalisation', but rather instead HIV 'medicalisation'. Flowers et al. (2001) argue that there is still nothing 'normal' about living with HIV. The notion of HIV 'normalisation' seems somewhat problematic in that current treatments transform HIV from an infectious disease to a chronic manageable rather than providing a cure, as is the case with other sexually transmitted infections like syphilis and gonorrhoea. While an HIV positive diagnosis may no longer be a 'death sentence', the choices HIV positive individuals face may be more accurately described as a 'life sentence', where decisions regarding quality of life, such as, may be more important than clinical markers for health. Furthermore, this has major implications in terms of understanding the contemporary lived experience of having HIV. The experience of individuals suffering from other chronic conditions, for example, diabetes, asthma or heart disease, may begin to present a more appropriate reference group than individuals suffering from infectious diseases per se. HIV has presented health psychology with unique challenges in coming to terms both theoretically and methodologically with the rapidly changing nature of the epidemic. Making sense of gay men's responses to HIV ‘normalisation’ in the era of HAART presents another challenge: that is to identify the complex processes involved in risk perception and decision making where the meanings associated with the threat of HIV infection, disease outcome and treatment options are rapidly changing (Flowers et al., 2001). Flowers et al. (2003) further argue that a number of important psychosocial factors can affect testing decisions. These related to the meaning of testing HIV positive on the gay scene, as assumptions of negative HIV status and negative attitudes to sex with HIV positive men all provide distinct psychosocial costs to testing HIV positive. Indeed, it is factors such as these that increase fear of HIV positive test results. Therefore, it is not much the changing medical aspects of HIV that shape contemporary testing decisions, but the meaning and the social consequence of HIV diagnoses. A way to address this is to challenge the stigma and discrimination associated with being HIV positive through a safety net of anti-discrimination and equal opportunity polices as a key way to reducing the costs associated with testing and diagnosis, thus facilitating access to treatment.

The HIV treatment *‘cascade of care’* envisages *‘treated HIV’* as the end point of a process of sequential care engagements - from HIV testing, to diagnosis, to linkage and access to medication, to retention in treatment - sufficient to bring about viral suppression (Paparini and Rhodes 2016). This cascade creates a framework which provides an overview of key indicators (diagnosed and undiagnosed infections; numbers on or off treatment) and their public health implications, and offers a surveillance grid for monitoring patient dis/engagement through pathways of care. The cascade construct therefore tends to define HIV care (and its success or failure) narrowly in relation to the ultimate benchmark of vital suppression, resulting from patients being sufficiently and appropriately engaged throughout each of its steps.

With treated HIV dependent upon patient engagement, HIV treatment is inevitably a process. Discourses of care cascade imply certain types of patient expectation and responsibility. Additionally, critical perspectives in the social sciences have reflected upon HIV and its care as constituted through situated health practices, identities and subjectivities, with implications for different social and political contexts (Doyal, 2013). Much of this empirical work is qualitative in orientation and has focussed on: experiential accounts of life with HIV often contrasted to 'biomedical' articulations (Davis, Frankis and Flowers, 2006); the 'identity' work involved in reconstructing life around and HIV diagnosis and related treatment (Flowers et al., 2011); the engendered dimensions of HIV and health-seeking behaviours (Doyal, 2009); and the *biopolitical* and *therapeutic citizenship* (Paparini and Rhodes, 2016).

An undetectable HIV viral load in the blood significantly reduces the chances of HIV being transmitted. In the 'treatment-as-prevention' era, measuring HIV viral load to indicate the impact of being on anti-retroviral medication is central to definitions of what constitutes 'HIV health' and also to projecting the trajectory of HIV epidemics.

However, there are three obvious limitations to the cascade concept. Firstly, the narrow focus on viral load progression from detectable to undetectable detracts attention from the broader aspects of HIV as a health and social condition, and not only a virus. 'Treated HIV' represented as a product of the care cascade is blind to the complex of individual and social practices, which situate HIV and its care relative to wider definitions of 'health'. Secondly. viral suppression is not a 'goal' that needs to be reached, but rather a 'state' that must be maintained over time via ongoing systemic care provision coupled with continuous patient re-engagement. Thirdly, by delineating the accomplishment of viral suppression as and for public heath control, the cascade distinguishes success and failure, of services and patients alike, in stark biomedical terms (Paparini and Rhodes, 2016). These biomarkers also shape interpretations of life and self for people living with HIV (Mazanderani and Paparini, 2015).

Social discourses of responsibility emerged from public health framings of the management of HIV risk, as moral counteraction to the negative sanctioning of people with HIV as 'deviant'. Testing, or 'knowing one's status' begins the process for responsible citizens who have taken action. Additional demonstrations of health promoting and responsible behaviours might include abstaining from sex or using condoms, disclosing one’s HIV-positive status to partners, following guidance on ‘positive living’, advocating for those with the same condition, keeping informed, ‘active’ and engaged with healthcare and surrounding issues (Flowers, 2010; Mazanderani and Paparini, 2015). Davis et al. (2006) argue that some patients struggles with the negative aspects of treatment such as intolerance and side-effects, the emotional impact of uncertainty and the ongoing problems of social interaction connected with living with HIV. These are familiar challenges for people living with HIV that can be traced back to the beginning of the epidemic. Uncertainty, and the social challenges of HIV infection, in particular, are themes that have not been erased because of HAART. Instead, the advent of HAART intersects with uncertainty and identity in complex ways. Davis et al. (2006) suggest that diversity among gay men using treatment characterises the post-HAART generation. For example, some people living with HIV want to be actively involved in their HIV care, in keeping with the focus on the relationship or partnership-centred HIV clinical care. Active involvement in treatment is also indicative of the notion that people living wit HIV have resisted and re-deployed medical power, such as by increasing access to treatment and user involvement in both clinical research and practice. Davis et al. (2006) also suggest other HAART users prefer a more traditional relationship with the prescribing clinician, leaving the medical practitioner to make the best decisions. Davis et al. (2006) focused on the different modes of accounting for life with HAART (before treatment; good health; post-illness; loss of confidence) as a way of exploring the interplay of the use of HAART, uncertainty and expectations. Davis et al. (2006) argue that the different modes of HAART identify specific psychosocial support needs of different people living with HIV. The ‘post-illness’ and ‘loss of confidence’ groups may need different types of support which are very different to the needs of those without serious illness or side-effects. McNaught snd Spicer (2000) suggest that there are high levels of psychiatric morbidity amongst gay men. It may especially difficult for such patients as they may not be the main focus for HIV care.

2.2.6 Disclosure of a person’s HIV Positive status

The tension between the need to maintain control over personal information and the moral and ethical obligation to warn others of the potential for HIV-related risk is at the core of the debate concerning the use of criminal law to encourage or punish non-disclosure of an individual’s HIV positive status.

Thinking about disclosing that you are HIV positive can feel like a daunting or even frightening thing to consider having to do. When thinking about disclosing your HIV positive status the two most important things to consider are: who you are going to tell and your motivation for wanting to tell them. Once someone has disclosed their HIV positive status to another person they cannot undisclosed it. A further concern that needs to be thought about is what the person who has been disclosed to will do with that information. How much control does a person infected with HIV have over who might know that have HIV? The issue here is how confidential information is handled by organisations, such as the NHS or a person’s employer, and how this information is both stored and shared.

2.2.7 Practicalities to consider when thinking about disclosure

There are several things to consider when thinking about disclosure. A person living with HIV needs to think carefully about what they are going to say, and how, where and when they are going to make the disclosure. Further considerations are to think about how the other person might react and be prepared to answer questions that they might have about what has been disclosed to them. There is also a conversation to be had around who the person disclosed to can share the disclosure with and how much information can be shared. It is what might happen to the disclosed information once it has been disclosed that causes the most anxiety for individuals living with HIV when they think about disclosing their HIV status. Informing someone you are infected with HIV can trigger a range of reactions and anxieties in the person being disclosed to. For example, the disclosure might tap into prejudices they have about sexuality, illness, disability, race or HIV itself. Sometimes it is difficult for the person making the disclosure to know how to respond to the other person's reaction, particularly if it is hostile. Is it because they are upset or is it because they do not understand? After masking the disclosure some people who are HIV positive feel they have to reassure the person they have made the disclosure to, for example, that HIV is no longer a death sentence. In addition, the person disclosed to might feel under pressure to offer or provide support to the person infected with HIV, but not be able to or know how to.

Disclosing one's HIV positive status to a partner, family and friends can be both a frightening and liberating experience for the person who makes the disclosure and the person disclosed to.

Another dilemma surrounding disclosure for someone living with HIV is whether to inform work colleagues. This is becoming an issue for individuals who are still well enough to remain in employment. Although there is no legal requirement to for someone living with HIV to inform an employer of his or her HIV positive status, an individual might feel under pressure to disclose the reason why they have so many doctor's appointments or why they have had so many days off sick. The Equality Act 2009 makes it illegal for an employer to discriminate against an HIV person in the workplace because of their health status.

Disclosing one's HIV positive status to healthcare professionals is another area of anxiety for individuals living with HIV. It is not just about making the initial disclosure that causes most people lining with HIV anxiety, but what happens to that information once it has been disclosed to the healthcare professional. Major concerns are how is the information being stored and who has access to the information. Concerns about confidentiality of patient information in healthcare settings can have a detrimental impact on HIV testing, and treatment and also reinforce the stigma surrounding HIV.

2.2.8 Criminal transmission of HIV

Criminal transmission of HIV is defined as the intentional or reckless infection of another person with HIV. This term is often used, in laws and discussion, to include criminal exposure to HIV, which does not require the transmission of HIV and often, as in spitting and biting, does not constitute a realistic means of transmission. Some countries or jurisdictions, such as some areas of the United States, have enacted laws to expressly criminalise both exposure and transmission of HIV. This has resulted in some individuals being accused and charged with criminal transmission of HIV when only exposure to HIV has occurred. Other countries, including the United Kingdom, use existing laws relating to murder, manslaughter, attempted murder or assault to charge someone accused of the criminal transmission of HIV.

In the United Kingdom, transmission of HIV may fall under s18, 20, 23, 24 or 47 Offences against the person Act 1861. There have been seven convictions for the sexual transmission of HIV in England and Wales under s.20 of the 1861 Act which criminalises the reckless inflicting of grievous bodily harm on another person. There have been two cases where the defendant pleaded 'not guilty' and the cases where taken to appeal. In the first case, Regina v Dica (Mohammed) [2004] the Court of Appeal ruled that a person was reckless if, knowing that they were HIV positive, they transmitted the virus to a person who had not been informed of the infection. Dica was found guilty and sentenced to 8 years in prison. It was necessary to prove that transmission has involved an assault for the *'inflicting*' of the disease. The Court of Appeal quashed the conviction because the judge had misdirected the jury on the question of consent. However, the Court of Appeal did accept that that transmission of HIV could, in certain circumstances, amount to a criminal offence.

In Regina v Konkani the Court of Appeal ruled that a person recklessly transmitting HIV to another person could only argue the defence of consent in cases where the consent was a *'willing'* or *'conscious*' consent. This means that the Court of Appeal distinguished between *'willingly running the risk of transmission'* and *'willingly consenting to the risk of transmission'*. This suggests that consent could only act as a defence where there had been prior disclosure of known HIV positive status.

In Scotland, in February 2001 Stephen Kelly who was an ex-prisoner and former intravenous drug user, was convicted of the Scots common law offence of *'recklessly injuring'* his former partner by infecting with HIV. A further issue that has arisen is where proof of transmission is required to establish the source of a claimant's HIV infection. Although it cannot provide proof of the route and timing of transmission, phylogenetic analysis has been used in criminal trials to demonstrate how closely related the HIV strains in samples taken from the defendant and the complainant are.

It is important to stress that prosecutions for the transmission of HIV are extremely rare. There have been none in Scotland since Stephen Kelly's conviction in 2001 although there have been two further convictions in England since the Dica case. In the quashing of the conviction in the Dica case, the Court of Appeal ruled that, where a person chooses to consent to the risk of HIV transmission that is that they know their sexual partner is infected with HIV and they choose to have unprotected sexual intercourse, then that would be a valid defence to a criminal prosecution. Where it becomes more complicated is when the consenting partner actually wants to become infected with HIV and the other party had intended this to happen. In this scenario consent would not be accepted as a defence on the grounds that someone would not consent to act that they know would result in them being harming.

Further questions arise surrounding what happens if condoms are used or high risk activities are avoided. What happens if someone who is HIV positive does not disclose their HIV status to their sexual partner, but although they use condoms, their partner still becomes infected with HIV? In the Court of Appeal ruling regarding the Dica case it could be argued that using condoms might mean that the HIV positive person could not be said to have acted '*recklessly'* and therefore would not have intended to infect their sexual partner. Likewise, if the parties concerned abstain from high risk sexual activities, again *'recklessness'* would be present.

All the prosecutions to date seem to have involved allegations of deception on the part of the persons prosecuted, such as a false claim that they had tested HIV negative, rather than a failure by someone to disclose their HIV positive status. The offence is not limited to HIV as it could equally be applied to any sexually transmitted infection which could be considered as amounting to *'grievous bodily harm'.*

These rulings have important implications for people living with HIV when it comes to deciding whether or not to disclose their HIV positive status to other people. Given, that in the legal cases mentioned above, consent is deemed a valid defence, it seems fair to say that the Dica case effectively places a legal duty on HIV positive individuals to disclose their HIV status before engaging in high risk sexual activities.

2.2.9 Stigma

Early government and media scare tactics such as the United Kingdom's *'Don't Die of Ignorance (1987)* public health campaign, and the fear it triggered in the general public, helped to form HIV-related stigma that has continued through the epidemic, particularly towards certain groups. As soon as scientists identified HIV, responses of fear, denial and stigma have been present (AVERT, 2017). The World Health Organisation (WHO) in 2001 estimated that 25 percent of the worldwide population was affected by a mental or behavioural disorder at some time in their lives. This issue is thought to contribute to 12 percent of the worldwide burden of disease and projected to increase 15 percent by 2020 (Hugo, Boshoff, Traut, Zungu-Dirwayi and Stein, 2003). Further research has shown that individuals who are in need of care often do not engage with services and those who do initially seek help frequently do not complete the recommended treatment (Corrigan, 2004). It has been estimated that less than 40 percent of individuals experiencing severe mental illness receive consistent mental health treatment throughout the year (Kessler, Berglund, Bruce, Koch, Laska, Leaf, et al, 2001). Why might this be the case? There are several potential reasons why there is lack of participation in treatment. One likely explanation is that individuals suffering from mental health conditions are so disabled by their conditions that they are not able to seek treatment. Another explanation is that many individuals experiencing mental health issues are not able to identify that they have issues that require treatment. However, there is another explanation that has been identified in the research literature. Both the U.S. Surgeon General (1999) and the WHO (2001) have identified stigma as a barrier to successful engagement in treatment. Stigma can also prevent seeking and sustaining participation in appropriate services.

To understand how stigma might prevent individuals who are in need of treatment for mental health, behavioural and medical conditions seeking treatment it is necessary to examine the definitions and dimensions of stigma. Stigma can be experienced on numerous levels. There is social stigma, self-stigma, stigma by association and health professional stigma.

Stigma is defined as “an attribute that is deeply discrediting” that reduces a person “from a whole and usual person to a tainted, discounted one” (Goffman, 1963: p.3). An individual who is stigmatised is perceived as having a “spoiled identity” (Goffman, 1963: p.3). Dudley (2000) further defined stigma as stereotypes or negative views attributed to an individual or group when their characteristics or behaviours are perceived as different from or inferior to societal norms. This definition, which is derived from social work literature provides a vantage point from which to develop an understanding of stigma. Most conceptualisations of stigma focus how individuals from a variety of backgrounds, including race, ethnicity, gender and sexual orientation are discriminated against by others. However, these conceptualisations do not specifically focus on the impact of stigma on mental health. Therefore, is necessary to establish a definition of mental disorders so that its relationship to stigma can be better understood. The Diagnostic and Statistical Manual of Mental Disorders 5 ([DSM-5]; American Psychiatric Association [APA], 2013) defines mental disorder as a '*clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that associated with present distress or disability or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom'* which comes from *'a manifestation of a behavioral, psychological or biological dysfunction in the individ*ual' (APA, 2013, p: xxxi). This definition can also be used to form the basis of how stigma impacts on the lives of people living with HIV through exploring the underlying constructs that constitute the concept of stigma.

Jones et al. (1984) identified six dimensions of stigma. These include concealability, course, disruptiveness, peril, origin, and aesthetics (Feldman and Crandall, 2007; Jones et al., 1984). In addition Corrigan et al. (2001; 2000) identified stability, controllability and pity as further dimensions. These dimensions can present independently or simultaneously in the creation of stigma. Furthermore, stigma is more than simply a combination of these elements impacting on each person as an individual because stigma is believed to be widespread in the structure of society (Feldman and Crandall, 2007).

The first of dimension of stigma is peril or dangerousness. This considered an important aspect in the development of stigma because it is how the general public perceives others. In the case of people living with HIV/AIDS they are perceived as being dangerous because HIV can be transmitted to other people through sexual contact or contaminated blood products. Corrigan

(2004) also argues that fear and discomfort arise as a consequence of the social cues attributed to individuals. Social cues include psychiatric symptoms, changes in physical appearance and through labels (Corrigan, Markowitz, Watson, Rowan and Kubiak, 2003). In the early days of people living with HIV changes in physical appearance, such as lipodystrophy, were particularly distressing and stigmatising. This also highlights the role of aesthetics or the displeasing nature of the condition (Jones et al., 1984). When society attributes to a person or group behaviours that do not adhere to the expected societal norm discomfort may be experienced. This often leads to labelling and avoidance of the identified individual or group. Certain characteristics such as being gay can be generalised to being an identifying characteristic of people who are most likely to be infected with HIV and, therefore, other groups such as heterosexual men and women are less likely to be perceived as being at risk of being infected with HIV. This has further increased the likelihood of certain groups, such as men being demonised and blamed for having and spreading HIV.

Another dimension relating to stigma is origin. This is particularly relevant in the case of HIV where the origins of HIV are hotly debated and certain groups of people and particular parts of the world have been identified as being the most likely origins of HIV.

Controllability can also lead to certain individuals or groups becoming stigmatised because they are perceived as being responsible for their condition or behaviour and, therefore, they are to blame not only for becoming infected with HIV, but also for the continuing spread of HIV within the general population (Corrigan, et al., 2001). There is more sympathy for individuals suffering from conditions that are perceived as less controllable (Corrigan, et al., 2001).

Concealability or visibility of the illness is a dimension of stigma that parallels controllability, but also provides further insight into stigmatisation. Crocker (1996) argues that stigmatised attributes such as race can be readily identified, and less concealable which allows society to discriminate and stigmatise on the grounds of the visibility of the individual. This conclusion is supported by research which found that society attributes more stigmatising stereotypes towards like such as schizophrenia which have more visible symptoms than other disorders such anxiety or depression (Angermeyer and Matschinger, 2005; Lundberg, et al., 2007). One of the most visible signs of HIV is lipodystrophy which can include a buildup or loss of body fat or both. Since the widespread use of antiretroviral therapy, HIV, lipodystrophy occurs in 30 to 50 percent of people infected with HIV.

Course and stability refer to how likely someone living with a disability is to recover and/or benefit from treatment (Corrigan, et al., 2001). The dimension of disruptiveness assesses how much a disorder or disability may impact on relationships or success in society. While disorders and disabilities are often to be associated with an increased of poverty, lower socioeconomic status and lower levers of education (Kohn, Dohrenwend and Mirotznik, 1998), the stability and disruptiveness of the conditions have implications as to whether someone will be able to get and maintain employment and engage in healthy relationships, as evidenced by the differences in stigma based on social class status. This suggests that where disorders are less disruptive, in which case they may be perceived as being more stable, they are also less stigmatised (Corrigan, et al., 2001).

There are three main types of stigma: social stigma, self-stigma, stigma by association and health professionals stigma.

2.2.10 Social Stigma

Social Stigma is structural in society and may create barriers for individuals with a mental or behavioural disorders. Structural implies that stigma is a belief held by a large faction of society in which persons with stigmatised conditions are less equal or are part of an inferior group. Stigma is embedded in the social framework and creates inferiority. This form of stigma may result in unequal access to treatment provision or the creation of policies which disproportionately and differentially affect the population. Social stigma can also result in further disparities in an individual's ability to access basic services and needs.

Researchers in social psychology have suggested that here are three specific models of public stigmatisation. The socio-cultural model suggests that stigma forms a justification and rationalisation for social injustices (Crocker and Lutsky, 1986). An example of this might be that individuals suffering with mental and behavioural disorders are identified and labelled as unequal. The motivational model emphasises the importance of the basic psychological needs of the individual (Crocker and Lutsky, 1986). An example might be that since people with mental health or behavioural problems are often in lower socio-economic groups, they are also perceived as inferior. The social cognitive model tries to make sense of basic society by using a cognitive framework (Corrigan, 1998). A person identified as having a mental illness would be given a label, placed in a category and differentiated from individuals not suffering from a mental illness.

Psychologists tend to favour the social cognitive model to explain and understand stigma (Corrigan, et al., 2001). One perspective that is derived from this understanding is Attribution Theory and is related to three specific dimensions of stigma, which are stability, controllability and pity (Corrigan, et al., 2001). A study found that the general public often stigmatises mental and behavioural conditions to a greater extent than physical conditions (Corrigan, et al. 2001).

2.2.11 Self Stigma

Stigma is not only held among others in society, but can also be internalised by the person with the condition (Crocker, 1999). Moreover, the continued impact of social and public stigma can influence an individual to experience guilt and feel inadequate about their condition (Corrigan, 20004). Collective representations of meanings in society, such as, shared values, beliefs and ideologies can act in place of direct social and public stigma in these situations (Crocker and

Quinn, 2002). Therefore, in self-stigma, the knowledge that stigma is present within society, can have an impact on an individual even if that same individual has not already experienced being directly stigmatised. This can also have a serious negative impact on an individual's self-esteem, and self-efficacy, which in turn may lead to changes in how that person behaves (Corrigan, 2007). However, Crocker (1999) argues that individuals may internalise stigma differently according to their situations and this suggests that personal self-esteem may or may not be as affected by stigma depending on the application of coping mechanisms (Crocker and Major, 1989).

Other theories have provided further insights into self-stigma. For example, labelling theory argues that the expectation of becoming stigmatised, in addition to actually becoming stigmatised, can be factors that influence psychosocial wellbeing (Link, Cullen, Straining, Shrout and Dohrenwend, 1989). A study by Weiner (1995) found that stigmatised beliefs can provoke an emotional response. For example, an individual who feels stigmatised may react with shame, anger or feel marginalised by society.

2.2.12 Stigma by association

In addition to research to research that has sought to understand the impact of stigma on those living with HIV, there has also been research conducted into how stigma might impact on those associated with individuals living with HIV. Goffman (1963) refers to stigma by association as *'courtesy stigma'*. He described two types of person that could be affected in this way.

Firstly, individuals who share a special, often familial bond, relationship with the stigmatised person, such as spouses and children. Secondly, those working in an environment that caters for the needs of the stigmatised individual. HIV-related courtesy stigma has been explored amongst those who might constitute informal care-providing networks, for example family, friends and significant others who often provide care and support to individuals living with

HIV. Research has shown that some care providers, specifically family members and significant others, may sometimes experience stigma that can often result in complex social interactions with others in their lives and this can result in them withdrawing socially and avoiding any discussion of HIV (Thomas, 2006). Stigma by association also leads to social isolation and a loss of social support, both of which can be linked to poor physical and psychological outcomes (Corrigan and Miller, 2004; Thomas, 2006). In addition, stigma by association may have a negative impact on relationships with family and friends. This can result in feelings of shame arising in other family members and them not wanting to discuss the topic with the person affected. Another characteristic of stigma by association is the fear of *'being known by the company we keep'* (Kulik et al., 2008). Kulik et al. (2008) stated that in a work environment, employees who associated with a stigmatised work colleague were more likely to be regarded negatively. Physical proximity may be enough to link the two individuals in the mind of another which in turn results in that person making a negative evaluation of both the stigmatised person and those who associate with them.

2.2.13 Stigma by Health Professionals

In one study involving psychiatrists, nurses and psychologists found that health professionals did not differ from the general public on their desired social distance from individuals with mental health conditions (Nordt, Rössler, and Lauber, 2009). Other studies have down similar conclusions (Lauber, et. al, 2006; Tummala and Roberts, 2008; Sriram and Jabbarpour, 2005). Clients have also described how they have felt 'labeled' and 'marginalised' by health professionals (Liggins and Hatcher, 2005).

2.2.14 HIV as a chronic condition

In June 1989, Samuel Broder, the then head of the National Cancer Institute, declared in a speech at the international AIDS meeting in Montreal, Quebec, that AIDS was a chronic disease and that treatment should follow the model of cancer (ref). This public statement marked a shift in the social definition of AIDS from an acute to a chronic illness, a shift with economic and cultural repercussions for the treatment and understanding of AIDS at the national, local and individual levels (Fee, Fox, 1992). However, it was not until the advent of protease inhibitors in 1996, which ushered in the era of highly active antiretroviral therapy (HAART), that the view of HIV/AIDS as a chronic illness became widely accepted. These medications were often described by the mass media as 'miraculous' because they reduced the risk of opportunistic infections and extended survival rates by suppressing viral replication and boosting CD4 counts. The availability of HAART was said to have given hope back to patients infected with HIV for the first time in over a decade of treatment (Kobayashi, 1997) and offered those infected with HIV a 'second life' (Rabkin and Ferrando, 1997).

While in the Western world recent treatment advances have had a profound effect both on the illness trajectory and the life expectancy of many infected individuals (Centers for Disease Control, 1997). AIDs-related mortality is still an issue in parts of the world where access to the newer medications is limited. The prohibitively high cost of antiretrovirals coupled with inadequate and inefficient health delivery systems have enable AIDS to reach catastrophic levels in many developing countries (UNAIDS and WHO, 2001).

Even in North America not all those infected with HIV have access to or choose to take the new treatments. Some doctors are less likely to prescribe HAART to patients they assume to be at risk of low adherence, such as those with a history of drug abuse, the homeless and the mentally ill (Bassetti, Battegay, Furrer, et al, 1999; Maisels, Sternberg, Tobias, 2001; Gerbert, Bronstone, Clannon, Abercrombie, Bangsberg, 2000), although the evidence supporting these views remains inconclusive (Chesney, Ickovics, Hecht, Sikipia, Rabkin, 1999; Fogarty, Roter, Larson, Burke, Gillespie, levy, 2002). Further research indicated that women, African-Americans and those with low levels of education are less likely to have ever tried the new medications (Cook, Cohen, Grey, et al, 2002; Jacobson, Gore, Strathdee, Phair, Riddler, Detels, 2001). These finding have been attributed not only to a lack of access to HIV medication amongst these socio-economically disadvantaged groups, but also to their own reluctance to take these more effective medications due to factors such as fear of adverse side-effects and a general distrust of doctors.

2.2.15 What is a chronic illness?

Chronic illnesses are typically incurable and, therefore, the goals of medical care take the form of containment, slowing disease progression and symptom management rather cure. Chronic diseases tend to share a variety of characteristics (Cordin, Strauss, 1991; Royer, 1998). Frequently, they have an uncertain disease trajectory which is often characterised by alternating periods of remission and relapse, or stable periods interrupted by episodic outbreaks of symptoms (Lubkin, Larsen, 2002). Most require adherence to a treatment regimen, although these are likely to differ significantly across different diseases both in complexity and efficacy. Chronic diseases often require considerable self-care, such as self-monitoring of symptoms on the patient's part, because much of the daily management of chronic illnesses occur outside health institutions or medical facilities. As illness could be described as a form of deviance, it is an undesirable state and carries a degree of stigma. However, this stigma can vary greatly and depends on a variety of factors, for example, whether the individual is deemed responsible for having acquired the illness, whether the illness is contagious and whether there is visible disfigurement. Lastly, chronic diseases often bring about identity changes as the patient attempts to integrate the illness into his or her life and self-perception in the long term. Psychological distress is often experienced by individuals living with chronic conditions, because of the inherent uncertainty which is common to many of these illnesses. Each of these aspects of living with a chronic illness pose an adaptive challenge to the individual. These challenges include tolerating uncertainty, managing stigma, and adhering to treatment regimens. How well a chronically ill individual adapts to his or her disease will depend to a large extent on his or her ability to master, or at least successfully manage, these tasks.

While available treatments can render a patient's viral load undetectable, HIV cannot be fully eradicated from the body and, left untreated, the viral load will rebound. Consequently, there is no cure for HIV. Also while the natural history of the disease has been delineated, the course of HIV disease progression varies considerably amongst individuals (Hogan, Hammer, 2001). Furthermore, the drug treatments for HIV are not equally effective for all patients (Friedland, Williams, 1999). It is also recognised that living with HV can have a profound impact on intimate and social relationships. The fact that the disease can be transmitted through sexual behaviours renders intimate relationships fraught with anxiety and ambivalence. Infected adults often feel that others unwilling to enter into long term relationships with them for fear of having to assume care-giving responsibilities when the disease progresses. In addition, self-care is a component of living with HIV. Many patients engage in self-initiated strategies, for example diet, relaxation exercises, stress avoidance, which are aimed at managing illness or treatment-related symptoms, boosting their immune system, or reducing stress.

Davis et al. (2006) argue that a type of post-HAART fatalism has begun to emerge as a way of defining the limits of personal responsibility. This fatalism can be characterised as a failure of the reflexive self, in the form of giving up. They further argue that fate has value for patients because it give a freedom to exist without blame. Chronic illness self-management discourse is often critiqued because it mobilises moral judgement of those who are seen to fail to act to care for themselves in a responsible manner. In this discourse, fatalism is regarded as a type of denial or failure of reflexivity. Davis et al. (2006) state that the chronic illness discourse can be overly blaming, particularly where a lack of reflexivity could be also understood as an act of freedom. People living with HIV need to be free to settle on fatalism as way of existing within the limits of HIV treatment.

2.2.16 Pre-exposure prophylaxis (PrEP)

Pre-exposure prophylaxis (PrEP) is the preemptive use of drugs to prevent disease in individuals who have not yet been exposed to the disease-causing agent. More specifically, the term is used to refer to the use of anti-retroviral drugs that interrupt the life cycle of HIV as a strategy for the prevention of HIV infection. PrEP is an optional treatment which may be taken by individuals who are HIV negative, but who have a substantial, higher than average risk of contracting HIV infection.

Currently, the only drug which any health organisation recommends for HIV/AIDS PrEP is Truvada, which is a combination of tenofovir and emtricitabine. The Centers for Disease (CDC) says that PrEP is a powerful HIV prevention tool can be combined with condoms and other preventative measures to provide even greater protection than when used alone'. However, individuals who are given PrEP must commit to taking the drug every day and seeing his or her health care provider for follow-up checks every three months (CDC, 2014).

2.2.17 Approval for use

The CDC's HIV prevention guidelines were amended on 14 May 2014. It was recommended that PrEP be administered to high infection risk populations due to research indicating that PrEP effectively prevented transmission from mother to child (15). Prior to that date PrEP was only approved to treat existing HIV infections (CDC, 2015) In 2012, the World Health Organisation (WHO) issued PrEP guidelines which stated that PrEP may be considered as possible additional HIV prevention intervention for the uninfected partner in couples where one partner is HIV-positive and when additional HIV prevention choices for them are required (WHO, 2012;). The WHO made similar recommendations for men and transgender women who have sex with men. It was further stated that international scientific consensus is emerging that antiretroviral medication, including PrEP, significantly reduce the sexual acquisition and transmission of HIV regardless of population or setting (WHO, 2012; 8 10 11). Also in 2014, on the basis of further evidence, the WHO updated their recommendation for men who have sex with men to state that PrEP is to be recommended as an additional HIV prevention choice within a comprehensive HIV prevention package (WHO, 2014; Celum, 2011). This advice by the WHO was expanded, on the basis of more evidence, and stated that it had broadened the recommendation and advice to include all population groups at substantial risk of HIV infection. The WHO emphasised that PrEP should be an additional prevention measure in an already comprehensive package of services (WHO, 2014).

The IPERGAY study (Molina et al, 2015) investigated the efficacy of an alternative strategy of 'on-demand' PrEP where Truvada was taken between two to twenty-four hours before sexual activity and only continued for two days afterwards. In a clinical population of gay men in France and Canada at hight risk of becoming infected with HIV, this strategy lead to a drop of 86% in HIV infections over the average nine month followup in the study. As of December 2015 non-continuous PrEP methods have not been endorsed by WHO or national guidelines (United States Public Health, 2014; WHO, 20150.

Moves towards the widespread adoption and acceptance of PrEP has proved divisive, politically, and within gay culture. It has lead to a perception in some quarters that PrEP is likely to be misused, and undermine existing safer sex policies (McNeil, 2014).

Young et al. (2015) identified how deeply entrenched forms of HIV-stigma and homophobia can shape and obfuscate the consumption of PrEP. Furthermore, rather than seeing PrEP as liberating through reduced levels of infectiousness or risk of transmission, social and legal requirements of responsibility in relation to HIV risk reinforced unequal forms of biomedical self-governance. The research of Young et al. (2015) also highlights how responses to PrEP are grounded not solely in an expert/lay divide or economic inequalities per se, but in a sero-divide that is perpetuated through the emergent dividing practices of the very biomedical practices themselves. The uneven patterning of biomedicalisation is amplified by and further manifested in the nexus of traditional lines of inequalities such as sexual identity, ethnicity, migration/mobility, gender and geography. Young et al. (2015) suggest there is a potentially growing gulf between HIV-positive and HIV-negative communities in terms of health expectations and experiences of negotiating biomedical prevention. It also raises a number of questions about what equitable and fair HIV prevention looks like, how this might manifest across diverse communities and who is or will be implicated in the increasingly biomedical moral imperative to prevent HIV.

Key messages from Public Health England in 2019 were:
Providers of HIV care should encourage timely treatment initiation for people living with HIV. The number and proportion of people who begin taking HIV medication and achieve viral suppression promptly is increasing, but further work is needed to achieve equity between population sub-groups. As undiagnosed HIV infections become rarer, strengthening the delivery of Partner Notification is essential to ending HIV transmission by 2030 (PHE 2019).

2.3 HIV/AIDS as a research topic

HIV/AIDS is a topic that has been greatly discussed and researched due to its' impact on human beings. My research will attempt to investigate some of the psychological manifestations of living with HIV/AIDS using a qualitative methodology, but first I need to discuss some of the research that has been conducted using both quantitative and qualitative methodologies.

2.3.1 The impact of HIV infection on a person's quality of life

Some studies have attempted to measure the impact HIV-infection has on a person's quality of life. For example Cleary et al. (1993) and de Boer et al. (1995) used multidimensional self-report questionnaires to measure how HIV-infected patients evaluated their health-related quality-of-life. The findings from these studies could not be generalised to other HIV-infected populations such as women, children, intravenous drug users and patients from Africa and other developing countries.

It is a widely held, although largely unexamined, assumption that the experience of living with HIV in the era of HAART is significantly less distressing compared to the past because of the prospects for extended survival and enhanced quality of life offered by the new and effective treatments. One empirical study by Rabkin et al (1997) followed a group of gay and bisexual men with symptomatic illness over a period of time which included before and after the availability of protease inhibitors. Findings from this study showed a statistically significant, although clinically modest, decrease in psychological distress. However, when the researchers further compared subjects whose status on medical markers had either improved or not improved, no significant differences in either a decrease of hopelessness or an improvement in quality of life were found.

Another study (Low-Beer, Chan, Yip, et al. 2000) which looked at changes in depressive symptomatology looked at 456 HIV-positive individuals (433) receiving HAART. These men were asked to complete a self-administered questionnaire annually. All participants had completed at least one survey before and after receiving treatment. The researchers found that, between assessment points, the percentage of individuals with a score indicative of probable clinical depression declined from 52% to 46%. Whilst this decrease may not be statistically significant, there were improvements in the total score of the Center for Epidemiological Studies-Depression scale, as well as on the depressive mood, positive affect and somatic sub scales.

Furthermore, a study (Judd, Cockram, Komiti, Mijch, Bell, 2000) which investigated changes in depressive symptomatology amongst 125 HIV-positive adults (mostly gay/bisexual males) assessed at six-monthly intervals over a two year period were examined. In this study the researchers found a pattern of declining scores on the Beck Depression Inventory over time. This was especially the case after the third assessment (12 months after the baseline scores was taken) when 51% of participants were on HAART. However, there was a substantial drop out of participants before the six-month assessment, and the number of cases included at each assessment varied. It would seem from the evidence on whether living with HIV is less psychologically stressful and distressing since the availability of HAART remains inconclusive. If this were to be ultimately shown to be the case this could have implications for much needed mental health services. Catalan et al. (Catalan, Meadows, Douzenis, 2000) suggests that as AIDS becomes a more manageable disease there will be a decreased need for acute mental services, such as psychiatric hospitalisation and crisis management, and greater need for interventions assisting individuals in making the long term adjustment to chronic psychosocial stressors over the course of his or her lifetime. Whilst this may be true for gay and bisexual men and drug users who can remember the bleaker prospects of HIV infected individuals living in the pre-HAART era, the need for acute psychiatric services may increase amongst more recently impacted clinical populations, such as infected adults living in rural areas, heterosexual women without a history of drug abuse and adolescences.

2.3.2 Experience of and response to stigma

Another area of research has focussed on how HIV-infected people experience and respond to being stigmatised. Taylor (2001) explored individual concepts of health and the role of stigma in coping with HIV-infection. It was found that as a social construct stigma had a significant impact on the life experiences of people both infected and affected by HIV. Thomas et al. (2005) investigated the nature and intensity of the AIDS stigma by examining how it is shaped by the social construction of the epidemic in different cultures. It was found that the actual stigma experienced among those with HIV was much less (26%) compared with (97%) who felt in fear of being stigmatised. Internalising stigma was found to have a highly significant negative correlation on quality of life. However, those individuals who did experience actual stigma seemed more determined to live and experience a better quality of life. Therefore, people with HIV need to rise above stigma, avoid internalising their stigmatised feelings and work towards a better quality of life. How this might be possible is not clear. It seems to me that further research needs to be done into what enables some people with HIV to cope better than others with a view to perhaps identifying and developing coping strategies that could be taught to individuals less able to cope with stigma. A way of doing this might be to explore the beliefs and assumptions held by individuals with good coping skills and how these differ from those with poor coping skills. For example, Barroso (1996) studied how the attitudes of long-term AIDS survivors enabled them to focus on living by planning for the future, and the importance of having a focus for one's energies. Lechner et al. (2003) found that cognitive-behavioural interventions improved the quality of life in women with AIDS by providing stress-management/supportive group therapy. Similar studies by Chesney and Folkman (1994) and Lutgendorf et al. (1998) provide similar evidence.

2.3.3 Hope, despair and hopelessness

Kylma et al. (2001) studied hope, despair and hopelessness in individuals living with HIV/AIDS. 10 HIV positive people were interviewed and the transcripts were analysed using a grounded theory methodology. It was discovered that the dynamics of hope were a multifaceted and complex combination of 'hope', 'despair' and 'hopelessness'. These factors contributed to a 'folding' and 'unfolding' of possibilities in everyday life. Further research by Kylma (2005) confirmed the findings above. Although both these studies investigate an individual's lived experience, these do so by identifying specific emotional responses to HIV infection. In this way respondents might have felt unable to respond in ways that did not reflect the researchers' assumptions as to what they were experiencing. Purnell (1996) examined the relevance of attachment theory in the provision of psychological support to people affected by HIV. Themes of change, loss and vulnerability were identified as being central to the issues confronted by this client group. Examples of a variety of attachment-related behavioural responses which can be activated by these conditions are given along with illustrations of how activation of attachment behaviour can destabilise the relationships of some clients that are anxiously attached. The notion of a secure base, developed by John Bowlby (1988), is presented as being a necessary provision by the therapist in work with clients affected by HIV. An example of this is expressed by Sullivan (1997) in an article for The Sunday Review which examined his personal experience of living with HIV and how his relationship to the disease had changed over time. In particular he identified how his relationship to his own mortality has changed since testing positive. Yalom (1980) identified significant anxieties relating to the four existential concerns of Death, Isolation, Meaningless and Freedom as being particularly relevant to psychotherapy when HIV is a consideration.

2.4 Rationale of the current research

In the brief summary of some of the relevant literature I have presented above it can be seen that much of the research explores the phenomenon of being HIV positive from a medical perspective. For example, how an individual might cope with the symptoms of having HIV or by measuring their quality of life in terms of the quality of their health. Many of these studies also used quantitative research methodologies to analyse the data and these do not give any information about how individuals made sense of their experience of being infected with HIV. However, other studies attempted to examine the lived experience of someone who is infected with HIV by using a variety of qualitative research methodologies. The weakness of these studies is that they made assumptions about what individuals were experiencing. For example, hope, despair and stigma were themes which individuals were asked to comment on in their research interviews. What I feel is lacking is research that explores the lived experience of being HIV-positive by simply asking the question: ‘What is it like to be diagnosed HIV-positive?’ This might appear to be naïve, but in my experience of working in the field of HIV it is the one question very few people bother to ask. The preoccupation of most HIV workers seems to be focussed on health-related issues e.g. CD4 T-cell counts and viral-loads, medication and their side-effects. It seems to me that the person disappears and all that is left is a diagnosis and accompanying symptoms. Therefore, in my research I want to address this imbalance by putting the person before the diagnosis. In other words I want to give a voice to the person with HIV and not continue to provide a voice only for HIV.

2.5 Reflexive process

This research topic is something I have previously written about by presenting a case of my own (Palamountain, 2011), so there is no question I held a fairly established view when I began this research process. I am also a practicing existential psychotherapist and trainee existential counselling psychologist who is acutely aware of the drive and appetite for evidence-based practice in our profession.

I have been working with individuals infected with the Human Immunodeficiency Virus (HIV) since 1995. Over the years I have witnessed significant changes to the way HIV is understood and conceptualised as a disease. When HIV was first identified as a disease in 1983 it was seen as life-threatening terminal illness which resulted in the infected person developing Acquired Immune Deficiency Syndrome (AIDS). This is where the immune system becomes compromised and subsequently damaged by opportunistic infections eventually leading to premature death. At that time there was little that could be done once a person became infected with HIV. Often the progression to full-blown AIDS was alarmingly rapid. Doctors were helpless to do anything in the fight against the spread of HIV/AIDS.

In June 1989, Samuel Barber, head of the National Cancer Institute, declared at the international AIDS meeting in Montreal, Quebec, that AIDS was a chronic illness and that treatment should follow the model of cancer. Although this public statement marked a shift in the social definition of AIDS from acute to chronic illness, it did little to change the perception of people who were living with HIV. For them testing positive to HIV infection was still a death sentence because once a person got sick with an AIDS defining infection there was no treatment available to slow the inevitable progression of the disease. The medical profession has been playing catch-up ever since the beginning of the AIDS crisis. Over time there has medical advances and breakthroughs in the fight against HIV/AIDS to the extent that there are more people living longer with HIV and new infection rates are on the decrease. New drug treatments are being introduced all the time and so at last it is possible to say that having HIV is no longer the death sentence it once was. However, this is not the whole story for someone infected with HIV. There may be numerous treatment options available which enable people with HIV to remain healthier for far longer, but this does not take into account the impact living with HIV has on a person's psychological wellbeing. John, one of client's told me what happened recently when he went to get his latest test results from his HIV consultant. The consultant told John that his CD4 count was 750 and his viral load was undetectable. The consultant was delighted to be able to inform John that he was "the picture of health". John replied "if that's the case, then why do I feel s**t most of the time?" John's experience is far from unique. There appears to be a discrepancy between how the medical profession defines health and how a patient might experience his or her condition. It seems to me that the primary concerns of the clinicians treating patients with HIV are reducing the viral load to undetectable and boosting the immune system. From a medical perspective this makes perfect sense, however, the person living with HIV is more that a cluster of symptoms. They are emotional beings living in a world with others. What is the day-to-day experience of people living with HIV? How does having HIV impact on a person's emotional and psychological health? It is these quality of life issues which seem to be overlooked by many HIV clinicians, particularly now that HIV is seen as being a long-term chronic condition managed by anti-retroviral drugs. Many of the patients living with HIV that I see for counselling express concerns about not feeling heard and understood by their HIV consultants. They have also spoken to me about their experiences of attempting to get psychological support through their HIV clinics. A number of HIV clinics are reducing access to HIV specific psychological services. One clinic no longer has any psychologists working there. So, in many cases, if a patient needs emotional support they either have to go to a generic counselling service or get help from an HIV Charity. Over the years I have provided both one-to-one and group counselling to people attending HIV Charities.

Working with these clients taught me the importance of 'being with and being for the client' instead of using techniques or theories. Spinelli (1994) places the emphasis on *being* and *not doing* in therapy. When I am with my clients I need to focus on being with and being for my clients. In *'being with the client',* as a counselling psychologist I need to attempt to stay with the experienced truths of the client as they are being related in order that they and whatever implications these truths might hold, may be exposed to further examination and clarification by both the counselling psychologist and the client (Spinelli, 1994). *'Being for'* the client reminds me that as a counselling psychologist, within the confines of each sessional encounter, I am there to attempt to *'enter'* the client's experiential world with the sole intention of allowing the client a specific form of encounter with another who seeks to be the self (Spinelli, 1994). A number of common themes have been expressed by the people living with HIV that have seen me for counselling. Although HIV may now be considered by the medical profession as a long-term chronic condition no different from cancer or diabetes, for someone living with HIV it is not the same. Someone with cancer or diabetes can talk openly about having the disease and can rely on getting a sympathetic reaction from other people. The same cannot be said about other people's reaction to someone disclosing the fact that they have HIV. Having HIV is highly stigmatising and most people with HIV find themselves having to lead a double life. They cannot be open about having HIV. There is a constant anxiety about being found out for having HIV. People with HIV feel shunned and rejected by others in society. The psychological services that are offered within the NHS they are often part of a generic service. Again, this type of service is not the most appropriate for people living with HIV because having HIV is not like having any other medical condition. As a counsellor to people with HIV I found myself needing to learn about the medical aspects of HIV such as how anti-retro viral medications affect the body and the brain. These medications are highly toxic and many people experience side-effects which often require additional treatment. Common side-effects are fatty liver disease, coronary artery disease, lypodystrophy, peripheral neuropathy, sleep disorders and cognitive impairments. It could be argued that as a counselling psychologist I should not be concerning myself with an individual's medical treatment and only explore with them their psychological experience. I do not believe it is possible to make this distinction between the medical and psychological when it comes to treating someone living with HIV because both the illness and the anti-retroviral drug treatments have a significant impact on a person's physical and psychological well-being. The two are inseparable and so it is necessary to adopt a holistic approach to counselling individuals living with HIV. People living with HIV, who are long-term survivors, often feel disenfranchised and feel that they have become invisible. They feel they do not have a voice. This could be because the emphasis is now on prevention of the spread of HIV and also treating the newly diagnosed. Exploring these concerns with my clients made me reflect on my role as a counselling psychologist working with people living long-term with HIV. Three questions stem from these concerns:

1. Was what I was offering them what they needed or wanted?
2. Did they feel heard and understood by me?
3. What might need to happen for someone living with HIV to feel heard and understood?

In an attempt to both address these concerns and begin to provide answers to these questions I set about thinking how I might research the lived experience of someone who is living with HIV. I realised that in order to give a voice to someone's experience of living with HIV would require me to explore with them their lived experience of being HIV-positive.

3. Research Method

Central to any research investigation is an understanding of the method that underpins. Having outlined the rationale for my project by reviewing the associated existing literature, in this chapter I will explain my epistemological vantage point and how this both determined and guided the research method I choose to adopt.

Forrester (2010: p.17) identified some fundamental questions underlying the uncovering of knowledge, beliefs and 'truth': 'How do we recognise knowledge when we see it? How do we determine what a fact is? What is truth and how we know when we've got it? My existential raining and experience as a practitioner have informed me that by encouraging our clients or participants to describe their feelings, values and emotional responses to the world in which they are engaged, we can explore and reveal their unique worldview - their truth - within the confines and safety of a collaborative alliance. This enable current assumptions to be challenged and alternative ways of being contemplated ever mindful of the contextual realms and relational matrix in which we all exist.

In this chapter, I explain my reasoning for selecting Colaizzi's (1978), as my research method and include an account of the alternative methods considered during the design phase of the research. I then go on to provide a detailed description of the preparation and implementation of the data collection process and subsequent analysis. The chapter concludes with an exploration of my reflexive process across the different stages of the research. However, by way of understanding and positioning the epistemology, I turn first to a discussion of natural sciences versus human sciences.

3.1 Natural Sciences versus Human Sciences

Wilhelm Dithley proposed a distinction between the Natural Sciences and the Human Sciences (Hodges, 1952). He argued that these different approaches required different methodologies. Natural Science methodologies are based upon providing explanations whereas Human Sciences are based on intuitive understanding. During much of the twentieth century the Human Sciences were largely dismissed. However, more recently there has been a shift towards the Human Sciences. The impact of this is most apparent in psychotherapy research where persistent criticism has been levelled at psychotherapeutic analyses which are based on natural scientific assumptions which, in turn, are predicated on a logico-empiricist methodology (Denizen and Lincoln, 1994; Kvale, 1994; Mahrer, 2000). The dominant attitude towards psychology research claims to be the production of 'a body of facts …. that can be objectively discovered using a methodology modelled on the natural sciences' (Kaye, 1995:36). Natural Science examines psychological variables by a) reducing them to observable, quantifiable elements; b) employing controlled experimental design; and c) seeking verification via replication. 'As a result … psychology has come to treated for research purposes as an in principle lawful process, the components of which can be isolated, in which cause and effect can be empirically discovered and in which the critical variables lawfully related to change might be systematically established' (Kaye, 1995:36).

The implications of this perspective need to be considered. The Natural Science approach to research both disconnects psychology from its appropriate context and is itself disconcerted from any legitimate form of investigation at either the outcome or process level. This method of research transforms the central questions of psychology into something that conforms to the dictates of a Natural Science paradigm. The alternative is to adopt a Human Science approach to psychology research. This approach argues that interpretatively-focused investigations 'cannot be accomplished by observing the individual as a complex mechanism geared to respond to certain conditions in regular ways; rather we have to get inside the forms of life and socially normative regularities in which the person's activity has taken shape. This requires… [an] empathic approach and imaginative identification with the subject…' (Gilett, 1995:112).

When looked at within the framework of psychology, Human Science research highlights that psychology inevitably involves the investigation and interpretation of meaning. This serves as the distinguishing factor between Human and Natural sciences in that the former perspective runs counter to the prevailing positivist assumption that there is an objectively knowable, empirically derived reality subscribed to by the latter. Furthermore, the distinctive feature of Human Sciences emphasises the role of language as the primary constituent of 'reality'. Denzin and Lincoln (1994) have argued that Human Science investigations involve alternative notions to Natural Science investigations. These include terminology such as trustworthiness, credibility, dependability and confirmability which are intended to re-contextualise the Natural Science idea of validity within the Human Science paradigm. Likewise, while reliability and validity which remain central components of a Natural Research methodology are not directly employed in Human Science research, such approaches do rely on upon the verifiability of the researcher's conclusions in so far as verifiability refers to whether another researcher can assume the perspective of the original researcher and after reviewing the original protocol data can see how the proposed insights meaningfully illuminate the situations under investigation (Churchill and Wertz, 2001).

Colaizzi (1973) argues that 'without thereby first disclosing the foundations of a phenomenon, no progress whatsoever can be made concerning it, not even a first faltering step can be taken towards it, by science or by any other kind of cognition' (Colaizzi, 1973: 23).

3.2 Phenomenological and Traditional Psychological Research

Husserl's declared aim was to attempt to resolve one of the central problems that has plagued Western philosophy, namely the dichotomy between subjectivity and objectivity and its implications for our statements about the nature and structure of reality. Husserl wanted to create a truly scientific philosophy - not a philosophy of science, but, instead, a philosophy that would form the basis of any scientific enquiry.

Husserl developed a method of approaching the questions raised by scientific enquiry which is known as 'the phenomenological method of reduction'. This method raises and crucial objections to many of the assumptions that underpin the 'Natural Scientific' approach to scientific enquiry that has been so dominant in Western thought. One fundamental objection focuses on the naive of the Natural Scientific approach that we can speak with any certainty about what is the true, or objective, nature of reality. On contrary, phenomenology argues that that we can never know the real world, only the interpreted world. This interpreted world emerges through our reflections upon it. All our statements about the world are at best, only approximations. We can never truly speak of 'facts' or with any final certainty because all our statements reveal limitations and assumptions that impede our ability to describe or comprehend things as they really are. Phenomenological research does promise the kind of data that Natural Science methods can generate. However, instead of offering a definitive or final statement on any focus of investigation, it provides an openness of possibilities, an open-mindedness in the exploration of any facet of human lived-experience that may be desirable not just for its own sake, but also the possibility for its impact upon such issues as decision-making analyses, social change polices and so forth.

Phenomenology stands in juxtaposition to the Natural Scientific viewpoint and its underlying assumptions because the questions it poses and methods it employs are grounded in a different set of philosophical assumptions.

What might be some of the implications of phenomenological research upon contemporary psychology?

Firstly, unlike traditional psychology, phenomenological psychology denies the possibility of truly objective observation and research. Instead, it assumes an insoluble inter-relationship between the investigator and his or her focus of investigation. Both are said to co-constitute the other. The components of co-constitutionality are dialogue and disclosure. Individuals and their world are constantly in dialogue with one another in that each is a necessary constituent to the construction of phenomenon-derived reality. Each is partly active and partly passive in relation to the other. All interactions reveal, identify, define and disclose the co-constituents of the interaction. This fundamental assumption can be expressed through such terms as *'figure-ground', 'self-other'* or *'I-not I'*.

Secondly, in the more typical psychological research model the nature of consciousness as such rarely comes up as an issue. For phenomenological psychology, consciousness is central to all investigation since the primary aim of phenomenological investigation is to approach as adequately as possible direct and immediate experience.

Phenomenological research is reliant upon the phenomenological method in order that the researchers might more adequately attempt to set aside or *'bracket'* their assumptions and preconceptions. To be able to undertake this process of attempted bracketing researchers must first make their own assumptions as explicit as is feasibly possible. When researchers attempt to do this, they are likely to uncover further previously unsuspected assumptions underneath their initial assumptions. As these additional assumptions emerge, these too need to be bracketed as far as possible. As such, this process of bracketing is never final, but this process leads us away from the Natural Science attitude that posits a subjective-objective dichotomy and towards a phenomenological stance that acknowledges and positions acts of the investigation within co-constitutionality.

Thirdly, phenomenological research rejects the idea of causality in its linear form. The focus of investigation is not understood in a manner that focusses on explanations that are claimed to be related to some causal chain of events that are perceived to be unidirectional from an arbitrary point in the past to the present circumstances. The meaning of both past and present events may certainly be considered and both may prove to be interesting, but there cannot be any justification for assuming that the first event caused the second event to occur. Implicit in this viewpoint is the rejection of standard research concepts such as control groups, dependent and independent variables, preliminary hypotheses and so on, since they all assume to a lesser or greater extent, the notion of linear causality.

Phenomenological research does not demand the researcher defines in advance any productive causality, nor is it the case that the researcher must reduce his or her focus of investigation to a set of operational definitions that might impose a bias on the subject under investigation and also limit the range of meaning possibilities to those which may remain open to specific types of quantitative tests. Furthermore, unlike traditional approaches it avoids taking a stance that might involve the rejection of some data in favour of others because of competing, unique or mutually exclusive variants. Instead, phenomenological research is complementary-focused in so far as all data are considered without needing to reject their meaning possibilities. The aim of phenomenological research is to accumulate an ever increasingly adequate description of any given phenomenon as it presents itself to one’s experience.

Phenomenological research is based on collaboration. This means researchers and their participants are partners in the given enterprise whose meanings and purposes are uncovered and discussed without intending to deceive, misrepresent or obscure any part of the research process.

In the main, traditional psychological research methodologies exclude enquiries that is directly focused on human experience. However, this is the primary area of concern to both the practice of and research in psychology since each demands the exposition and clarification of human lived experience. Phenomenological researchers are required to seek out a way of listening or investigating which neither denies experience, nor denigrates it, nor transforms it into operational defined behaviour. The aim is to remain with the human experience, as it is experienced, and to stay connected to the experience as it is given.

Whilst the majority of psychologists seek to provide the 'truth', in the form of statistical analysis, from their experiments and studies, phenomenological researchers focus upon statements of 'increasing adequacy' with regard to the structure of the lived experience. Phenomenological research emphasises the importance of investigation, description and clarification of qualitative variables.

The overall aim of phenomenological research is to provide increasingly adequate meaning statements rather than final laws or incontestable truths. Leslie Farber (2000) argues that phenomenology is more concerned with 'speaking truthfully' about an experience than focussing upon the achievement of a final, or 'arrived at' truth.

3.3 Phenomenological method

Phenomenology as a research methodology emerged in the 1970's, led by Amadeo Giorgi and the Duquesne Circle (Wertz, 2005). Their explicit aim was to create a method, modelled upon traditional scientific principles which includes criteria such as replicability, while at the same time acknowledging that knowledge cannot be separated from how we understand the lived world. It is underpinned by Husserl's (1967) notion of Lebenswelt, or Lifeworld, which constitutes the focus for phenomenological investigation and consists of the cultural, temporal, social and embodied contexts in which we all exist. This perceiving occurs before we can be aware of it and so is concerned with how we pre-reflectively experience the objects around us as well as our own physical self. Finlay (2008: p.1) argues, the central tenet of Lifeworld 'is that we exist in a day-to-day world that is filled with complex meanings which form the backdrop of our everyday actions and interactions'. Employing Husserl's eidetic reduction, the goal of phenomenological research is to examine by way of bracketing one's presuppositions of the fundamental structures of a phenomenon as it presents itself (Giorgi, 1985; Giorgi and Giorgi, 2003). So the intention is to bring to awareness and identify the actual characteristics of what is being investigated by how they are revealed to us.

It is fundamental for us to both acknowledge and, also doubt our presuppositions so might view the world experientially, through a lens of bias and assumptions. Husserl refers to this as our natural attitude and as Langdridge (2007: p. 17) argues, it is our 'most basic way of experiencing the world, with all our taken-for-granted assumptions in operation'. Therefore, our lived experience determines that which can subsequently be described and comprehended: 'living precedes *knowing*…we have experiential relationships with the world before we objectify our experience…Consciousness of the world' (van Deurzen and Kenward, 2005: p.96; emphasis in the original). The aim is to uncover the hidden essential features of the lived experience. An essential element of this is the process of imaginative variation which involves the introduction of alternative components or different perspectives in order to strip away and arrive at the true meaning of the phenomenon, unhindered by the natural attitude (Langdridge, 2007).
However, the intended scientific rigour has been questioned by phenomenological psychologists who argue that it is ultimately an impossible endeavour (Dahlberg, Drew and Nystrom, 2001). In particular, they query the viability of comprehensively bracketing one's worldview, by claiming that at best this can only be partially achieved and therefore any subsequent findings or conclusions derived from this approach must inevitably be regarded with caution.

This overview provides a short introduction to qualitative research and examines some of the different methodological approaches to qualitative research. I begin this overview with a definition of qualitative research and an explanation of how it can inform practice. I will summarise some of the theoretical frameworks on which qualitative research is based. I will explore the connection between different theoretical and conceptual frameworks and methodologies.

There will also be a brief examination of the specific benefits and disadvantages, including ethical issues, associated with the approaches outlined in this overview.

3.4 What are 'qualitative research methods'?

I will begin by answering the question posed above, 'Qualitative research methods' is a broad term which can be applied to a variety of approaches which have their theoretical origins in numerous disciplines including anthropology, sociology, philosophy, social psychology and linguistics. Although great diversity exists in the kinds of studies which could be described as 'qualitative', it is, nevertheless, possible to identify a set of core characteristics. These characteristics include:

1. aims which are directed at providing an in-depth and interpreted understanding of the social world of the research participants by learning about their social and material circumstances, their experiences, perspectives and histories;
2. samples which are small in scale and purposively selected on the basis of salient criteria; data collection methods which involve close contact between the researcher and the research participants, which are interactive and developmental and allow for the emergent issues to be explored;
3. data which are very detailed, information rich and extensive;
4. analysis which is open to emergent concepts and ideas and which may produce detailed description and classification, identity and patterns of association or develop typologies and explanations;
5. outputs which tend to focus on the interpretations of the social meaning through mapping and 're-presenting' the social world. (Snape and Spencer 2003 p:5)

Hammersley (2000), Shaw (2003) and Green and Thorogood (2004) give a summary of the main advantages of qualitative research. Firstly, qualitative research methods 'reach the parts that [quantitative] methods can't reach' (Green and Thorogood, 2004). This is particularly true of research investigating the links between processes and outcomes (Shaw, 2003). Secondly, where research questions are not based on assumptions about the existence of a single reality, but attempt to uncover a 'plurality of truths' (Fraser, 2004 p:181) then qualitative research methods might be deemed more appropriate in offering an explanation of causal relationships. Through tracing the processes that may have contributed to different individuals' experiences and by collecting individuals' own accounts and explanations of what has happened to them, it is possible to make sense of why people behave as they do in specific situations or in response to particular stimuli or interventions.

Finally, qualitative research methods are useful for both practitioners and policymakers (Green and Thorogood, 2004). For example, qualitative research can provide a better appreciation of each others' viewpoints (Hammersley, 2000).

3.4.1 Consideration of alternative research methods

All approaches to research have their limitations. Rogers (cited in Kirschenbaum and Henderson, 1996: p.284-285) argued that *'phenomenological methods are the best tool of research, but simply one tool appropriate to some kinds of situations'.* Willig (2008: p.13-14) identifies three epistemological questions which need to be addressed in order to evaluate research in a meaningful way. To begin with we need to understand what its objectives were and the kind of knowledge it aimed to produce. To be able to compare methodological approaches with one another and to evaluate the extent to which studies employing these approaches have met their objectives, we need to have a clear understanding of their epistemological underpinnings and their methodological requirements.

Specifically, this research is about making sense of the unique lived experience of a small group of people living with HIV. As part of this I recognise that my equally unique lived experience of conducting this investigation will also contribute to the shape of my findings. Therefore, this investigation adopts a critical realist position (Willig, 2008) which accepts that a person's reality as *their* truth and so starts from the 'purist' realist position in line with phenomenological philosophy, but also accepts that knowledge is not generated in isolation. My epistemological position therefore acknowledges this subjectivity inherent in the process of understanding and attributing meaning.

In accordance with this epistemological stance, I decided that Colaizzi's (1978) Approach to descriptive phenomenology was the most appropriate method of qualitative analysis. In the following sections I will elaborate on the characteristics of Colaizzi's (1978) approach, consider some of the key criticisms of it and explain how I considered alternative methods before finalising my decision.

3.4.2 What kind of knowledge does the method aim to produce?

Qualitative research can produce descriptions or explanations. It can 'give voice' to those whose accounts have a tendency to become marginalised or discounted. It can also aim to interpret what people have said in order to provide an explanation as to why they might have said it. Another aim might be to attempt to make links between micro-processes, for example therapist-client communications and macro-structures, for example social and economic relations. The design of a research study might aim to attempt to capture the subjective 'feel' of a particular experience or condition. It may also aim to identify recurring patterns of experience amongst a particular group of people. In essence, what kind of knowledge a methodology attempts to produce is dependent on its epistemological position. In other words, its view of what be known and how.

3.4.3 What assumptions does this method make about the world?

This question requires us to explore the realm of ontology. Ontology is concerned with the nature of the world. Epistemology asks the question 'How can we know?' whereas ontology asks '*What is there to know?'* It could be argued that the concerns of ontology are fundamental and that it impossible not to make assumptions about the nature of the world. For example, we might assume that events are generated by underlying structures such as socioeconomic relations. This assumption would be classed as a materialist ontology. We might assume that psychological phenomena are independent from such structures. This position would described as idealist. Ontological positions can be described as *'realist'* and *'relativist'*. A realist ontology argues that the world is constituted of structures that have cause-effect relationships with one another. For example, materialism subscribes to a realist ontology. On the other hand, a relativist ontology rejects such a view and claims instead that the world is not orderly and law-bound in the way realists believe it to be. A relativist ontology questions the *'out-thereness'* of the world and places its emphasis on the diversity of interpretations that can be applied to it. An example of a relativist ontology is idealism.

3.4.4 How does the methodology conceptualise the researcher's role in the research process?

All qualitative methodologies recognise that the researcher is, in one way or another, implicated in the research process. However, there are differences in the extent to which these methodologies perceive the researcher as being the author, as opposed to being a witness, to his or her research findings. Some methodologies see the researcher as being the central figure in the research process because it is the researcher who constructs his or her findings. A good analogy might be to describe the researcher as being like a builder who constructs a house out of bricks. The same bricks (the raw data) could be used to construct a number of very different buildings. Other methodologies, whilst acknowledging the important role of the researcher, do not see the researcher as someone who uses his or her skills to unearth the evidence. In other words, the research process is more like a treasure hunt than a building process.

I will now discus my consideration of alternative qualitative research methods and why I choose to reject them in favour of Colaizzi's Descriptive Method (1978). It is not my intention to criticise or discredit any specific research method, but rather to assess how appropriate each research method is to what is being researched. I will outline my consideration of two alternative research approaches on account of them being either often considered as a suitable alternative to Colaizzi’s Descriptive Method or sharing similar philosophical underpinnings. The two alternative research approaches are: Grounded Theory and Interpretative Phenomenological Analysis (IPA).

3.4.5 Consideration of alternative research methods

Grounded Theory

Origins

Grounded theory originated in sociology with the publication of ‘Discovery of Grounded Theory’ (Glaser and Strauss, 1967). This approach is derived from symbolic interactionism which attempts to study patterns and processes in human interactions and understand how a group of individuals might define their reality through social interactions such as gestures, words, clothing and so forth (Cutcliffe, 2000).

Traditional positive approaches based on deductive reasoning start with the development of a hypothesis based on existing theory, whereas, grounded theory utilises inductive reasoning in which theories emerge from the data (Hodkinson, 2008).

Characteristics of Grounded Theory

There have been numerous theoretical and methodological debates regarding Grounded Theory. The most famous of which was the acrimonious split between Glaser and Strauss which arose from personal and methodological differences (Bryant, 2009) and resulted in the publication of two books (Strauss and Corbin, 1990; Glaser, 1992). Constructivist grounded theory (Charmaz, 2000) has been particularly influential in that it reaffirms the relativist approach to grounded theory, in which the world is seen as consisting of multiple individual realities.

Chamaz (2003) identified the core characteristics of Grounded Theory as:

> simultaneous involvement in data collection and analysis phases of research; developing analytic codes and categories from the data, and not from preconceived hypotheses; constructing middle range theories to explain behaviour and processes; memo-writing, in the form of analytic notes to explain behaviour and processes; making comparisons between data, data and concept, concept and concept; theoretical sampling, which is, sampling for theory construction to check and refine conceptual categories, not for the representativeness of a given population; delaying the literature review until after forming the analysis.

Advantages of Grounded Theory

Grounded Theory can provide new information on under-researched areas because grounded theory attempts to generate ideas rom the data, rather than establish the accuracy of the existing hypothesis. Therefore, it is most suited to the investigation of under-researched or sensitive topics. For example, Chung et al. (2008) interviewed carers of individuals suffering with dementia in South East England about their experience of caring for someone with dementia living in their own home. This study was important because while guidelines and good practice point to the therapeutic value of activities for individuals suffering dementia (National collaborating Centre for Mental Health, 2006) most of the information on this subject has been derived from data collected outside the home, most often in day centres and care homes. This study demonstrates how the process of theory development can be used to provide practical advice for both professionals and organisations. The relevance of this approach further illustrates the way in which, starting from the beginning of this under-researched area and ending with new insights into the different facets of activity engagement undertaken by individuals suffering with dementia in the all the stages from initial diagnosis to moving into long-term care or dying. Furthermore, when different strategies employed by carers to engage with the individual suffering with dementia and living in their own home were examined it was discovered that some carers had developed more successful strategies than others. This led to the conclusion that professionals needed to provide better support to carers by sharing information with carers about successful strategies for activity engagement.

Limitations of Grounded Theory

The original purpose of Grounded Theory was to enable new theories to emerge from data. This means that Grounded Theory gives rise to new ideas through observation or induction. This approach was meant to free researchers from the limitations of the hypothectico-deductive method of research. A problem associated with induction is that it pays insufficient attention to the role of the researcher because it assumes that the data speaks for itself. Critics of positivism have argued that all observations are made from a particular vantage point. In other words, whatever emerges from a specific observation depends upon the observer's relative position to what is being observed. Likewise, whatever emerges from the data analysis is theoretically informed because all analysis is necessarily guided by the questions asked by the researcher. Dey (1999, p:104) argues 'even if we accept the (doubtful) proposition that categories are discovered, what we discover will depend to some degree on what we are looking for - just as Columbus could hardly have "discovered" America if he had not been looking for the "Indies" in the first place.'

Therefore, Grounded Theory has been criticised for addressing the issue of reflexivity satisfactorily. Stanley and Wise (1983, p: 152) argue that as long as it does not deal with the question of *'what grounds Grounded Theory?',* Grounded Theory as a method of research remains a form of inductive positivism. Attempts to answer this criticism have come in the form of Social Constructionist approaches to Grounded Theory (Charmaz, 1990, 1995) which attempt to develop a reflexive version of Grounded Theory. Categories can never ‘capture the essence’ of a concept in its entirety and that categories do not simply emerge from the data because they do not exist before the process of categorisation, instead, they are constructed by the researcher as part of the research process (Dey, 1999, p;66).

Is Grounded Theory suitable for psychological research?

Grounded Theory was designed to study social processes from the bottom up. In other words, as a research method it enabled researchers to trace how actions gave rise to consequences and how patterns of social interaction combined to produce particular, identifiable social processes (Dey, 1999).

More recently, Grounded Theory has become a qualitative method used for psychological research and it now features in psychology research method textbooks (Hayes, 1997; Murray and Chamberlain, 1999). However, it could be argued that when it is applied to questions about the nature of experience, as opposed to the unfolding of social processes, Grounded Theory is reduced to a technique for systematic categorisation. In other words, studies concerned with the capturing of the meaning a specific experience might hold for a particular individual are more likely to be in the form of one-off interviews with research participants. These interviews are transcribed and coded utilising the principles of Grounded Theory. The outcome of this coding method is a systematic map of the concepts and categories employed by research participants to make meaning of their lived-experience. Whilst such a map may give researcher a better understanding of the structure of the research participant’s lived-experience, it does not constitute a theory. Moreover, it is a descriptive not an explanatory exercise. Therefore, it is not geared towards developing a theory. Grounded Theory is better utilised in the study of social psychological processes. Furthermore, it could be argued that research questions seeking to explore the nature of experience are better investigated by phenomenological research methods.

My research involves a small participant sample and therefore cannot claim to be able to uncover social processes and thereby generate a theory representative of the wider population. Research studies employing Ground Theory methodology involve much larger numbers of participants that would normally be the case with Colaizzi's Descriptive Method. Having said that my research findings could form the basis of a larger future study employing Grounded Theory.

Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is an approach to qualitative research in psychological with an ideographic focus. In other words, it aims to provide insights into how a specific person, in a specific context, makes meaning out of a specific experience. This experience can take the form of a significant life event or the development of an important relationship. The theoretical underpinnings of IPA are served from phenomenology and hermeneutics. IPA is distinct from other qualitative research approaches because of its combination of psychological, interpretative and idiographic components.

IPA involves the close examination of both the experiences and the meaning-making activities of a small group of individuals. Research participants are chosen on the basis that they might be able to provide the researcher with a meaningful insist into the topic under investigation. Participants in an IPA research study are expected to have certain experiences in common with each other. The aim of IPA is to attempt to understand how an experience can be made sense of within a given context. However, sometimes multiple perspectives on a shared experience are examined, such as patients and their psychiatrists. IPA can also be used to compile research participants' accounts of their experiences over a period of time in the form of a longitudinal study.

Data collection in IPA does not attempt to test a research hypothesis. The researcher begins by reflecting his or her own assumptions, biases and preconceptions about the research subject under investigation. The purpose of this reflection by the researcher is so that they can become aware of how their own understanding of the subject being examining could contaminate the meaning making of the research participant's experience. Therefore, IPA might be employed as a research method where the research question aims to understand what a specific experience is like (phenomenology) and an individual makes sense and meaning of his or her experience (interpretation). The analysis of the data is *'bottom-up'*, which means that the researcher creates codes from the data instead of utilising an existing theory to attempt to identify codes that might be applied to the research data. IPA is used to test theories, but the findings of an IPA research study can often be relevant to the further development of pre-existing theories. For example, the conclusions drawn from a study into the meaning of sexual intimacy for gay men in a close relationship might offer ways of exploring the adequacy of theories attempting to predict and explain safer sex practices. IPA encourages an open-ended dialogue the researcher and study participants which, in turn, may provide fresh vantage points to our understanding of the topic under investigation.

Once the data has been transcribed, the researcher works closely with the text, annotating it (coding) for insights each research participant's experience and perspective on his or her world. As the analysis develops, the researcher lists the codes as they emerge and begins to identify patterns within the codes. These patterns or themes are formed from patterns of meaning that are to be found within the text. Furthermore, these themes will often identify what matters most about an experience to a particular individual and also how an individual might drive personal from an experience.

Some themes might be grouped together under broader themes (superordinate themes). An example might be where someone describes, *'feeling anxious during their driving lesson'.* This might be a superordinate category which captures numerous patterns in an individual's embodied, emotional and cognitive experience during the early stages of learning to drive, where there might be sub-themes relating to *'feeling nervous', 'fearful of losing control'* and *'struggling to master the complexities of the task'.* The final list of themes are usually summarised and put into a table where evidence from the text is provided to support the themes produced by quotations from the text.

Limitations of IPA

IPA is concerned with experiences and their meaning. It explores phenomena from the perspective of those who are having the experience. It aims to capture the an experience and unpack its meaning. IPA provides researchers with clear and systematic guidelines which enable researchers to identify and progressively integrate themes. On completion of the research a table of master themes will have been generated which attempts to capture the essence of the phenomenon under investigation. The introduction of IPA into psychological research has made phenomenological methodology accessible to researchers who do not have a philosophical background. However, IPA does suffer from several conceptual and practical limitations. These limitations concern the role of language, the suitability of accounts and explanations versus description and, finally, IPA's claim to be a phenomenological method. Each of these limitations will be examined in turn.

The role of language

IPA works with texts and data collection takes the form of semi-structured interviews, diaries and other descriptions of events or situations. Research participants use language to describe their experiences to the researcher. Since phenomenological research is interested in the actual experience itself, it assumes that language provides research participants with the tools to capture the experience. IPA relies on the representational validity of language. However, it could be argued that language constructs, rather than describes, reality. The words I choose to describe a particular experience always construct a particular version of that experience. However, the same experience can be described in numerous ways. This means that language can never simply express the experience, but instead words provide meanings which are contained in the words themselves. Therefore, it renders direct access to an individual's experience impossible. From this perspective, an interview transcript informs us more about the different ways a person speaks about a specific experience within a particular context, than about the experience itself. It can sometimes be the case that particular ways of speaking about an issue can provide us with the categories of experience. As a consequence, language precedes and, therefore, moulds experience. Language does not constitute the means by which I express something I think or feel. Language prescribes what I can think or feel. IPA conceptualisation of language can be criticised for not paying sufficient attention to its constitutive role.

Suitability of accounts

Phenomenology is concerned with the texture of the experience and the aim of phenomenological analysis is the exploration of the quality of the experience in order to attempt to obtain a better understanding of what it is like to experience a specific moment or situation. Transcendental phenomenology attempted to suspend judgement or bracket common sense conventional and scientific knowledge about phenomenon so as to attempt a better understanding of the essence of the phenomenon as it revealed itself in a specific experience. IPA attempts to capture the experience and the associated meanings rather than identify opinions about the experience. Phenomenology as an approach to philosophy relies on introspection, in other words, the philosopher reflects upon his or her own experiences. Phenomenology as a social science research method requires research participants to be able to describe fully their own experiences. However, this is not as easy as it might first appear. Several issues with this approach need to be considered.

Firstly, to what extent do research participants' descriptions provide us as researchers with suitable material for phenomenological analysis?

Secondly, is it really possible for research participants to communicate the complexity of their experience to the researcher?

Finally, how many people are able to use language to express the subtleties and nuances of their experiences? In other words, is it possible to fully share our experiences through language with others?

It could be argued that complex descriptions of our experiences are difficult to produce, particularly, for individuals not used to reflecting upon and articulating their thoughts in words to others. This highlights a limitation to the applicability of this method of research.

Explanation versus description

The focus of phenomenological research is our perception of our experiences. Its aim is to attempt to obtain a better understanding of how the world is experienced by others, how those individuals perceive and experience the world, from their own unique perspective (Kvale, 1996). Phenomenological research is concerned with how the world presents itself to people as they engage with it in specific contexts and with specific intentions. Phenomenology does not make any claim to be able to uncover the nature of the world itself. So, from a phenomenological perspective it would not make sense to talk of 'the world' and 'the person' as though they were separate entities. In fact, it makes more sense to think of 'the world' which is formed from our experiences as being co-created by us in 'the world'. There is only the experience of the world as constituted from our relationship of self and the world (O'Connor and Hallam, 2000). Therefore, we see the world, not as it is, but as we are. Phenomenological research describes and documents our lived experiences, but it does not attempt to explain them. It could be further argued that focussing on appearances, without reference to their cause or origin, limits our understanding of the phenomenon under investigation. Much of what we, as human beings, perceive is not a direct reflection of the conditions that give rise to our perceptions. If we seek to move beyond simply sharing an experience with our research participants, and attempt to comprehend their experiences sufficiently enough to be able to provide an explanation, we need to be aware of the conditions that may have given rise to these experiences in the first place. These conditions can exist far beyond the moment and location of the experience. They could be discovered in past events, histories or the social and material structures within which we live our lives (Willig, 1999).

Smith (1996) argues that IPA looks at cognition because it is concerned with comprehending what a specific individual thinks or believes about a particular topic under discussion. He proposes that IPA is compatible with a social cognition paradigm because it subscribes to ‘a brief in, and concern with, the chain of connection between verbal report, cognition and physical state’ (Smith et al., 1999: p.219). However, it could be argued that being concerned with cognitions is not compatible with, at least, some aspects of phenomenological thought. The reasoning behind this argument is that phenomenologists challenge the subject/object dichotomy implied by cognitive theory. Their aim is to attempt to transcend the separation between ‘*the knower’* and the *known’*, between the *‘person’* and *‘world’.* Therefore, phenomenology aims to capture the way in which the world presents itself to us in an immediate and unmediated sense. This includes vague feelings, pleasures, hunches, moods and ideas on the margins of consciousness (O’Conner and Hallam, 2000). These precognitive aspects of our experience are regarded as central because they form an existential backdrop for our cognitive attempts at making sense and meaning of the world. In other words, phenomenological research should not be concerned with studying people’s cognitions, but instead, it should attempt to examine an individual’s lived experience.

Conclusion

IPA is, however, just one version of phenomenological research methodology, which has emerged from a rich tradition of philosophical thought. Phenomenology as an approach to philosophy in not unified as there are diverse strands, which include existentialist, transcendental and hermeneutic approaches (Spinelli, 1989; Moran, 2000). Each of these approaches makes different assumptions about the role of language and interpretation, the nature of being and human action. Consequently, to describe an approach as phenomenology or phenomenological will mean different things to different people. Therefore, it is vitally important to be specific about which version of phenomenological thought is being referred to. Kvale (1996: 38-9) states that 'A phenomenological perspective includes a focus on the life world, an openness to the experiences of the subject, a primacy of precise description attempts to bracket foreknowledge, and a search for invariant essential meanings in the description'.

3.4.6 The Methodology of Phenomenological Research

How then is phenomenological research conducted? The structured method devised by Paul Colaizzi (1978) provides an approach which contains key methodological characteristics of phenomenological research although there is no one phenomenological means to enquiry. The assumption of a specific method is a fallacy. Instead, each phenomenological researcher employs unique descriptive approaches derived from the phenomenological method. Colaizzi (1978) argues 'each particular psychological phenomenon, in conjunction with the particular aims and objectives of a particular researcher, evokes a particular descriptive method' (Colaizzi, 1978:53).

The starting point of any phenomenological research lies in the clarification of the researcher's own involvement, biases, assumptions and aims. He or she needs to clarify how his or her personal inclinations and predispositions might influence their research investigation. For example, the phenomenological investigator's relative success in accurately describing or reflecting the research participant's world-views so they are clarified, considered and evaluated is entirely dependent upon the more or less adequate attempt to bracket the investigator’s biases and assumptions so that they do not transform the research participant’s intended meaning.This research focused application of the phenomenological method uncovers the willingness of the investigator to acknowledge and respect the autonomy, authority, and experiential responsibility of the research participant. It exposes the power and powerlessness of the researcher. It also acknowledges and clarifies the researcher’s role in and impact upon the research. Any ‘*factual truth’* contained in his or her data becomes both relative and relational.

Any phenomenological investigation will be exhausting, time-consuming, fraught with interpretative dangers and never complete. Yet, at the time, it can also be exhilarating, surprising, in terms of what often emerges, intellectually and emotionally stimulating, moving and capable of creating a level of intimacy between researcher and his or her research participants that parallels that of the psychotherapeutic relationship and which can reach a depth of value and meaning to all participants that more traditional research methods can never begin to approach.

Descriptive Phenomenology

Descriptive phenomenology is an approach to research that is informed by some of the principles and methods associated with a branch of philosophy known as phenomenology. Phenomenology is concerned with the ways in which human beings obtain knowledge about the world around them. Phenomenology identifies different approaches to human understanding and it argues that certain types of knowing may be more constructive than others. Phenomenology provides detailed guidance as to how these superior types of knowing can be achieved.

Colaizzi's Descriptive Method (1978)

This method places the emphasis on describing universal essences. It sees the person as one representative of the world in which they live. Self-reflection and the conscious *‘bracketing'* of pervious knowledge helps to enable the researcher to present a researcher-free description of the phenomenon.

The end point of descriptive phenomenological research is to present a theoretical model that represents the essential structures of the phenomenon under investigation (Colaizzi, 1978). Once the true structure of the phenomenon has been identified, then anyone who has experienced the phenomenon should be able to identify their own experience in the proposed description.

Transcripts will be analysed following the procedural guidelines proposed by Colaizzi (1978). These guidelines take the form of a sequence of steps:

Step 1: The researcher designs a brief unbiased statement or question whose purpose is to clarify the focus of investigation and to enable selection of appropriate research participants who are qualified by their lived-experience to engage in a descriptively focused enquiry. This step also requires the researcher to engage in preliminary process of self-reflection in order to examine his or her assumptions regarding the phenomenon to be explored so that these can be *'bracketed'* so that they do not inadvertently contaminate the research question.

Step 2: The researcher engages in a structured, focused enquiry with each research participant. This is normally carried out in a one-to-one interview lasting on average one hour.

Step 3: The interviews are transcribed verbatim.

Step 4: The interviewer reads each of the transcribed interviews (protocols) several times in order to gain a *'feel'* for their content.

Step 5: The researcher returns to each protocol and extracts those phrases or sentences directly pertaining to the investigated phenomenon so that by the conclusion of this step the researcher has compiled a list of significant statements from each protocol.

Step 6: The researcher endeavours to extract the meanings contained in each significant statement. This formulation of meanings is the most precarious interpretive step of the phenomenological research process and requires the researcher's creative insight to both remain true to the research participant's statement while at the same time seeking to draw out of it its embedded implicit meaning.

Step 7: Having formulated meanings from all the significant statements extracted from all the protocols, the researcher now organises the aggregate formulated meanings into clusters of themes that may be shared by one, some or all of the research participants. The themes may be contradictory or even unrelated to one another and require the researcher's tolerance for ambiguity. There may be formulated meanings that do not fall into the clusters of themes in that they stand alone. These too can be added to the final list of thematic elements.

Step 8: The list of thematic elements is integrated into an exhaustive description of the investigated phenomenon.

Step 9: The research returns to each research participant with exhaustive description so that each research participant can respond in terms of its verifiability as a statement that captures the experiential structure under investigation.

Step 10: On the basis of the research participants' comments, amendments, corrections or additions, if any, the researcher produces a further, usually final, exhaustive description of the phenomenon. While never fully completed, at the very least it enables the researcher to go back to the original statement and re-examine how well or poorly it reflected the research participants' actual statements, what previously unforeseen assumptions may have either remained within it or were left out that be significant for future research.

The previous steps were employed to conduct the research as follows:

Step 1: Each transcript was read several times in order to obtain a sense of the whole narrative. During this stage, any thoughts, feelings, assumptions or ideas that arose in the researcher due to previous work undertaken with people living with HIV were put to one side or *'bracketed'.* This was to enable the researcher to attempt to explore the lived experience of the emotional impact of living with HIV of the research participants themselves without undue contamination from the attitudinal bias of the researcher.

Step 2: In this stage of the analysis, significant statements and phrases pertaining to the emotional impact of living with HIV were extracted from each transcript. These statements were written up on separate sheets and cross-referenced with their relevant transcript.

Step 3: Meanings were formulated on the basis of the significant statements. Each underlying meaning was clustered into categories which, in turn, became an exhaustive description.

Step 4: All the formulated meanings were grouped into categories that reflected a unique structure of thematic clusters. Each cluster of themes included all formulated meanings related to that group of meanings. Then, groups of thematic clusters that reflected a particular concern or issue were further grouped together to build up a distinctive construct of themes.

Step 5: At this stage of the analysis, all the themes were compiled into an exhaustive description. After this process was completed a generic lived experience of what it was like to live with HIV emerged.

Step 6: This step was similar to step 5, except no exhaustive meanings were sought. Instead, a reduction of the findings was undertaken to eliminate redundant descriptions or repetitions were removed from the overall structure. This helped to deepen the understanding of the lived experience of the emotional impact of living with HIV.

Step 7: In essence, qualitative research has to be able to demonstrate trustworthiness in providing rigour and strength to the study validity and reliability in all stages including data collection, data analysis and descriptions (Speziale and Carpenter, 2007). This step involved an attempt to validate the research findings. This was done by contacting the research participants by phone and discussing the results with them. This validation procedure was discussed with the participants at the time of the original interview. By the end of this validation process all participants indicated that their lived experience of living with HIV had been accurately captured.

3.5 The ethical imperatives of research

The purpose of this research was to record, analyse and describe the experiential accounts of a small cohort of people living with HIV. An important part of this research process was to consider the ethical dilemmas and concerns that emerged in order to safeguard the wellbeing of the research participants. Firstly, I want to explore what I mean by ethics in counselling psychology research.

3.5.1 Research ethics in counselling psychology research

As discussed in Chapter 2, the ascendancy of the Cartesian objectivism and the associated rise of scientific research universities meant that studying the subjective, socio-historical and culturally influenced experience was largely displaced by deductive observations of human behaviour (Bellah et al., 1985). Moreover, within this climate of investigating phenomena in '*value neutral environments'* (Brinkmann and Kvale, 2008: p.264), there has been a renewal of interest in qualitative research in the past decade. It is within this context that counselling psychology's commitment to subjectivity and the relational milieu of human existence is duly acknowledged and recognised (Walsh and Frankland, 2009).

Nevertheless, when the research paradigm of our current age is concerned with manipulating variables and minimising individual difference, the challenge faced by qualitative researchers is to ensure that they uphold the important role that values, morals and societal norms have in moulding a participant's unique perspective. Also the acceptance of difference and meeting the client free of any assumptions of how they 'should be' are core attributes of our discipline. Levinas' (1969: p.47) concept of '*welcoming the Other'* captures this most fundamental ethical imperative for qualitative research. He further argued that we must unequivocally accept the characteristics and qualities that make up '*the Other'* and also their unquestionable individuality. Their being is *'irreducibly strange'* and *'infinitely transcendent'* for we can never assume to be able to accurately and sufficiently portray or encapsulate all that is someone else.

Levinas stated that this attitude demands a *'non-allergic reaction with alterity'*; which requires, as Cooper (2009: p.121) explained, *'a deeply challenging willingness'* to resist any temptation to classify or quantify the participant or client we encounter. In fact, such as commitment is fundamental to the pursuit of counselling psychology. For this a profession that is *ethics in action* as Cooper (ibid, p.120) argues: *'our respect our client's autonomy, our trustworthiness, our commitment to maintaining confidentiality are not just corollaries of our work - they are the essence of what we do'.* There fore, the attitude of the researcher from conception to conclusion of a research project and their readiness to remain attuned to these professional values is of vital importance.

Ethical dilemmas and concerns are an inevitable part of the research process as we attempt to balance our desire to make a meaningful contribution to the knowledge-base of counselling psychology with our ethical responsibilities to our research participants. It is important that when ethical concerns are identified and raised that they are acknowledged acted upon in a manner that respects both the autonomy of our research participants and, equally importantly safeguards their wellbeing. Therefore, when conducting a research interview it is important that the researcher respects the the participant's account as being his or her truth. Furthermore, this also means that as researchers we must be mindful of our role in that we are not there to challenge the account of the research participant in the way we would if we were engaging in a therapeutic encounter with the participant. However, Brinkman and Kvale (2008) argue that without making such a challenge we might only gain a superficial account of the research participant's lived-experience and so impede the process of the production of more meaningful research.

A potential ethical dilemma for me to reflect upon as researcher is how I conduct myself in the interview process with my research participants. In order to encourage the research participant to reflect upon his or her experiences that I might consider to be of relevance or significance to my research question, which they might be hesitant about disclosing because of how it might make them feel I would need to use my skills as a therapist to build rapport and convey a sense of empathy with the research participant. Duncombe and Jessop (2002) refer to this as being a 'commodification of rapport'. What they are describing is a sense of empathy with the research participant in order to obtain more useful data.

For example, a research participant who might not to want to be seen to be criticising his clinicians or the treatment he or she receiving might say that everything is fine when their body language and tone of voice conveys a different picture. The dilemma for me here would be that I might want to explore this experience more deeply, but at the same time be aware of the sensitivity of the issues being spoken about and so not want to cause the research participant any unnecessary distress. This is an important consideration when conducting semi-structured interviews, which by definition means that there is likely to be unscripted prompting and follow-up questioning. This requires judgement and being guided by one's own personal and professional integrity, and most specially a sense of responsibility to the research participant. Therefore, it is important for the researcher to stay alert and be reflexive regarding potential ethical concerns throughout the entire research process.

Such ethical tensions as those described above are inevitable when attempting to balance often conflicting priorities. Brinkmann and Kavle (2008: p.268) argue that they *'cannot be health with simply by appeal to ethical guidelines and review committees'.* Foucault (1984: p.343) argues that *'the ethico-political choice we have to make every day is to determine which is the main danger'.* Furthermore, it our responsibility as researchers to remain reflexive and maintain an awareness of all ethical risks and conflicts throughout the research process. This is most important to remember when conducting semi-structured interviews, with by definition mean that there is a substantial element of unscripted prompting and follow up questions. Obviously these cannot be echoed against protocols or clears by ethical committees in advance. It is about exercising judgement and being guided first and foremost by one's personal and professional integrity, and more specifically a sense of responsibility to the participant.

Nevertheless, it is essential that the research being conducted complies with the professional ethical standards of the relevant professional bodies. The ethical guidelines followed for this research were those contained within 'The Ethical Principles for Conducting Research with Human Participants' (2009) published by thee British Psychological Society. Further guidance is to be found was found in 'Standards of Conduct, Performance and Ethics' (2012) published by the Health and Care Professions Council (HCPC). Both these sets of ethical guidelines focus on safeguarding the wellbeing, dignity and respect of research participants. I would further like to highlight the following ethical considerations which form part of the specific guidelines:

Deception

My study did not require me to withhold or disguise any details regarding the true nature or purpose of my research from the research participants. The Participant Information Sheet (PIS) clearly stated the topic under investigation and what this would involve for the research participants. Those that expressed an interest in participating in my research were asked to read and sign a consent form which included their right to withdraw at any time. Each research participant was given a copy for his or her own records.

Risk of Harm

There was a need to identify the potential for emotional distress caused by asking research participants to reflect upon and explore their experience of living with HIV. As well as providing details of the purpose of the study, the PIS made explicit reference to this specific risk. The rationale for this was that those considering participating would have the necessary information for making an informed choice regarding their participation in this study. There was also an acknowledgement that this investigation could reactivate unsettling emotional material from the past and this was to be expected. A risk assessment concerning the practicalities of conducting field research was conducted and is included in the Appendix section of this research study.

Debriefing

On the completion of each research interview, the research participants were asked to reflect on his or her experience of being interviewed and how it felt. In the event that any upset or emotional distress had been caused he or she was given the opportunity to discuss this with me was offered.

Confidentiality and anonymity

There is an important distinction to be made between confidentiality and anonymity (Smith, Flowers and Larkin, 2009). In the case of qualitative research all that can be assured to a research participant is that his or her identity will be concealed. However, to suggest to a research participant that their involvement will be completely confidential would imply that nobody else will have sight of their data which is obviously not possible. Nevertheless, protecting a research participant's identity was treated with the upmost importance by following Data Protection Act (1998) procedures employed by the HIV Charity were I conducted my interviews. On receiving the referral from the HIV Charity I was I was only given a first name and either an email or telephone number in order to contact potential research participants. I did not have access to any other information about these potential research participants. Once a potential research participant had agreed to take part I allocated each person a pseudonym and stored any personal identifying information separately and securely from their recorded interview. It was explained to each research participant that after analysis their recording would be destroyed. It was also explained that any data referenced in any subsequent reporting would not be identifiable as theirs because pseudonyms would be used throughout.

My primary aim in this section has been to convey how ethical considerations transcend simply obtaining authorisation to proceed from the university's Ethics Committee. Instead, it has been wider and continual process of contemplating the context in which the research was prepared and conducted, along with an awareness of the tension between my role as both researcher and practitioner. Protecting the participants as far as possible has governed both attitude and approach to this investigation, up to and including the final report submission.

3.5.2 Assessing research validity

In this section I will explore the need to be able to assess the validity of my research. In so doing I am aware that qualitative research should aim for a similar level of validity to that of quantitative research. For both safeguarding the research participant's wellbeing and for qualitative research to be sufficiently respected, research must be responsible, disciplined and systematic. Yardley (2000) identified four principles for quality assessment. These guidelines were written for health psychology research, have been subsequently widely recognised as being equally relevant and applicable to other areas of qualitative research (Landridge, 2007; Shinebourne, 2011; Smith et al, 2009). These guidelines also include an ethical dimension, in terms of how to reflect upon conducting your research in the most appraise way. I will now discuss each of the four principles in relation to my own research.

Sensitivity to context

From the start of my research project through to its completion, acknowledging and understanding the context of what I attempted to explore has been central to the process. Securing access to suitable research participants involved discussions with a number of HIV charities before I was able to obtain permission to interview service users. My discussions centred around what was the purpose of my research and who was going to be assessing it. Also confidentiality was raised as an issue because of the stigma surrounding having HIV is still a concern for many people living with HIV. This was also seen as an issue concerning the safeguarding of the wellbeing of potential research participants. Before agreeing to allow me to have access to their service users I need to be able to satisfy the Chief Executive of the Charities I approached that I would treat the wellbeing of research participants as paramount. A key aspect of this first principle is of the wider socio-cultural context the participants exist in as well as the particular research setting. Furthermore, with reference to issues of governance, I engaged in a process of drafting and redrafting this report in collaboration with feedback from both my supervisors.

Commitment and rigour

This refers to the level of competence of the researcher including his or her depth of engagement with the topic, and ensuring good governance during both the data collection and analysis phases. This research topic arose from my own work in the field of HIV as both a psychotherapist and group facilitator. I have working the field of HIV for over two decades which shows the level of commitment have to both this topic and this particular client. I also have the profound respect for this client group and feel privileged to be able to contribute to a greater understanding of what it like to be living with HIV.

Transparency and coherence

These principles require being able to clearly demonstrate to the reader how the research process was conducted. By systematically describing each stage involved in the following Method of Data Collection section it is my intention to provide transparency in my method. By working closely with my supervisors and integrating their feedback, the aim has been to produce a coherent and logical presentation of my findings. Whilst there is no intention to present my findings as being the definitive *'truth',* there has, nevertheless, been an objective present them as being both plausible and most likely. Of course, my analysis and conclusions are open to challenge and any alternative conclusions would be considered as a welcome contribution. Given the current economic climate which has resulted in substantial reductions in funding of HIV specific services and the reliance on the voluntary sector to provide support for people living with HIV, this research aims to identify the concerns that have the greatest impact on the lives of people living with HIV so that resources can be more effectively targeted to benefit this client group.

Impact and importance

This final principle is regarded by Yardley (2000) as the most important of all since addresses attending to the value potential of the research study. Such impact may be immediate or delayed, but there should nevertheless be some effect from the contribution.

3.6 Method of data collection

Having already explained the theoretical and epistemological underpinnings of this project, I will now describe how the actual data was collected and analysed. A principle intention in the following sections is to show the key issues of validity and ethics described above have guided how the research was designed, conducted and subsequently reported. Included are details of the sampling and recruitment process, interview design and the systematic stages of the subsequent data analysis. I start however, by providing a description of the setting in which the actual research was conducted.

3.6.1 Research setting

I contacted several HIV charities and asking if they would allow me to interview some of their service users who had been living with HIV for a number of years. Eventually, an HIV charity in east London gave me permission to interview some of their service users about their experience of living with HIV.

3.6.2 Research preparation and quality assurance

In preparation for the actual research, I conducted a pilot study in which I recruited and interviewed one research participant. I analysed this data and submitted my report to my supervisors for assessment. Essentially the purpose of doing this was to ensure an appropriate level of overall quality for my research by identifying and addressing problems or difficulties I may have encountered.

Before conducting the pilot and aware of the sensitivity of the material I was asking people to share, I decided to first test my research questions on a colleague who was living with HIV. Since the subsequent actual pilot interview involved a real service user, this ‘pre-pilot’ exercise was intended to further safeguard the participants’ wellbeing.

3.6.3 Participants selection criteria

As an idiographic study, the selection of participants was purposive and homogeneous (see Table 3.1 for the profile of all the participants in this study).

6 participants aged over 18 years of age infected with HIV and living in the United Kingdom were recruited to take part in the present study. Anyone who had been given an AIDS diagnosis was excluded from this research study. The criteria for establishing an AIDS diagnosis are given in Appendix 1. Also excluded was anyone who was newly diagnosed with HIV.

Potential research participants were given details of my research project and my contact details. If anyone was interested they were asked to either phone me or email me for more information. The demographic profile for this research was determined by those who volunteered to participate, provided they satisfied the selection criteria.

3.6.4 Recruitment process

This HIV charity provided support not only to people living with HIV, but also to those affected by HIV, such as partners, and other family members.

I negotiated with the Counselling manager the best way of contacting potential research participants. It was agreed I could provide information about by intended research to Counsellors who had clients who were living with HIV. I emailed my contact details along with the information sheet explaining my research question to the Counselling manager who then gave out this information to Counsellors who he thought might of suitable clients. I was given a list of fifteen people who expressed an interest in knowing more about research. I contacted each person by either telephone and/or email. From this list I was able to recruit six people who satisfied the selection criteria.

Table 3.1 below provides details the principle profile characteristics of my research participants. Most of this information was obtained during the initial contact stages, but some of the information (i.e. ethnicity and how long they had been living with HIV) was obtained when I met them at the interview stage. All the men I interviewed identified as gay and the two women identified as heterosexual.

Table 3.1 Profile of the participants

Alias	Gender	Age	Ethnicity	Number of years they have been living with HIV
Maria	Female	38	White/South American	15
Mark	Male	51	White British	22
Tina	Female	40	White British	19
Gary	Male	52	White British	25
Nigel	Male	48	White British	22
Claude	Male	50	Jamaican	14

3.6.5 Interview design

In accordance with Colaizzi's (1978) descriptive phenomenology method, I conducted semi-structured interviews with the intention of facilitating a participant-led exploration of their experience of living with HIV. I informed each participant that I would contact them after I transcribed and analysed their interview. The principle of contacting each participant a second time was both to provide the participants and myself the opportunity to clarify and elaborate on the reflections made during their interview. Being relatively inexperienced as a qualitative researcher, this gave me the opportunity to read through each interview transcript and highlight comments that may have deserved deeper exploration or clarification at the time, but for example I may have simply missed. Indeed, Flowers (2008: p.25) refers to this being an issue for any interviewer by arguing that the *'cognitive load of remembering what the participant has said in order to probe and funnel for more information'* means that the likelihood of such lost opportunities can be potentially high.

Each interview lasted between forty-five and sixty minutes. The subsequent analysis of the data for each participant required careful management and systematic working. The associated process and procedures followed are described in the following section.

1.
2.

3.6.6 Data Analysis

I will now apply Colaizzi's (1978) process for descriptive phenomenological data analysis to the transcripts of the participants' interviews. Each transcript was read several times to obtain a sense of the whole narrative. During this stage, any thoughts, feelings, assumptions or ideas that arose in me because of my work with people living with HIV were put to one side or *'bracketed'*. This was to enable me to attempt to explore the lived experience of people living with HIV without undue contamination from my attitudinal bias.

Significant statements

In this first stage of the analysis, significant statements and phrases pertaining to the experience of living with HIV extracted from each transcript. These statements were written up on separate sheets and coded based on their transcript, page and line number. I have set out the significant statements below:

Participants names have been changed to protect the identities of those interviewed.

Maria

The images that I had in my head were falling tombstones from those scary HIV adverts that were around in the early 1980's. (Transcript 1: Line 19-20)

My one and only thought was "I'm going to get sick real quick and die" (T1: L 21)

The next two years were a bit of a haze. I felt dirty and ashamed and somehow became convinced that becoming HIV positive was all my own fault. (T1: L41-42)

It really hurt to feel that someone who I knew and trusted was avoiding me just because I had an illness that I could do nothing about. I was still the same person she had been speaking to all along. I felt it was me in the wrong not her. (T1: L112-115)

You see so much publicity for diseases like heart disease and cancer, but the image of HIV is still swathed in secrecy and shame. (T1: L140-141)

We need the same kind of care and compassion, the same as anyone with a terminal illness, but if no-one will talk about it you know discuss having HIV it will always remain a dirty secret. (T1: L144-145)

Mark

At work the one problem I had was that when I became unwell, I couldn't tell anyone in senior management or my immediate colleagues at work. I couldn't go to the Personnel Department because even if it was only said to someone in Personnel believe you me when I say it would get around the office, around the building like wildfire and everyone would know. (T2: L32-36)

So when I was feeling ill which was a lot of the time I had to disguise it as best I could by taking days off as holiday. (T2: L37-38)

In those days it was a death sentence.(T2: L43)

Funnily enough, one area where I did get some prejudice, which surprised me, was from some gay friends who I would have thought would have known better. They suddenly dropped me like a ton of bricks. Probably, they didn't want to be associated with someone who was HIV positive at that time because there was prejudice around having HIV and to have HIV was an instant death sentence. They didn't want to seen around with somebody who would perhaps reflect on them that they might be associated with something like that and also in a mercenary sense you find out who your friends are when things start going wrong, but it did surprise me that it was in the Gay friends I had, close friends. (T2: L45-49)

I think most people think it’s something that affects gay men and that we are responsible for spreading the virus, transmitting it. so you often get the reaction from someone who is heterosexual and having unsafe sex that they can’t get HIV. It is not something that can ever affect their community. (T2: L53-59)

Supposing I had cancer I could more openly talk about in a freer way and would probably get a more sympathetic reaction, more understanding and a kindly response from other people, whereas if I were tell people in the wider community, excluding health professionals and doctors, that I have HIV then I would not be able predict the reaction, even all information available today and the fact it is no longer a death sentence so even the fear has been taken away there is still a huge prejudice in all sorts of groups, where you might think there would be compassion, but there often isn’t. You can get you're an evil type of person reaction or you’re a sinner and it’s against God’s will and all that kind of thing. (T2: L150-160)

I would be very reluctant to openly share that I had HIV in a group, I also know that it says more about my fear and anxiety about how others are going to react rather than possibility the reality. I would be guarded about my disclosure until I got to know the others in the group and felt safe in the knowledge that I would to be judged, but there is need to protect oneself, but it is also challenging one’s own inbuilt prejudice about others and they might be thinking. (T:2 L175-181)

You are likely to be reticent about you disclose given the innate prejudice that is ever present when considering HIV. People still have the misunderstanding that you can pick up HIV from a toilet seat or touching somebody so there is a big fear still there in the general population. T:2 L193-197)

Tina

It’s naive, but despite growing up with the terrifying Government campaigns that warned that HIV kills I still didn't think I could catch it. Didn't think HIV was something I could catch myself. (T3: L14-16)

I was a such a shock I could hardly breathe. I could not take it all in. I was only 22 with what I thought was my whole life ahead of me. What I was being told it just didn't register with me. All I could think of, think about was I’m going to die. Was it going to happen tomorrow, in three years or ten? I felt utterly alone, numb and sick and I asked if I could phone my Mum. (T3: L51-55)

All of a sudden I felt sick. It was as if I had been handed a death sentence. (T3: L58)

What am I going to do? How can I live with HIV? These thoughts kept going round my head. (T3: L62-63)

Suddenly I felt like I had a big secret. Half of me wanted to tell everyone, but at the same time I was too frightened of the consequences. Being HIV-positive felt like a massive stigma, a taboo no-one talks about it. It is not something you can speak openly about. (T3: L87-90)

It wasn't until I went swimming a couple of days later that the fear enveloped me. I was in the pool and I suddenly felt convinced that people could tell I had HIV. All those negative Government slogans and adverts with tombstones filled my mind. I felt so scared, so frightened. (T3: L103-108)

I felt it was my fault the condom had spilt, but I didn't want to find the man who had given me HIV. It was much more important for me to figure out how to live with it.(T3: L179-181)

Having HIV made me more likely, left me prone to infection. The first I got a cold I was really petrified. I soon recovered and know now not to panic. (T3: L213-216)

I try to boost my immune system holistically with plenty of healthy food, massage and exercise. I always try to stay optimistic about the future. (T3: L221-222)

It's not like a nine-five job where you can switch off at home time. I try to look after myself. I make sure I get plenty of sleep every night. I've cut down on alcohol and changed my diet to include plenty of organic fresh food as possible.(T3: L224-228)

One person did react quite badly and banned me from visiting their house and seeing their five year old daughter as he was so frightened. I tried to explain to him HIV can only be passed on through blood, semen or breast milk, not from kissing or toilet seats as people thin, but he would not listen. He just did not want to know. (T3: L240-245)

I've lived with HIV for a little over 8 years now, but discrimination and ignorance surrounding the disease can still be very upsetting. There are days when I break down crying on a crowded bus or tube because I suddenly feel so alone. (T3: L252-255)

Gary

I think now as positive sort of see it as a closure, sort of end, you don't see a future so i didn't plan ahead so to speak. I expected to die years ago, so I'm still surprised I'm still here now. So I feel like I stopped for 20 years and now I've restarted. (T4: L4-9)

I had to stop working so I could start looking after myself then there was a phase of hibernation so it has been like hibernation. I think that's a brilliant word for it where you just look after yourself and just keep well because that's all you could do ten fifteen years ago as nobody knew what was round the corner at that stage. (T4: L10-14)

There was that mortality thing going on in the back of my mind as well so there was a detachment and isolation that comes into it as well as you didn't want to hurt family members, my family don't know. (T4: L15- 18)

I don't think you should allow it (HIV) to consume you, you should live with it, learn to deal with it, treat not quite like a friend, but treat your body as temple in s way, don't burn the candle at birth end, give yourself time to recover, that sort of thing because it's always there, but never let it consume you.(T4: L54-57)

I've seen people who reject people, but I would know they were positive themselves so there is a whole cycle of fear going on as well. They're rejecting because they don't want people to suspect they might be positive because of the association. (T4: L68-71)

You can become really isolated, you can get trapped in your own little world really, become completely delusional and that's the worst thing you can be. (T4: L87-89)

I know quite a few people who are self-absorbed and is mainly because of isolation. When you get detached you can slip into your own world quite easily if you don't have friends to challenge you. (T4: L95-97)

It (HIV) does take over their lives. I've seen it happen, but what's nice is now that with the treatments that are available now is that people are being encouraged to carry on with their live, get back to work, form friendships. It's not the death sentence it was before. It has moved on, my generation didn't have this choice, so now we are trying make this change, to get back and reconnect which is the difficult bit. (T4: L121-126)

In the '80s you were very isolated when you got given your positive diagnosis. You were scared, especially in the black community, you got stigmatised, it was horrible and it still is horrible now to some extent. I don't think it ha completely gone away, it's still here, that's still a hard thing to deal with, the stigma. (T4: L149-153)

The worst thing about HIV is that it's very visible and that scares people. It's so visible and that's what causes all the anxiety, you know. And so compared to other illnesses like cancer, for example, cancer if you've had cancer you get more sympathy even those who might have been smoking sixty a day can get that sympathy you know it's like "You poor thing". (T4: L162-167)

Well I mean a haemophiliac infected with HIV through a blood transfusion would get definitely more sympathy because it wasn't their choice, it wasn't a sexual thing. Likewise a child would probably get more sympathy because they were born with it - it wasn't their fault - gay men on the other hand have it rough, still have a hard time of it because some people think that they are the cause of it. (T4: 174-178)

It can also be a way of trying to protect yourself from getting HIV by identifying certain groups who are more likely to be at risk and stigmatising those individuals and groups so you can say “I’m not one of those. That’s not what I do”. That way you can think yourself safe. It’s quite sad really. It can be a way of thinking I’m special, different, that it can’t happen to me, but of course it can and does. It can be a real wake up call. (T4: L344-349)

When I was first diagnosed I was given five years maximum, but that was twenty years ago. The hardest thing was not dying after five years, I know that might sound strange, but I had spent all my time preparing myself and my family and friends for the inevitable and when it didn't happen, it initially felt like a let down. Then I started to live again, think about having a future, dare to have a future. Learn to live with HIV. Not make it the whole of my life, my identity. I am someone living with HIV, but that is only one aspect of my life. Some people identify with HIV. It becomes them, who they are, their identity. They say “I am HIV” when talking to friends and family. That’s when having HIV can become all consuming. Then your whole life revolves around HIV, having HIV, that is really not healthy. (T4: L358-368)

Nigel

I felt numb, I couldn't take in what I was being told. Didn't really process it. (T5: L33-34)

Nowadays HIV is survivable, when I’m having a bad day I have to keep reminding myself that having HIV is survivable. (T5: L42-44)

My family know I’ve got HIV. I told some of my gay friends. I thought there was no point keeping it a secret. You hear a lot about stigma. I know some people have had really bad experiences when they have disclosed their status to others. You can let fear and anxiety get the better of you, but I’ve nothing to be ashamed off, I will tell people if I think they need to know and let them deal with it. (T5: L69-74)

Getting HIV made me think about what really mattered. You know, what did I want to achieve in life. I didn't find God and get all spiritual, but it did make me question my values. I used to be very driven at work, very materialistic very hedonistic, not now. I am much more reflective and I'm more considered in how I approach life. (T5: L84-87)

For me, it was about taking stock. It was about saying to myself "What are my choices?" I asked questions, found myself a good consultant and took charge of my situation. I don't allow myself to have self pity. I'm not one for self pity, never have been. I always try to face my challenges and learn from them. (T5: L114-117)

Having HIV has given a focus I didn't have before. I try to make my health a priority now. Staying well is the key to living with HIV. (T5: L162-163)

Claude

So when I tested positive it was a case of oh well s**t happens. That was it really. I didn't think anymore about it until I got home. I was living on my own at the time, so I got home, I had taken a few days off work and I made myself a coffee and lit a cigarette. I was numb. (T6: L22-25

Testing positive wasn't meant to happen. I kept repeating it over and over in my head. Life was living as you're too long time dead. That's what I'd always believed. That's how I'd lived my life. (T6: L34-36)

I don't think I was ready to engage with anyone. Not ready to have the conversation about being HIV positive. It wasn't something I discussed with friends, even those that had HIV. It wasn't really a conversation I really wanted to have, to be perfectly honest. (T6: L42-45)

I'm not saying I regret my life. I had a good time, but now I want something more substantial, more fulfilling, more worthwhile. That's what being positive had done. It has made me more reflective. It has made think more about what's important. (T6: L54-57)

It took me nearly a year to tell anyone, my family and friends, that I was HIV positive. I suppose I thought that if I didn't say anything, you know, tell anyone, then it would not be real. I could still believe, or at least pretend that I was still HIV negative. (T6: L64-67)

I did sort of go into hibernation. I withdrew from the world. (T6: L68-69)

Some of my friends did ask me if there was anything wrong. I wouldn't answer the question and would often just change the subject. I don't think it was it was because I didn't think they would understand. At the time it was more to do with not wanting to talk about it, HIV. (T6: L71-74)

It took me a long time to understand that being infected with HIV was not reversible. When I say it took a long time for me to understand I mean on an emotional level. At the time the only way I could deal with having HIV was to split off my emotions. I deal with everything a purely intellectual cognitive level. (T6: L78-81)

I only started to come to terms with having HIV when I started to engage with it on an emotional level. I realised I had to embrace having HIV. By that I mean I accept it as part of you and what I am, but at the same time not allow it to define me. (T6: L89-91)

I've seen lots of people with HIV be consumed by it. It becomes their life. They make a career out of having HIV. It's all they seem to think and talk about. I think that's a mistake. You need to have a life that's not just about having HIV. Admittedly, in the past when HIV was a death sentence the only way to survive even short term was to focus on having HIV and the most out of your life in the time you had left. Now HIV is a chronic condition and there are many treatment options it's not like it was. I mean, there is a lot less anxiety, but it's still a challenge. You still have to keep on top of it. There is no room for complacency. (T6: L89-98)

For me having HIV is about choosing how to live with HIV. As I've already said you can choose to allow HIV to consume you or you can embrace. I don't really like the word "embrace", but I think you know what I mean. Perhaps, acceptance it a better word. You have to become proactive. When I go to see my HIV clinicians I engage with them and ask about staying healthy, explore what options are available to me. (T6: L109-114)

In the beginning when I was first diagnosed I did feel isolated, but to be honest I did isolate myself. (T6: L129-130)

One of the hardest things and most difficult things about having HIV is having to disclose your HIV status to other people. You can imagine the conversation can't you? Hello my name is….and I’m HIV positive. Not exactly a good chat up line, is it? I know it’s different now. HIV is almost commonplace in the gay community at least, but back in the day when I was newly diagnosed things were very different. (T6: L137-141)

The stigma around having HIV was huge. There was so much fear. I could understand why there was such a hostile reaction from the straight world and how people in the gay world became the target for so much anger and hostility from the straight community. The straights had always been hostile and AIDS give them the reason the justification for how they felt towards us. We were to blame and the cause of AIDS. We deserved to suffer. (T6: L143-147)

Soon as AIDS started to affect the straight world things changed. If you were a straight woman or a child born with HIV, or you became infected with HIV through a blood transfusion then you were a victim and got sympathy, but if you were a gay man with HIV you got condemnation from everywhere. (T6: L 148-151)

Even the gay community turned on itself. Again I think it was fear that made a lot of gay men reject someone as soon as they found out that person was HIV positive. Friends would suddenly stop speaking to one another and blank each other in the street or in a club. It was the fear of being seen with someone who was known to have HIV in case you were thought to have it as well. It was this stigma by association that made having HIV almost unbearable for a lot of my friends who were diagnosed around the same time as me.(T6: L151-157)

One friend stopped talking to me when they found out I was HIV positive. He was angry when I told him I was HIV positive. I was quite shocked by his reaction, to this day I don't really understand what made him react the way he did. He was so irrational. Again I think it was fear as much as anything. (T6: L157-160)

HIV cannot be the focus of your life otherwise you can easily become consumed by it. Not let it, HIV, define you. If you do it can take away your choices. I am the same person I was before I tested HIV positive. I may have changed my attitude to life as result of testing positive, but I’m more than my diagnosis. My diagnosis is not what defines me. (T6: L170-174)

Having HIV in a strange way has proved to be an immense gift for me. It has made me think about my life, what's important, what matters, what doesn't matter, what I want to achieve before I die. I don't want to have regrets. (T6: L194-196|)

Younger people on the gay scene will do everything to avoid thinking about HIV. I think they think HIV is no big deal anymore, but at the same time they don't want to get it. It doesn't make sense, does it? It's a real contradiction. I think PrEP has a lot to do with it. I think it has given a lot of people a false sense of security. They see to think that if they are on PrEP they can't get positive. It may significantly reduce the risk, but the risk is still there. (T6: L211-216)

Formulating meanings

The next stage of the data analysis involved formulating meaning from each of the significant statements:

The images that I had in my head were falling tombstones from those scary HIV adverts that were around in the early 1980's. (T1: L19-20)

They were reminded of the scary HIV advertisements they had seen in the 1980's.

My one and only thought was "I'm going to get sick real quick and die". (T1: L21)

Their one and only thought was that they were going to get sick real quick and die.

The next two years were a bit of a haze. I felt dirty and ashamed and somehow became convinced that becoming HIV positive was all my own fault. (T1: L41-42)

They felt dirty, ashamed and convinced that becoming HIV positive was all their own fault.

It really hurt to feel that someone who I knew and trusted was avoiding me just because I had an illness that I could do nothing about. I was still the same person she had been speaking to all along. I felt it was me in the wrong not her. (T1: L112-115)

They felt really hurt when someone they knew and trusted avoided them because they had an illness he/she could do nothing about. They had not changed. He/she felt they were in the wrong not the person avoiding them.

You see so much publicity for diseases like heart disease and cancer, but the image of HIV is still swathed in secrecy and shame. (T1: L140-141)

Diseases such as heart disease and cancer get publicity, but HIV is still swathed in secrecy and shame.

We need the same kind of care and compassion, the same as anyone with a terminal illness, but if no-one will talk about it you know discuss having HIV it will always remain a dirty secret. (T1: 144-145)

People living with HIV need the same care and compassion that is given to people suffering from other terminal illnesses. However, if HIV is not openly discussed it will always remain a dirty secret.

At work the one problem I had was that when I became unwell, I couldn't tell anyone in senior management or my immediate colleagues at work. I couldn't go to the Personnel Department because even if it was only said to someone in Personnel believe you me when I say it would get around the office, around the building like wildfire and everyone would know. (T2: L32-36)

When he/she became unwell they could not inform anyone at work as to the real reason why they were sick because they feared the information disclosed would not remain confidential.

So when I was feeling ill which was a lot of the time I had to disguise it as best I could by taking days off as holiday. (T2: L:37-38)

When he/she felt ill they had to disguise the fact as best they could by taking days off as holiday.

In those days it was a death sentence. (T2: L43)

In the past having HIV was a death sentence.

Funnily enough, one area where I did get some prejudice, which surprised me, was from some gay friends who I would have thought would have known better. They suddenly dropped me like a ton of bricks. (T2: L45-47)

Probably, they didn't want to be associated with someone who was HIV-positive at that time because there was prejudice around having HIV and to have HIV was an instant death sentence. They didn't want to seen around with somebody who would perhaps reflect on them that they might be associated with something like that and also in a mercenary sense you find out who your friends are when things start going wrong, but it did surprise me that it was in the gay friends I had, close friends. (T2: L53-59)

One surprising area of prejudice was when gay friends avoided contact with the person infected with HIV. They appeared not to want to be seen to be associated with someone infected with HIV because of the prejudice attached to having HIV. There was a sense of stigma by association.

I think most people think it’s something that affects gay men and that we are responsible for spreading the virus, transmitting it. so you often get the reaction from someone who is heterosexual and having unsafe sex that they can’t get HIV. It is not something that can ever affect their community. (T2: L140-144)

It is a commonly held belief that HIV only affects gay men and that they are responsible for spreading the virus. At the same time heterosexuals believe they can have unsafe sex because they think they are not at risk of infection from HIV.

Supposing I had cancer I could more openly talk about in a freer way and would probably get a more sympathetic reaction, more understanding and a kindly response from other people, whereas if I were tell people in the wider community, excluding health professionals and doctors, that I have HIV then I would not be able predict the reaction, even all information available today and the fact it is no longer a death sentence so even the fear has been taken away there is still a huge prejudice in all sorts of groups, where you might think there would be compassion, but there often isn’t. You can get you're an evil type of person reaction or you’re a sinner and it’s against God’s will and all that kind of thing. (T2: L150-160)

He/she believes they could talk more openly and freely about their illness if they were suffering from cancer and would be more likely to receive a sympathetic reaction from other people whereas there is still prejudice surrounding having HIV. People living with

HIV feel there is a lack of compassion towards them from others who are not infected. People living with HIV are sometimes labelled as evil or sinful by others.

I would be very reluctant to openly share that I had HIV in a group, I also know that it says more about my fear and anxiety about how others are going to react rather than possibility the reality.

I would be guarded about my disclosure until I got to know the others in the group and felt safe in the knowledge that I would to be judged, but there is need to protect oneself, but it is also challenging one’s own inbuilt prejudice about others and they might be thinking. (T2: L175-181)

He/she would be reluctant to openly share that they had HIV in a group of strangers because of the fear and anxiety experienced by the infected person. The fear and anxiety comes from not being able to predict how other group members might react to hearing that someone in the group has HIV.

You are likely to be reticent about you disclose given the innate prejudice that is ever present when considering HIV. People still have the misunderstanding that you can pick up HIV from a toilet seat or touching somebody so there is a big fear still there in the general population. (T2: L193-196)

He/she would be think carefully about what they disclose to others because of the innate prejudice that exists about HIV. For many people there is lack of understanding about how you can become infected with HIV and this creates a fear response in the general public towards anyone infected with HIV.

It’s naive, but despite growing up with the terrifying Government campaigns that warned that HIV kills I still didn't think I could catch it. Didn't think HIV was something I could catch myself. (T3: L14-16)

He/she was naive in thinking that they could not becoming infected with HIV.

I was a such a shock I could hardly breathe. I could not take it all in. I was only 22 with what I thought was my whole life ahead of me. What I was being told it just didn't register with me. All I could think of, think about was I’m going to die. Was it going to happen tomorrow, in three years or ten? I felt utterly alone, numb and sick and I asked if I could phone my Mum. (T3: L51-55)

He/she was so shocked that they could hardly breathe and not take it all in. They thought they had their whole life ahead of them. He/she could not process what they had been told. All he/she could think of was that they were going to die. He/she felt utterly alone, numb and sick and needed to phone their mother.

All of a sudden I felt sick. It was as if I had been handed a death sentence. (T3: L38)

He/she suddenly felt sick as if they had been handed a death sentence .

What am I going to do? How can I live with HIV? These thoughts kept going round my head. (T3: L62)

He/she had the questions "what am I going to do?" and "how can I live with HIV?" going round inside their head.

Suddenly I felt like I had a big secret. Half of me wanted to tell everyone, but at the same time I was too frightened of the consequences. Being HIV-positive felt like a massive stigma, a taboo no-one talks about it. It is not something you can speak openly about. (T3: L87-90)

He/she felt that they had a big secret. They wanted to tell everyone, but at the same time they were too frightened of the consequences of disclosing their status. He/she felt it was a massive stigma and a taboo that could not be spoken openly about.

It wasn't until I went swimming a couple of days later that the fear enveloped me. I was in the pool and I suddenly felt convinced that people could tell I had HIV. All those negative Government slogans and adverts with tombstones filled my mind. I felt so scared, so frightened. (T3: L103-108)

He/she went swimming a couple of days after they had tested HIV positive and they felt the fear envelope them. He/she suddenly became convinced that other people could tell that he/she had HIV. All the negative Government slogans and advertisements with tombstones filled his/her mind and he/she felt so sacred and frightened.

I felt it was my fault the condom had spilt, but I didn't want to find the man who had given me HIV. (T3: L179-180)

He/she felt it was their fault the condom had split, but they did not want to find the person who had infected them with HIV.

It was much more important for me to figure out how to live with it. (T3: L180-181)

It is more important for someone infected with HIV to figure how to live with it once they were infected.

Having HIV made me more likely, left me prone to infection. The first I got a cold I was really petrified. I soon recovered and know now not to panic. (T3: L213-216)

Having HIV can make more you prone to other infections. The first time he/she caught a cold they were petrified. However, they soon recovered and now have learnt not to panic when they get a secondary infection.

I try to boost my immune system holistically with plenty of healthy food, massage and exercise. I always try to stay optimistic about the future. (T3: L221-222)

He/she tries to boost their immune system holistically with plenty of healthy food, massage and exercise. In this way he/she always tries to remain optimistic about the future.

It's not like a nine to five job where you can switch off at home time. I try to look after myself. I make sure I get plenty of sleep every night. I've cut down on alcohol and changed my diet to include plenty of organic fresh food as possible. (T3: L224-228)

It is not like a nine to five job where he/she can switch off at home time. He/she tries to look after themselves by making sure they get plenty of sleep. He/she has also cut down on the amount of alcohol they consume and has changed their diet to include as much organic fresh food as possible.

One person did react quite badly and banned me from visiting their house and seeing their five year old daughter as he was so frightened. I tried to explain to him HIV can only be passed on through blood, semen or breast milk, not from kissing or toilet seats as people thin, but he would not listen. He just did not want to know. (T3: L240-245)

He/she experienced a bad reaction from a person they visited. They were banned from seeing this person's five year daughter because of the father's fear of HIV. The father did

not want to listen to any explanation they were given about how you can become infected with HIV.

I've lived with HIV for a little over 8 years now, but discrimination and ignorance surrounding the disease can still be very upsetting. There are days when I break down crying on a crowded bus or tube because I suddenly feel so alone. (T3: L252-255)

He/she has felt upset by the discrimination and ignorance surrounding the disease. He/she still breaks down crying because they suddenly feel so alone.

I think now as positive sort of see it as a closure, sort of end, you don't see a future so I didn't plan ahead so to speak. I expected to die years ago, so I'm still surprised I'm still here now. So I feel like I stopped for 20 years and now I've restarted. (T4: L3-9)

He/she thought of being HIV positive as an ending, closure where they did not see a future and so they did not make plans for the future. He/she expected to die years ago so they are surprised they are still alive. His/her life stopped for 20 years and has only now re-started.

I had to stop working so I could start looking after myself then there was a phase of hibernation so it has been like hibernation. I think that's a brilliant word for it where you just look after yourself and just keep well because that's all you could do ten fifteen years ago as nobody knew what was round the corner at that stage. (T4: L10-14)

He/she described looking after him/herself as a period of hibernation where the most important thing was to remain healthy because very little was known about HIV fifteen years ago.

There was that mortality thing going on in the back of my mind as well so there was a detachment and isolation that comes into it as well as you didn't want to hurt family members, my family don't know. (T4: L15-17)

In the back of his/her mind was their mortality. A sense of detachment and isolation is also present because he/she did not want to hurt his/her family and so they have not disclosed their HIV positive status to any family members.

I don’t think you should allow it (HIV) to consume you, you should live with it, learn to deal with it, treat not quite like a friend, but treat your body as temple in s way, don't burn the candle at both ends, give yourself time to recover, that sort of thing because it’s always there, but never let it consume you. (T4: L54-57)

He/she does not think you should allow HIV to consume you. Instead you should live with, and learn to deal with it. Treat it not quite like a friend, but treat your body with respect and give yourself time to recover. The one thing you must never do is let it consume you.

I’ve seen people who reject people, but I would know they were positive themselves so there is a whole cycle of fear going on as well. They’re rejecting because they don’t want people to suspect they might be positive because of the association. (T4: L68-71)

Some people who have HIV reject others who also have HIV because of the fear of being stigmatised by association.

You can become really isolated, you can get trapped in your own little world really, become completely delusional and that’s the worst thing you can be. (T4: L87-89)

Having HIV can make you become isolated and you get trapped in your own little world. Some people can even become delusional as a result of the isolation.

I know quite a few people who are self-absorbed and is mainly because of isolation. When you get detached you can slip into your own world quite easily if you don’t have friends to challenge you. (T4: L95-97)

Some people living with HIV can become self-absorbed because of the isolation. When you become detached from reality you can slip into your own world. This can easily happen, particularly if you do not have people around you who are prepared to challenge you.

It (HIV) does take over their lives. I’ve seen it happen, but what’s nice is now that with the treatments that are available now is that people are being encouraged to carry on with their lives, get back to work, form friendships. It’s not the death sentence it was before. It has moved on, my generation didn't have this choice, so now we are trying make this change, to get back and reconnect which is the difficult bit. (T4: L121-126)

People who have HIV can become self-absorbed because of their isolation. Having HIV has taken over their lives. Now people living with HIV are being encouraged to carry on with their lives, find employment and socialise. It is no longer a death sentence for newly diagnosed people, but for previous generations, who did not have the treatment choices that are now available it is more difficult to make that reconnection.

In the 80s you were very isolated when you got given your positive diagnosis. You were scared, especially in the black community, you got stigmatised, it was horrible and it still is horrible now to some extent. I don't think it ha completely gone away, it's still here, that's still a hard thing to deal with, the stigma. (T4: L149-153)

In the 80s people living with a positive diagnosis were very isolated. They were scared, especially in the black community where they got stigmatised. It was horrible then and still is horrible now to some extent. Stigma is a hard thing to deal with.

The worst thing about HIV is that it's very visible and that scares people. It's so visible and that's what causes all the anxiety, you know. And so compared to other illnesses like cancer, for example, cancer if you've had cancer you get more sympathy even those who might have been smoking sixty a day can get that sympathy you know it's like "You poor thing". (T4: L162-167)

The worst thing about HIV is that it can be very visible and that is what scares people the most. It is this visibility that causes anxiety in both the person infected with HIV and in others. There is a perception amongst many people living with HIV that they would get more sympathy if they were suffering from another terminal illnesses even if your lifestyle had contributed to your health condition.

Well I mean a haemophiliac infected with HIV through a blood transfusion would get definitely more sympathy because it wasn't their choice, it wasn't a sexual thing. Likewise a child would probably get more sympathy because they were born with it - it wasn't their fault - gay men on the other hand have it rough, still have a hard time of it because some people think that they are the cause of it. (T4: L174-178)

Individuals who become infected with HIV through a blood transfusion or if you are a child born with HIV it seems that you are more likely to get other people's sympathy because it is not regarded as their fault. However, gay men are given a hard time because they are perceived to be responsible for both the origin and the spread of HIV.

It can also be a way of trying to protect yourself from getting HIV by identifying certain groups who are more likely to be at risk and stigmatising those individuals and groups so you can say "I'm not one of those. That's not what I do". That way you can think yourself safe. It's quite sad really. It can be a way of thinking I'm special, different, that it can't happen to me, but of course it can and does. It can be a real wake up call. (T4: L344-349)

As a way of the general public protecting themselves from becoming infected with HIV some groups have been identified as being more at risk. These "at risk" groups have become stigmatised. The level of perceived risk is rationalised by some people by them thinking "I'm not one of those. That's not what I do." Therefore, it can be a way of thinking that he/she is special, different, that it cannot happen to them, but it can. When they do become infected with HIV it can be a real wake up call.

When I was first diagnosed I was given five years maximum, but that was twenty years ago. The hardest thing was not dying after five years, I know that might sound strange, but I had spent all my time preparing myself and my family and friends for the inevitable and when it didn't happen, it initially felt like a let down. Then I started to live again, think about having a future, dare to have a future. Learn to live with HIV. Not make it the whole of my life, my identity. I am someone living with HIV, but that is only one aspect of my life. Some people identify with HIV. It becomes them, who they are, their identity. They say "I am HIV" when talking to friends and family. That's when having HIV can become all consuming. Then your whole life revolves around HIV, having HIV, that is really not healthy. (T4: L358-368)

Having been told they had only five years to live after being diagnosed with HIV he/she began to prepare him/herself, along with family and friends for the inevitable. When this did not happen it felt like a let down. They then had to start to living again, think about having a future, dare to have a future. It is about learning to live with HIV and not make

it your whole life or identity. When you make having HIV your identity by saying "I am HIV" it can consume you because then your whole life revolves around having HIV which is really unhealthy.

I felt numb, I couldn't take in what I was being told. Didn't really process it. (T5: L33-34)

At the time they were unable to process what they were being told. They were left feeling numb.

Nowadays HIV is survivable, when I'm having a bad day I have to keep reminding myself that having HIV is survivable. (T5: L42-44)

You have keep reminding yourself that having HIV is survivable.

My family know I've got HIV. I told some of my gay friends. I thought there was no point keeping it a secret. You hear a lot about stigma. I know some people have had really bad experiences when they have disclosed their status to others. You can let fear and anxiety get the better of you, but I've nothing to be ashamed off, I will tell people if I think they need to know and let them deal with it. (T5: L69-74)

Some people are anxious and fearful about disclosing their HIV positive status to family and friends because there can still be a stigma to having HIV. Keeping your HIV positive status a secret can make your fear and anxiety worse. It can get the better of you. Having HIV is nothing to be ashamed about.

Getting HIV made me think about what really mattered. You know, what did I want to achieve in life. I didn't find God and get all spiritual, but it did make me question my values. I used to be very driven at work, very materialistic very hedonistic, not now. I am much more reflective and I'm more considered in how I approach life. (T5: L84-87)

Being HIV positive can make you re-evaluate your values and life choices.

For me, it was about taking stock. It was about saying to myself "What are my choices?" I asked questions, found myself a good consultant and took charge of my situation. I don't allow myself to have self pity. I'm not one for self pity, never have been. I always try to face my challenges and learn from them. (T5: L114-117)

Being HIV positive is about taking stock and considering your choices. Not allowing yourself to have self pity. It is also about facing your challenges and learning from them.

Having HIV has given a focus I didn't have before. I try to make my health a priority now. Staying well is the key to living with HIV. (T5: L162-163)

Being HIV positive makes you focus. Living with HIV is about making your health your priority.

So when I tested positive it was a case of oh well s**t happens. That was it really. I didn't think anymore about it until I got home. I was living on my own at the time, so I got home, I had taken a few days off work and I made myself a coffee and lit a cigarette. I was numb. (T6: L22-25)

Testing HIV positive was experienced as being inevitable, but left this person feeling numb.

Testing positive wasn't meant to happen. I kept repeating it over and over in my head. Life was living as you're too long time dead. That’s what I’d always believed. That’s how I’d lived my life. (T6: L34-36)

This person could not believe they had tested HIV positive. It was not meant to have happened.

I don’t think I was ready to engage with anyone. Not ready to have the conversation about being HIV positive. It wasn't something I discussed with friends, even those that had HIV. It wasn't really a conversation I really wanted to have, to be perfectly honest. (T6: L42-45)

Becoming HIV positive was not a conversation he/she wanted to have with anyone.

I’m not saying I regret my life. I had a good time, but now I want something more substantial, more fulfilling, more worthwhile. That’s what being positive had done. It has made me more reflective. It has made think more about what’s important. (T6: L54-57)

Since becoming HIV positive he/she reflected on their hedonistic lifestyle and realised that they wanted their life to be more substantial, fulfilling and worthwhile.

It took me nearly a year to tell anyone, my family and friends, that I was HIV positive. I suppose I thought that if I didn't say anything, you know, tell anyone, then it would not be real. I could still believe, or at least pretend that I was still HIV negative. (T6: L64-67)

Disclosing to others you have HIV can be difficult. By not disclosing your HIV positive status you can pretend to yourself that you do not have HIV.

I did sort of go into hibernation. I withdrew from the world. (T6: L68-69)

After testing HIV positive some people go into hibernation and withdrew from the world.

Some of my friends did ask me if there was anything wrong. I wouldn't answer the question and would often just change the subject. I don't think it was it was because I didn't think they would understand. At the time it was more to do with not wanting to talk about it, HIV. (T6: L71-74)

For some people having HIV is not something they want to discuss with anyone.

It took me a long time to understand that being infected with HIV was not reversible. When I say it took a long time for me to understand I mean on an emotional level. At the time the only way I could deal with having HIV was to split off my emotions. I deal with everything a purely intellectual cognitive level. (T6: L78-81)

It can often take a long to understand what it means to be HIV positive on an emotional level. It is often easier to deal with having HIV on a purely intellectual level.

I only started to come to terms with having HIV when I started to engage with it on an emotional level. I realised I had to embrace having HIV. By that I mean I accept it as part of you and what I am, but at the same time not allow it to define me. (T6: L89-91)

It is only when you start to deal with having HIV on an emotional that you really begin to process what it means to be HIV positive and accept it without letting HIV define who you are.

I’ve seen lots of people with HIV be consumed by it. It becomes their life. They make a career out of having HIV. It’s all they seem to think and talk about. I think that’s a mistake. You need to have a life that’s not just about having HIV. Admittedly, in the past when HIV was a death sentence the only way to survive even short term was to focus on having HIV and the most out of your life in the time you had left. Now HIV is a chronic condition and there are many treatment options it's not like it was. I mean, there is a lot less anxiety, but it's still a challenge. You still have to keep on top of it. There is no room for complacency. (T6: L89-98)

Some people who are HIV positive become consumed by having HIV. It is all they think and talk about. It becomes their life. It is a mistake to allow being HIV-positive consume you. You need to have a life outside of HIV. It may be now a chronic condition, but it is a challenge living with HIV.

For me having HIV is about choosing how to live with HIV. As I've already said you can choose to allow HIV to consume you or you can embrace. I don't really like the word "embrace", but I think you know what I mean. Perhaps, acceptance it a better word. You have to become proactive. When I go to see my HIV clinicians I engage with them and ask about staying healthy, explore what options are available to me. (T6: L109-114)

For some people having HIV is about identifying your choices and how you want to live with being HIV positive. It is about acceptance and being proactive in the way you engage with your HIV clinicians.

In the beginning when I was first diagnosed I did feel isolated, but to be honest I did isolate myself. (T6: L129-130)

Newly diagnosed HIV positive individuals can feel isolated, however some may isolate themselves.

One of the hardest things and most difficult things about having HIV is having to disclose your HIV status to other people. You can imagine the conversation can't you? Hello my name is….and I'm HIV positive. Not exactly a good chat up line, is it? I know it's different now. HIV is almost commonplace in the gay community at least, but back in the day when I was newly diagnosed things were very different. (T6: L137-141)

Disclosing your HIV positive status to others can be both hard and difficult.

The stigma around having HIV was huge. There was so much fear. I could understand why there was such a hostile reaction from the straight world and how people in the gay world became the target for so much anger and hostility from the straight community. The straights had always been hostile and AIDS give them the reason the justification for how they felt towards us. We were to blame and the cause of AIDS. We deserved to suffer. (T6: L143-147)

There was a huge stigma around having HIV and a great deal of fear. People in the gay world were perceived as being to blame for AIDS. People in the gay world deserved to suffer for the role they were perceived to play in the cause and spread of AIDS.

Soon as AIDS started to affect the straight world things changed. If you were a straight woman or a child born with HIV, or you became infected with HIV through a blood transfusion then you were a victim and got sympathy, but if you were a gay man with HIV you got condemnation from everywhere. (T6: L 148-151)

If you were a woman, a child or someone who had become infected with HIV through a blood transfusion you would be seen as a victim and likely to receive sympathy, whereas gay men with HIV would be condemned for having HIV.

Even the gay community turned on itself. Again I think it was fear that made a lot of gay men reject someone as soon as they found out that person was HIV positive. Friends would suddenly stop speaking to one another and blank each other in the street or in a club. It was the fear of being seen with someone who was known to have HIV in case you were thought to have it as well. It was this stigma by association that made having HIV almost unbearable for a lot of my friends who were diagnosed around the same time as me.(T6: L151-157)

Fear within the gay community made the gay community turn on itself. It was this stigma by association that made living with HIV unbearable for a lot of gay men.

One friend stopped talking to me when they found out I was HIV positive. He was angry when I told him I was HIV positive. I was quite shocked by his reaction, to this day I don't really understand what made him react the way he did. He was so irrational. Again I think it was fear as much as anything. (T6: L157-160)

One gay man disclosed he was HiV positive to a gay friend. His friend’s angry reaction shocked him and he could not understand why his friend was being so irrational.

HIV cannot be the focus of your life otherwise you can easily become consumed by it. Not let it, HIV, define you. If you do it can take away your choices. I am the same person I was before

I tested HIV positive. I may have changed my attitude to life as result of testing positive, but I'm more than my diagnosis. My diagnosis is not what defines me. (T6: L170-174)

You cannot let HIV become the focus of your life otherwise it can easily consume you. It can take away your choices. You are more than your diagnosis. Your diagnosis does not define who you are as person.

Having HIV in a strange way has proved to be an immense gift for me. It has made me think about my life, what's important, what matters, what doesn't matter, what I want to achieve before I die. I don't want to have regrets. (T6: L194-196|)

Having HIV can make you think about what is important, what matters, what does not matter in your life and what you want to achieve in life.

Younger people on the gay scene will do everything to avoid thinking about HIV. I think they think HIV is no big deal anymore, but at the same time they don't want to get it. It doesn't make sense, does it? It's a real contradiction. I think PrEP has a lot to do with it. I think it has given a lot of people a false sense of security. They see to think that if they are on PrEP they can't get positive. It may significantly reduce the risk, but the risk is still there. (T6: L211-216)

Younger gay men try to avoid thinking about HIV because to them it is no big deal anymore, but they still do not want to get infected with HIV. The introduction of PrEP may be a contributing factor to this way of thinking. PrEP may also contribute to giving some gay men a false sense of security when indulging in risk taking sexual behaviour.

Clusters of Themes

All the formulated meanings were grouped into categories that reflected a unique structure of thematic clusters. Each cluster of themes included all the formulated meanings related to that group of meanings:

Testing HIV positive

They were reminded of those scary HIV advertisements they had seen in the 1980's.

Their only thought was that they were going to get sick real quick and die.

He/she was so shocked that they could hardly breathe and not take it all in. They thought they had their whole life ahead of them. He/she could not process what they had bee told. All he/she could think of was that they were going to die. He/she felt utterly alone, numb and sick and needed to phone their mother.

They felt numb because they were unable to process the fact that they had tested HIV positive. Testing positive was experienced as inevitable, but left this person feeling numb.

At the time they were unable to process what they were being told. They were left feeling numb. This person could not believe they had tested HIV positive. It was not meant to have happened. Testing positive to HIV was not a conversation he/she wanted to have with anyone.

Fear

They were reminded of the scary HIV advertisements they had seen in the 1980's.

When he/she became unwell they could not inform anyone at work as to the real reason why they sick because they feared the information disclosed would not remain confidential.

When he/she felt ill they had to disguise the fact as best they could by taking days off as holiday.

He/she would be reluctant to openly share that they had HIV in a group of strangers because of the fear and anxiety experienced by the infected person. The fear and anxiety comes form not being able to predict how other group members might react to hearing that someone in the group has HIV.

He/she went swimming a couple of days after they had tested HIV positive and they felt the fear envelope them. He/she suddenly became convinced that other people could tell that he/she had HIV. All the negative Government slogans and advertisements with tombstones filled his/her mind and he/she felt so sacred and frightened.

Some people who have HIV reject others who also have HIV because of the fear of being stigmatised by association.

Some people are anxious and fearful about disclosing their HIV positive status to family and friends because there can still be a stigma to having HIV. Keeping your HIV status a secret can make your fear and anxiety worse. It can get the better of you. Having HIV is nothing to be ashamed about.

There was a huge stigma around having HIV and a great deal of fear. People in the gay world were perceived as being to blame for AIDS. People in the gay world deserved to suffer for the role they were perceived to play in the cause and spread of AIDS.

Fear within the gay community made the gay community turn on itself. It was this stigma by association that made living with HIV unbearable for a lot of gay men.

Death

Their one and only thought was that they were going to get sick real quick and die.

In the past having HIV was a death sentence.

He/she was so shocked that they could hardly breathe and not take it all in. They thought they had their whole life ahead of them. He/she could not process what they had been told. All he/she could think of was that they were going to die. He/she felt utterly alone, numb and sick and needed to phone their mother.

In back of his/her mind was their mortality. A sense of detachment and isolation is also present because he/she did not want to hurt their family and so they have not disclosed their HIV positive status to any family members.

He/she suddenly felt sick. It was as if they had been handed a death sentence.

Having been told they had only five years to live after being diagnosed with HIV he/she began to prepare him/herself, along with family and friends for the inevitable. When this did not happen it felt like a let down.

You have to keep reminding yourself that having HIV is survivable.

Disclosure

He/she had a big secret. They wanted to tell everyone, but at the same time they were too frightened of the consequences of disclosing their HIV positive status. He/she felt it was a massive stigma and a taboo that could not be spoken about openly.

When he/she became unwell they could not inform anyone at work as to the real reason why they were sick because they feared the information disclosed would not remain confidential.

Some people are anxious and fearful about disclosing their HIV positive status to family and friends because there can be still be a stigma to having HIV. Keeping your HIV positive status a secret can make your fear and anxiety worse. It can get the better of you. Being HIV positive is nothing to be ashamed about.

Disclosing to others you have HIV can be difficult. By not disclosing your HIV positive status you can pretend to yourself that you do not have HIV.

Disclosing your HIV positive status to others can be both hard and difficult.

One gay man disclosed he was HIV positive to a gay friend. HIs friend’s angry reaction shocked him and he could not understand why his friend was being irrational.

Shame

They felt dirty, ashamed and convinced that becoming HIV positive was all their own fault.

They felt really hurt when someone they knew and trusted avoided them because they had an illness he/she could do nothing about. They had not changed. He/she felt they were in the wrong not the person avoiding them.

Diseases such as heart disease and cancer get publicity, but HIV is still swathed in secrecy and shame.

People living with HIV need the same care and compassion that is given to people suffering from other terminal illnesses. If HIV is not openly discussed it will always remain a dirty secret.

He/she felt it was their fault the condom had split, but they did not want to find the person who had infected them with HIV.

For some people having HIV is not something they want to discuss with anyone.

Stigma

They felt really hurt when someone they knew and trusted avoided them because they had an illness he/she could do nothing about. They had not changed. He/she felt they were in the wrong not the person avoiding them.

When he/she became unwell they could not inform anyone at work as to the real reason why they were sick because they feared the information disclosed would not remain confidential.

When he/she felt ill they had to disguise the fact as best they could by taking days off as holiday.

One surprising area of prejudice was when Gay friends avoided contacted with the person infected HIV. They appeared not to want to be seen to be associated with someone infected with HIV because of the prejudice attached to having HIV. There was a sense of stigma by association.

He/she could talk more openly and freely about their illness if they were suffering from cancer and would be more likely to receive a sympathetic reaction from other people whereas there is still prejudice surrounding having HIV. People living with HIV feel there is a lack of compassion towards them from others who are not infected. People living with HIV are sometimes labelled as evil or sinful by others.

He/she would think carefully about what they disclose to others because of the innate prejudice that exists about HIV. For many people there is lack of understanding about how you can become infected with HIV and this creates a fear response in the general public towards anyone infected with HIV.

He/she felt that they had a big secret. They wanted to tell everyone, but at the same time they were too frightened of the consequences of disclosing their HIV positive status. He/she felt it was a massive stigma and a taboo that could not be spoken openly about.

Some people are anxious and fearful about disclosing their HIV positive status to family and friends because there can still be a stigma to having HIV. Keeping your HIV positive status a secret can make your fear and anxiety worse. It can get the better of you. Having HIV is nothing to be ashamed about.

He/she experienced a bad reaction from a person they visited. He/she was banned from seeing this person’s five year daughter because of the father’s fear of HIV. The father did not want to listen to any explanation they were given about how you can become infected with HIV.

Some people you know have HIV reject others you also have HIV because of the fear of being associated people who known to be HIV positive.

The worst thing about HIV is that it can be very visible and that is what scares people the most. It is this visibility that causes anxiety in both the person infected with HIV and in others. There is a perception amongst many people living with HIV that they would get more sympathy if they were suffering from another terminal illnesses even if your lifestyle had contributed to your health condition. Likewise children born with HIV appear to get other people’s sympathy because it is not regarded as their fault. However, gay men are given a hard time because they are perceived to be the cause of both the origin and the spread of HIV.

There was a huge stigma around having HIV and a great deal of fear. People in the gay world were perceived as being to blame for AIDS. People in the gay world deserved to suffer for the role they were perceived to play in the cause and spread of AIDS.

Fear within the gay community made the gay community turn on itself. It was this stigma by association that made living with HIV unbearable for a lot of gay men.

Specialness

He/she was naive in thinking that they could not becoming infected with HIV.

He/she suddenly felt sick as if they had been handed a death sentence.

It is a commonly held belief that HIV only affects gay men and that they are responsible for spreading the virus. At the same time heterosexuals believe they can have unsafe sex because they think they are not at risk of infection from HIV.

As a way of the general public protecting themselves from becoming infected with HIV some groups have been identified as being more at risk. These ‘at risk’ groups have become stigmatised. The level of perceived risk is rationalised by some people by them thinking “I’m not one of those. That’s not what I do.” It can be a way of thinking that he/she is special, different, that it cannot happen to them, but it can. When it does happen to them it can be a real wake up call.

Living with HIV

He/she had the questions ‘what am I going to do?' and “how can I live with HIV?” going round inside their head.

It is more important for someone infected with HIV to figure how to live with it once they were infected.

Having HIV can make you more prone to other infections. The first time he/she caught a cold they were petrified. However, they soon recovered and now have learnt not to panic when they get a secondary infection.

He/she tries to boost their immune system holistically with plenty of healthy food, massage and exercise. In this way he/she always tries to remain optimistic about the future.

It is not like a nine to five job where he/she can switch off at home time. He/she tries to look after themselves by making sure they get plenty of sleep. He/she has also cut down on the amount of alcohol they consume and has changed their diet to include as much organic fresh food as possible.

He/she thought of being HIV positive as an ending, closure where they did not see a future and so they did not make plans for the future. He/she expected to die years ago so they are surprised they are still alive. His/her life stopped for 20 years and has now restarted.

He/she described looking after him/herself as a period of hibernation where the most important thing was to remain healthy because very little was known about HIV fifteen years ago.

You have to keep reminding yourself that having HIV is survivable.

It can often take a long time to understand what it means to be HIV positive on an emotional level. It is often easier to deal with having HIV on a purely intellectual level.

It is only when you start to deal with on an emotional level that you really begin to process what it means to be HIV positive and accept without letting HIV define who you are.

Isolation

He/she has felt upset by the discrimination and ignorance surrounding the disease. He/she still breaks down crying because they suddenly feel so alone.

In the back of his/her mind was their mortality. A sense of detachment and isolation is also present because he/she did not want to hurt his/her family and so they have not disclosed their HIV positive status to any family members.

Having HIV can make you become isolated and you get trapped in your own little world. Some people can even become delusional as a result of the isolation.

Some people living with HIV can become self-absorbed because of the isolation. When you become detached from reality you can slip into your own world. This can easily happen, particularly if you do not have people around you who are prepared to challenge you.

People who have HIV can become self-absorbed because of their isolation. Having HIV has taken over their lives. Now people living with HIV are being encouraged to carry on with their lives, find employment and socialise. It is no longer a death sentence for newly diagnosed people, but for previous generations, who did not have the treatment choices that are now available it is more difficult to make that reconnection.

In the ‘80s people living with a positive diagnosis were very isolated. They were scared, especially in the black community where they got stigmatised. It was horrible then and still is horrible now to some extent. Stigma is a hard thing to deal with.

Newly diagnosed HIV positive individuals can feel isolated, however some may isolate themselves.

Hibernation

He/she described looking after him/herself as a period of hibernation where the most important thing was to remain healthy because very little was known about HIV fifteen years ago.

After testing HIV positive some people go into hibernation and withdraw from the world.

After testing HIV positive some people go into hibernation and withdraw from the world.

Experiencing having HIV as being all consuming

Some people living with HIV can become self-absorbed because of the isolation. When you become detached from reality you can slip into your own world. This can easily happen, particularly if you do not have people around you who are prepared to challenge you.

He/she does not think you should allow HIV to consume you. Instead you should live with, and learn to deal with it. Treat it not quite like a friend, but treat your body with respect and give yourself time to recover. The one thing you must never do is let it consume you.

People who are shave HIV can become self-absorbed because of their isolation. Having HIV has taken over their lives. Now people living with HIV are being encouraged to carry on with their lives, find employment and socialise. It is no longer a death sentence for newly diagnosed people, but for previous generations, who did not have the treatment choices that are now available it is more difficult to make that reconnection.

Some people who are HIV positive become consumed by having HIV. It is all they think and talk about. It becomes their life. It is a mistake to allow being HIV consume you. You need to have a life outside of HIV. It may be now a chronic condition, but it is a challenge living with HIV.

He/she started to live again, think about having a future, dare to have a future. It is about learning to live with HIV and not make it your whole life or identity. When you make having HIV your identity by saying 'I am HIV' it can consume you because then your whole life revolves around having HIV which is really unhealthy.

You cannot let HIV become the focus of your life otherwise it can be easily consume you. It can take away your choices. You are more than your diagnosis. Your diagnosis does not define who are as a person.

Re-evaluation of Life Choices

For some people having HIV is about identifying your choices and how you want to live with being HIV positive. It is about acceptance and being proactive in the way you engage with your HIV clinicians.

Being HIV positive can make you re-evaluate your values and life choices.

Being HIV positive is about taking stock and considering your choices. Not allowing yourself to have self pity. It is about facing your challenges and learning from them.

Being HIV positive makes you focus. Living with HIV is about making your health your priority.

Since becoming HIV positive he/she reflected on their hedonistic lifestyle and realised they wanted their life to be more substantial, fulfilling and worthwhile.

Having HIV can make you think about what is important, what matters, what does not matter in your life and what you want to achieve in life.

Misconceptions about HIV

He/she has felt upset by the discrimination and ignorance surrounding the disease. He/she still breaks down crying because they suddenly feel so alone.

It is a commonly held belief that HIV only affects gay men and that they are responsible for spreading the virus. At the same time heterosexuals believe they can have unsafe sex because they think they are not at risk of infection from HIV.

He/she would think carefully about what they disclose to others because of the innate prejudice that exists around HIV. For many people there is a lack of understanding about you can become infected with HIV and this creates a fear response in the general public towards people infected with HIV.

There was a huge stigma around having HIV and a great deal of fear. People in the gay world were perceived as being to blame for AIDS. People in the gay world deserved to suffer for the role they were perceived to play in the cause and spread of AIDS.

Not being able to be open about having HIV

Becoming HIV positive was not a conversation he/she wanted to have with anyone.

He/she believes they could talk more openly and freely about their illness if they were suffering cancer and would be more likely to receive a sympathetic reaction from other people whereas there is still prejudice surrounding having HIV. People living with HIV feel there is a lack of compassion towards them from others who are not infected. People living with HIV are sometimes labelled as evil or sinful by others.

He/she would be reluctant to openly share that they had HIV in a group of strangers because of the fear and anxiety experienced by infected person. The fear and anxiety comes from not being able to predict how other group members might react to hearing someone in the group has HIV.

He/she would think carefully about what they disclose to others because of the innate prejudice that exists around HIV. For many people there is a lack of understanding about you can become infected with HIV and this creates a fear response in the general public towards people infected with HIV.

Diseases such as heart disease and cancer get publicity, but HIV is still swathed in secrecy and shame.

People living with HIV need the same care and compassion that is given to people suffering from other terminal illnesses. If HIV is not openly discussed it will always remain a dirty secret. For some people having HIV is not something they want to discuss with anyone.

Good HIV/Bad HIV

Individuals who become infected with HIV through a blood transfusion or if you are a child born with HIV it seems you that you are more likely to get other peoples's sympathy because it is not regarded as their fault. However, gay men are given a hard time because they are perceived to be responsible for both the origin and the spread of HIV.

If you were a woman, a child or someone who had become infected with HIV through a blood transfusion you would be seen as a victim and likely to receive sympathy, whereas gay men with HIV would be condemned for having HIV.

Pre-exposure Prophylaxis (PrEP)

Younger gay men try to avoid thinking about HIV because to them it is no big deal anymore, but they still do not want to get infected with HIV. The introduction of PrEP may be a contributing factor to this way of thinking. PrEP may also contribute to giving some gay men a false sense of security when indulging in risk taking sexual behaviour.

Exhaustive Description

At this stage of the analysis, the themes were compiled into an exhaustive description. After this stage was completed a generic account of the lived experience of people living with HIV emerged:

A common reaction to testing HIV positive is shock. All they could think of is that were going to get die. They felt utterly alone, numb and sick. However, some people believed that could not get infected with HIV. This erroneous belief seemed to have originated in the way the media reported cases of HIV infection. The media identified gay men and intravenous drug users as being the ones at risk of becoming infected. The perceived level of risk of HIV infection is rationalised by some people by them saying *'I'm not one of them. It's not what I do'.* In other words, they believe themselves to be special or different in some way and this makes them immune from HIV infection. Likewise, younger gay men might avoid thinking about HIV because for them is no big deal anymore, but at the same time they do not want to become HIV positive. The introduction of pre-exposure prophylaxis (PrEP) could be a contributing factor to this way of thinking. It may also give some gay men a false sense of security, particularly those who continue to participate in risk taking sexual behaviour. So when someone who believes that they not at risk of becoming infected receive an HIV positive result it be a *'real wake up call'* for them. Becoming sick when you are HIV positive can be difficult for someone in employment if they have not disclosed their HIV positive status to their employer. So in order to disguise the fact they are sick they might take days off as holidays instead of taking sick leave. There is still a huge stigma around having HIV. This creates fear in some people and it make them anxious about disclosing their HIV positive status. At the same feeling you have to keep your HIV positive status a secret can make your fear and anxiety worse. Disclosing one's HIV positive status is not an easy thing to contemplate doing as you cannot predict how other people are going to react. They might be supportive or they might be hostile. Another form of HIV stigma manifests in physical changes to the body. This is not something you can easily hide and cause further anxiety for someone living with HIV. Stigma can also take the form of stigma by association. For example, someone avoids being seen with a person known to have HIV in case other people associate them with having HIV too. Coping with having HIV involves maintaining a healthy lifestyle as much as possible. It is important not to allow HIV to become all consuming or allowing it to define who you are. However, it is about reflecting on your life choices and values. It is about re-evaluating what matters in your life. Having HIV is not the death sentence it once was. It is now a chronic disease and with the advances in medication individuals living with HIV can expect to be able to live a normal lifespan.

Formulation of a Statement

This final stage is similar to creating the exhaustive description above, except that no exhaustive meanings were sought. Instead, a further reduction of the findings was undertaken to eliminate redundant descriptions or repetitions were removed from the overall structure. This helped deepen the understanding of the lived experience of people living with HIV:

Testing HIV positive is no longer the death sentence it once was. It is now defined as a chronic disease and with the advances in medication individuals living with HIV can expect to live a normal lifespan. It is important not to allow having HIV to consume you or define who you are. However, there is still stigma surrounding having HIV which makes some people living with HIV anxious about disclosing their HIV positive status to others. The introduction of Pre-exposure Prophylaxis (PrEP) has given younger gay men a false sense of security because they think that they can still participate in risk taking sexual behaviour, so when they test HIV positive it can be a *'real wake up call'* for them.

3.7 Reflexive engagement with the research

Kasket (2012) reminds of the importance of paying attention to both epistemological and methodological reflexivity when being engaged in qualitative research. From an epistemological standpoint, this is about acknowledging that alternative research methods could have been employed and so would have produced different results from than the ones presented here. In the preceding sections in this chapter, I have sought to demonstrate my acknowledgement of this. I adopted Colaizzi's (1978) descriptive phenomenological approach as my research method because it fitted best with what was being explored and, more importantly it reflected my per-

sonal vantage point. However, this is not meant to imply any notion of superiority of one research method over another. Rather, this is about research integrity in terms of appropriateness to the research question and my embrace of descriptive phenomenology.
In terms of methodological reflexivity, Colaizzi's (1978) descriptive phenomenological approach requires the researcher to be accountable for their reflexive stance as become immersed in the research process. In other words, by conducting semi-structured interviews from a descriptive phenomenological vantage point means I brought myself and my lived experience to the process. Working from this standpoint, as has been emphasised in this research paper, that we are *always* in-relation, the researcher inevitably has an impact upon what emerges and of course their interpretative process is a crucial component of this. So my questions and prompts, my way of being with the participants, how together we were relationally, how I made sense of was being conveyed to me, collectively moulded what I subsequently have reported here.

Nevertheless, but was of fundamental importance that I remained as close to the actual experiential accounts as possible. My primary role as a researcher was essentially to be a conduit or facilitator of the participants' reflections. Shaw (2001) cautions us to be aware of the importance of remaining aware of this or otherwise the researcher risks losing sight of what is actually being conveyed, and not becoming distracted by our own narrative. Being mindful of this possibly throughout and while it is entirely that someone else conducting this research would produce a variance of my findings, I have in my view reported what would generally be accepted as a reasonable reflection of the participants' experiential accounts.

In order to safeguard against being distracted by my own narrative as Shaw (2001) cautions, there are bias reduction techniques which be employed such as Heron's *Co-operative Inquiry model* (1996). This recommends relaying preliminary findings to the participant to give them the opportunity to challenge or confirm before they are finally reported. This was the rationale behind me asking each participant for feedback after had read my analysis of their interview.

While analysing the research I maintained a diary in which I reflected upon my emerging thought processes, feelings and emotions as I interacted with the data, again for the principle of containing and managing how this might contribute to the shape of my findings. I approached this aspect of the interviews as all others, with a genuine sense of curiosity about what was emerging. For example, I was curious about what specifically captured my attention or interested me the most and the reason why. I was mindful of embodied reaction to participants' distress about feeling stigmatised and in their fearing persecution and/or discrimination. I observed at times feeling both angry and profoundly sad, reflecting my personal distaste for such discrimination or stigmatising. The iterative process demanded of Colaizz's (1978) method together with my reflexive journal assisted me enormously in observing, owning and containing these felt responses which ensured I fairly reflected the participants' experiential accounts along with my description of them.

In following chapter I present my findings. It is intended that my awareness of the reflexive issues explored in this section will be evident, and that the participants' experiential accounts are both adequately and respectfully reported.

4. Analysis of Findings

As previously stated in the introduction of this study, I am attempting to convey a descriptive account of the experience of living with HIV from the unique perspectives of each participant and in particular, within the context of identifying commonalities in their experience.

The interview process took participants on an emotional journey from when they first tested HIV positive to living with HIV, firstly as a life-threatening terminal disease and now as a chronic condition. It is for this reason that I chose to present the major themes in the form of a journey. I will explain my reasoning in more detail before I proceed to my actual findings.

The experience of living with HIV involves travelling from one point in time and circumstance, through to another. Ideally this transition will take the form of learning how to cope with being infected with HIV, but in any event it will certainly be towards something else.

Firstly, given that the word *journey* implies moving from one place to another, it can be useful to apply this analogy to how participants living with HIV moved from one 'emotional place' to another as they came to terms with testing HIV positive and, then, learning to cope with living with HIV on a daily basis.

As part of the interview process I also embarked on an emotional journey through my exploration of my participants experiences of living with HIV and how I experienced these reflections. Primarily, there was a chronological aspect to my research questions in terms of what precipitated the decision to get tested for HIV, then the actual experience of receiving a positive result followed by how they learned to cope with living with HIV. The process I uncovered made the journey metaphor seem particularly relevant.

I then moved towards looking at what it was actually like for someone to be told they were infected with HIV. Finally, the logical conclusion to a journey arriving at a destination, which felt an important area to understand. In other words, what was it like to be living with HIV and what ways of coping had participants found most helpful.

Fear

The essence of this theme is the emotion that was evoked when someone was informed that they had tested HIV-positive. I wondered if their prior knowledge of HIV was helpful or something that provoked anxiety in them. In other words what they been told or had read about HIV? Collectively by conveying key aspects of the issues raised, the common and particular anxieties expressed by participants, the following themes are intended to offer a reflection of what each participant embodied as they each embarked on their unique journey.

In the following interview extracts I aim to show what it was like for someone to be informed that they were HIV-positive and their different responses to living with HIV.

Maria who had been living with HIV for 15 years unwittingly became infected with HIV by a boyfriend she had only known for a short while. She had grown up in small village in South America and when she was 20 years old she came to London to live with her sister. Her response to testing HIV-positive was fear because she knew very little about HIV apart from the Government advertising campaigns she had seen and heard about. The most famous of these advertisements were the falling tombstones and the slogan *'Don't die of ignorance'.* After testing HIV-positive she became a service user at the Charity were I was conducting my interviews.

Maria described what it was like to be told she had tested HIV positive. *"The images I had in my head were of falling tombstones from those scary HIV adverts that were around in the early 1980's." (Transcript 1: Line 19-20).*

Maria's immediate reaction that she was going to die is fairly typical response from someone who still believed having HIV was a death sentence. It also demonstrates how powerful the impact of the early HIV/AIDS advertising campaigns were and how they had become absorbed into the public consciousness. The impact of these HIV/AIDS advertisements also had a profound impact on the way Tina made sense of her HIV-positive test result. Tina, another service user, had been a welfare officer at a London based college. She had taken an HIV test when the college had an HIV awareness day. There was a nurse from a local hospital who was offering to conduct HIV tests as part of the awareness day. Tina took the test expecting it to be negative, so when the result came back HIV-positive at first she could not believe it. It took her couple of days to acknowledge she was now living with HIV. Her predominant emotion was fear which enveloped her.

Tina described her fear in the following way: *"It wasn't until I went swimming a couple days later that the fear enveloped me. I was in the pool and I suddenly became convinced that people could tell I had HIV. All those negative Government slogans and adverts with tombstones filled my mind. I felt so scared, so frightened." (T 3: L103-8).*

The other four participants, who were gay men, did not express any strong emotions when they tested HIV-positive.

Specialness

This theme intends to convey how some people believed they would not become infected with HIV because they believed themselves to be in some way different or *'special'* in some way. For example, someone who is heterosexual and believes that only gay people can become infected with HIV might continue to have unsafe sex because they think becoming infecting with HIV cannot happen to them.

Mark considered his HIV-positive diagnosis to be a consequence, maybe even an inevitability of his sexuality as much as his sexual behaviour. He was very matter of fact in the way he spoke about HIV. He was both a service-user and a volunteer support worker for the HIV charity that had allowed me access to people living with HIV who were willing to be my research participants. He had strong opinions and believed himself to be well informed about most topics. He believed that this way of being enabled him to cope effectively with having HIV.

Mark spoke about how he believed the general public held the view that the gay community were largely responsible for spreading HIV and how people who did not identify as gay thought they were *'special'* and, therefore, could not become infected with HIV. The belief was that HIV only affects gay men. None of the other commented on this notion of *'specialness'* .

"I think most people think it's something that only affects Gay men and that we are responsible for spreading the virus, transmitting it. so you often get the reaction from someone who is

heterosexual and having unsafe sex that they can't get HIV. It is not something that can ever affect their community." (T 2:L53-59).

Gary, another gay men also had a similar matter of fact way of dealing with having HIV. He was also both a service-user and a volunteer at the HIV charity. He too believed himself to be well informed about HIV. Both Mark and Gary used their knowledge of HIV as a way of coping with HIV. Neither of them allowed their emotions to dictate how they made sense of having HIV. For both of them this proved to be a successful coping strategy.

Gary described how some people believe they are *'special'* in some way and therefore cannot get infected with HIV. He said *"It can also be a way of trying protect yourself from getting HIV by identifying certain groups who are more likely to be at risk and stigmatising those individuals and groups so you can say 'I'm not one of those. That's not what I do.' That way you can think yourself safe. It's quite sad really. It can be a way of thinking I'm special, different that it cant happen to me, but of course it can and does. It can be a real wake up call." (T 4: L344-9).*

Death

A common theme that has become associated with HIV is death. Both Maria and Tina reacted to being told they had HIV by thinking it meant they were going to die. They both thought having HIV meant they would get ill very quickly and die. Of course, not everybody is likely to react to being informed they have HIV in the way Maria and Tina did. In the early years of the HIV epidemic testing HIV-positive would have been a death sentence, but now with the introduction of HAART and the reclassification of HIV as a chronic disease perhaps such a strong negative reaction to testing HIV-positive is less likely.

In contrast, all the gay men I interview appeared more accepting of their fate. For them having HIV was a part of life and you either got on with living your life or you allowed HIV to consume you. I will return to the notion of HIV being all consuming later in this section.

Maria said '*My one and only thought was I was going to get sick real quick and die' (T 1: L 21).* Her mindset was heavily influenced by the HIV/AIDS advertising campaigns she had seen and read about. In a similar way Tina's reaction was that she had been given a death sentence.

Tina spoke about her immediate reaction to being told she was HIV positive by saying: '*it was such a shock. I could hardly breathe. I could not take it all in. I was only 21 with what I thought was my whole life ahead of me. what I was being told it just didn't register with me. All I could think of, think about was I'm going to die. Was it going to happen tomorrow, in three years or ten? I felt utterly alone, numb and sick and I asked if I could phone my Mum.'* (T 3: L51-58). She also said *"it was as if I had been handed a death sentence." (T 3: L58).*

Shame, Stigma and not being able to be open about having HIV

Shame, stigma and not being able to be open about having HIV are the most difficult aspects of having HIV for most people. For some the shame of having HIV made them feel dirty and they would often blame themselves for becoming infected. This is exactly how Maria experienced living with HIV. She described how she felt ashamed of having HIV.

She said *"I felt dirty and ashamed and somehow became convinced that becoming HIV positive was all my own fault." (T 1: L41-42).*

Along with the shame she experienced the stigma of having HIV first hand. She went on to speak about she felt when someone she knew found out that she was HIV positive.

"It really hurt to feel that someone who I knew and trusted was avoiding me just because I had an illness that I could nothing about. I was still the same person she had been speaking to all along. I felt it was me in the wrong not her." (T 1: L112-115)

Maria also spoke about the stigma of having HIV which was not there with other diseases like heart disease and cancer. "*You see so much publicity for diseases like heart disease and cancer, but the image of HIV is still swathed in secrecy and shame." (T 1: L140-141).*

She went to say *"We need the same kind of care and compassion, the same as anyone with a terminal illnesses, but if no-one will talk about it you know discuss having HIV it will always remain a dirty secret." (T 1:144-145).*

Mark also spoke about his experience of stigma, but this time it was stigma by association. He spoke about how his gay friends reacted when they found out he had HIV.

He said *"They suddenly dropped me like a ton of bricks. Probably, they didn't want to be associated with HIV at that time because there was prejudice around having HIV." (T 2: L45-49).*

Stigma by association also leads to social isolation and the loss of social support, both of which can be linked with poor physical and psychological outcomes. Another characteristic of stigma by association is the fear of *'being known by the company you keep'.* In other words, physical proximity can be enough to link two individuals in the mind of another which in turn results in that person making a negative evaluation of both the stigmatised person and those who associate with them.

Another aspect of both shame and stigma is not feeling you can be open about having HIV. This dilemma manifests itself as the tension between, on the one hand wanting to keep your HIV-positive status a secret and on the other wanting to disclose your HIV-positive-status to everyone so that they cannot use it as a way of shaming you.

Tina spoke about her conflict over disclosing she had HIV. On the one hand she wanted to keep it a secret and on the other she felt compiled to tell everyone.
'*I felt I had a big secret. Half of me wanted to tell everyone, but at the same time I was too frightened of the consequences. Being HIV positive felt like a massive stigma, a taboo no-one talks about. It is not something you can speak openly about.' (T 3: L87-90).*

Gary talked about how some of his friends feared stigma by association and how they distanced themselves from anyone who they knew was HIV-positive in case anyone thought they were HIV-positive:
'*I've seen people who reject people, but I would know they were positive themselves so there is a whole cycle of fear going as well. They're rejecting because they don't want people to suspect they might be positive because of the association.'(T 4: L68-71).*

Claude spoke about his experience of stigma and how it was driven by fear in the gay community:
'*The stigma around having HIV was huge. There was so much fear. I could understand why there was such a hostile reaction from the straight world and how people in the gay world became the target for so much anger and hostility from the straight community. The straights had always been hostile and AIDS gave them the reason, the justification for how they felt towards us. We were to blame and the cause of AIDS. We deserved to suffer.' (T 6: L143-7).*

Claude also spoke about how the gay community turned on itself. This was another example of stigma by association:

'*Even the gay community turned on itself. Again I think it was fear that made a lot of gay men reject someone as soon as they found out that person was HIV-positive. Friends would suddenly stop speaking to one another and blank each other in the street or in a club. It was the fear of being seen with someone who was known to have HIV in case you were thought to have it as well. It was stigma by association that made HIV almost unbearable for a lot of my friends who were diagnosed around the same time as me.' (T 6: L151-7).*

Disclosure

Disclosing your HIV-positive status is complex because it does not simply involve a one-off declaration of one's HIV-positive status. For example, each time someone with HIV applies for a job they will need to consider whether or not to disclose they have HIV. Likewise, when someone with HIV is thinking about beginning a new relationship they also have to consider how their potential new partner might react to the disclosure.

Mark discussed the difficulty he had in being open about having HIV. He said '*Supposing I had cancer I could be more openly talk about it in a freer way and would probably get a more sympathetic reaction, more understanding and a kindly response from other people, whereas when if I were to tell people in the wider community, excluding health professionals and doctors, that I have HIV then I would not be predict the reaction, even all the information available today and the fact that it is no longer a death sentence so even the fear has been taken away there is still a hug prejudice in all sorts of groups, where you might think there would be compassion, but there often isn't, You can get you're an evil type of person reaction or you're a sinner and it's against God's will and all that kind of thing.' (T 2: L150-160).* He went to say '*I would be very reluctant to openly share that I had HIV in a group. I know it says more about my fear and anxiety about how others are going to react that possibly the reality. I would be guarded about my disclosure until I got to know the others in the group and felt safe in the* *knowledge that I would not be judged, but there is a need to protect oneself, but it is also challenging one's own inbuilt prejudice about others and what they might be thinking.' (T 2: L175-181).*

Gary reflected on what it was like to disclose he had HIV to his family and friends. He only disclosed his HIV-positive status to people that needed to know. For him having HIV was nothing to be ashamed of.

'*My family know I've got HIV. I told some of my gay friends. I thought there was no point keeping it a secret. You hear a lot about stigma. I know some people have had really bad experiences when they have disclosed their status to others. You can let fear and anxiety get the better of you, but I've nothing to be ashamed of. I will tell people if I think they need to know and let them deal with it.' (T 5: L69-74).*

Claude spoke about not wanting to disclose his HIV-positive status to anyone. He said '*I don't think I was ready to engage with anyone. Not ready to have the conversation about being HIV Positive. It wasn't something I discussed with friends, even those that had HIV. It wasn't really a conversation I wanted to have, to be perfectly honest.' (T 6: l42-5).*

Claude went on to say how he avoided discussing having HIV as way of not admitting to himself that he was really infected with HIV. '*It took me nearly a year to tell anyone, my family and friends, that I was HIV-Positive. I suppose I thought that if I didn't say anything, you know tell anyone, then it would not be real. I could still believe, or at least pretend that I was still HIV negative.' (T 6:L64-7).*

Claude also described how hard he found disclosing his HIV-positive status to others. '*One of the hardest things and the most difficult things about having HIV is having to disclose your HIV-positive status to other people. You can imagine the conversation cant you? Hello my* *name is ……. and I'm HIV-positive. Not exactly a good chat up line, is it? I know it's different now. HIV is almost commonplace in the Gay community at least, but back in the day when I was newly diagnosed things were very different.' (T 6: L137-41).*

Claude described how one person reacted when he told them he was HIV-positive. Claude was shocked by the other person's reaction to his disclosure:

'One friend stopped talking to me when they found out I was HIV-positive. He was angry when I told him I was HIV Positive. I was quite shocked by his reaction, to this day I don't really understand what made him react the way he did. He was so irrational. Again I think it was fear as much as anything.' (T 6; L157-60).

Living with HIV

Living with HIV is another complex subject because everyone who has HIV will have their way of coping with HIV.

Tina spoke about how she had learned to live with having HIV so she could stay healthy.;
'*It's not like a nine-to-five job where you can switch off at home time. I try to look after myself. I make sure I get plenty of sleep every night. I've cut down on alcohol and changed my diet to include plenty of organic fresh food as possible.' (T 3: L224-8).*

Gary also described was it was like to live with HIV:
'*When I was first diagnosed I was given five years maximum, that was twenty years ago. The hardest thing was not dying after five years. I know that might sound strange, but I had spent all my time preparing myself and my family for the inevitable and when it didn't happen, it initially felt like a let down. Then I started to live again, think about having a future, dare to have a future. Learn to live with HIV. Not make it the whole of my life, my identity. I am*

someone living with HIV, bt that is only aspect of my life. some people identity with HIV. It becomes them, who they are, their identity. They say 'I am HIV' when talking to friends and family. That's when having HIV can become all consuming. Then your whole life revolves around HIV, having HIV, that's really heathy.' (T 4 L:358-68).

Nigel spoke about his experience of being a long-term survivor. '*Nowadays HIV is survivable, when I'm having a bad day I have to keep reminding myself that HIV is survivable.' (T 5: L84-7).* He also said '*Having HIV as given a focus I didn't have before. I try to make health my priority now. Staying well is the key to living with HIV.' (T 5: L162-3).*

None of the other participants commented on how they coped with living with HIV.

Experiencing having HIV as being all consuming

Only two participants raised the issue of how some people allow HIV to consume them in such a way that having HIV becomes not only the focus of their lives, but it also becomes their identity. It is not why some people with HIV allow it to consume them while other people are able to live with without it overwhelming them. It may be that some people have better innate coping skills or are more robust psychologically. This phenomenon would need to be re-searched in depth to establish exactly what makes the difference when it comes to effective coping strategies.

Gary described how he had seen people with HIV allow themselves to become consumed by having HIV.

'*I don't think you should allow it (HIV) to consume you, you should live with it, learn to deal with it, treat it not quite like a friend, but treat your body as a temple in a way, don't burn the candle at both ends, give yourself time to recover, that sort of thing because it's always there, but never let it consume you.' (T 4: L54-7).*

Claude described how he had seen people become consumed by having HIV:

'I've seen lots of people with HIV be consumed by it. It becomes their life. They make a career out of having HIV. It's all they seem to think and talk about. I think that's a mistake. You need to have a life that's not just about having HIV. Admittedly, in the past when HIV was death sentence the only way to survive even short term was to focus on having HIV and make the most of your life in the time you had left.' (T 6: L89-98).

Isolation

The experience of being alone or feeling isolated because they had HIV along with their reaction to these feeling is commented upon below.

Tina talked about feeling alone. It would seem for Tina that the feeling of being alone can suddenly overwhelm her. She also linked the discrimination and stigma surrounding having HIV reinforced her sense of being alone:

'*I've lived with HIV for a little over 17 years now, but the discrimination and ignorance surrounding the disease can still be upsetting. There are days when I break down crying on a crowded bus or tube because I suddenly feel so alone.' (T 3: L252-5).*

Gary also spoke about his sense of isolation in a similar way to Tina:

'*There was the mortality thing going on in the back of my mind as well so there was a detachment and isolation.' (T 4: L15-18).*

He went on to say:

'*I know quite a few people who are self-absorbed and it's mainly because of isolation. When you get detached you can slip into your own world quite easily if you don't have friends to challenge you.' (T 4: L95-7).*

He then said:
'*In the 80's you were very isolated when you got given your positive diagnosis. You were scared especially in the black community, you got stigmatised, it was horrible, it still is horrible now to some extent. I don't think it has completely gone away, it's still here, that's still a hard thing to deal with, the stigma' (T 5: L149-153).*

Claude described what it was like when he was newly diagnosed with HIV and how he isolated himself from others as a way of dealing with his HIV-positive diagnosis.
'*In the beginning when I was first diagnosed I did feel isolated, but to be honest I did isolate myself.' (T 6: L129-30).*

Hibernation

The theme of hibernation follows on from the previous theme of isolation. However, in the case hibernation participants spoke about it in terms of an active response on their part. In other words, they put their lives *'on hold'* while they processed and attempted to come to terms with having HIV.

Gary described how when he first was diagnosed HIV positive he went into hibernation as a way of looking after himself. '*I had stop working so I could start looking after myself, then there was phase of hibernation, so it has been like hibernation. I think that's a brilliant word for it where you just look after yourself and just keep well because that's all you could do ten fifteen years ago as nobody knew what was round the corner at that stage.' (T 4: L10-14).*

Claude described how he withdrew from the world after he tested HIV Positive. '*I did sort of go into hibernation. I withdrew from the world.' (T 6: L68-9)*
Once again the other participants diid make any comment on this theme.

Re-evaluation of Life Choices and Values

This theme highlighted some of the ways the participants coped with having HIV. Their HIV-positive status made some of the participants re-evaluate the way they were living and want to make changes. Their focus had shifted from how they had become infected with HIV to how to stay healthy now they had HIV.

Tina described her attitude on becoming HIV positive:
'*I felt it was my fault the condom had split, but I didn't want to find the man who had given me HIV. It was more important for me to figure out how to live with it. (T 3: L179-81).*

Gary also spoke about the choices he made when he found out he was HIV positive:
'I think now as positive sort of see it as a closure, sort of end, you don't see a future so I didn't plan ahead so to speak. I expected to die years ago, so I'm still surprised I'm still hear now. So i feel like I stopped for 20 years and now I've restarted.' (T 4: L4-9).

Nigel spoke about becoming HIV positive changed his attitude to life. He said:
"Geting HIV made me think about what really mattered. You know, what did I want to achieve in life. I didn't find God and get all spiritual, but it did make me question my values. I was very driven at work, very materialistic, very hedonistic, not now. I am much more reflective and I'm more considered in how I approach life.' (T 5: L84-7). He elaborated by saying *'For me, it was about taking stock. It was about saying to myself 'What are my choices?' I asked questions, found a good consultant and took charge of my situation. I don't allow myself to have self pity. I'm not one for self pity, never have been. I always try to face my challenges and learn from them.' (T 5: L114-7).*

Claude spoke about how having HIV made him become more reflective:

‘I’m not saying I regret my life. I had a good time, but now I want something more substantial, more fulfilling, more worthwhile. That’s what being positive had done. It has made me more reflective. It has made me think more about what’s important.’ (T 6: L54-7).

Claude went on to describe his way of coming to terms with having HIV:
’I took me a long time to understand that being infected with HIV was not reversible. When I say it took a long timer me to understand I mean on an emotional level. At the time the only way I could deal with having HIV was to split off my emotions. I deal everything on a purely intellectual cognitive level.’ (T 6: L78-81).

Claude then described how he was not going to allow having HIV to define him as a person:
‘I only started to come to terms with having HIV when I started to engage with it on an emotional level. I realised I had to embrace having HIV. By that I mean I accept it as part of who and what I am, but at the same time not let define me.’ (T 6: L89-91).

Claude then described how he began his journey of re-evaluating his life choices:
‘For me having HIV is about choosing how to live with HIV. As I’ve already said you can choose to allow HIV to consume you or you can embrace it. I don’t really like the word ‘embrace’, but I think you know what I mean. Perhaps, acceptance is a better word. You have to become proactive. When I go to see my HIV clinicians I engage with them and ask about starting healthy, explore what options are available to me.’ (T 6: L109-14

Claude elaborated further:
‘HIV cannot be the focus of your life otherwise you can easily become consumed by it. Not let it, HIV define you. If you do it can take away your choices. I am the same person I was before I tested HIV Positive. I may have changed my attitude to life as a result of testing Positive, but I’m more than my diagnosis. My diagnosis is not what defines me.’ (T 6: L170-74).
He concluded by saying:

'Having HIV in a strange way has proved to be an immense gift for me. It has made me think about my life, what's important, what matters, what doesn't matter, what I want to achieve before I die. I don't want to have any regrets.' (T 6: L194-6).

Claude experienced becoming HIV-positive as a gift because it made him think about his life and what was most important for him to have achieved before he died. He was emphatic when he said that he did not want to have any regrets.

Misconceptions about HIV

It is interesting to note the prevalence of misconceptions about HIV and how it is transmitted. These misconceptions seem to be engrained in the public consciousness and no amount of scientific evidence to the contrary will change their minds. Mark gave a good example of how he had attempted to challenge someone's misconception about HIV transmission and failed to convince them that they were in error. He explained how some of the prejudice experienced by people living with HIV is because of the misconceptions some people have about how HIV is transmitted. He said:

'You are likely to be reticent about who you disclose to given the innate prejudice that is ever present when considering HIV. People still have the misunderstanding that you can pick up HIV from a toilet seat or touching somebody so there is a big fear still there in the general population.' (T 2: L193-7).

Tina also encountered a similar situation where she was banned from visiting someone because they were so frightened about being in the same room as someone who is infected with HIV. She described one person's reaction when they found out she was HIV positive:

'One person did react quite badly and banned me from visiting their house and seeing their five year old daughter as he was so frightened. I tried to explain to him HIV can only be passed

on through blood, semen or breast milk, not for kissing or toilet seats as people think, but he would not listen. He just did not want to know.' (T 3; L240-5).

None of the other participants raised this issue surrounding misconceptions about HIV and how it is transmitted.

Good HIV/Bad HIV

This is a somewhat controversial theme raised only Gary and Claude. They both described how they experienced discrimination because they were gay men who had HIV. The belief they both shared was that there was a lack of sympathy for gay men who had become infected with HIV because of the public perception of how the gay community was deemed in some way to responsible for spreading HIV around the world.

Gary described how he felt that was a lack of sympathy for people living with HIV who had become infected through having unprotected sex:

'I mean a haemophiliac infected with HIV through a blood transfusion would definitely get more sympathy because it wasn't their choice, it wasn't a sexual thing. Likewise, a child would probably get more sympathy because they were born with it - it wasn't their fault - gay men on the other hand have it rough, still have a hard time of it because some people think that they are the cause of it.' (T 4; L174-8).

Claude also spoke about people in the straight world got more sympathy for having HIV than their gay counterparts. He described how he believed women and children with HIV were often seen as victims whereas gay men who had HIV were discriminated against on the grounds it was their own fault that become infected.

'*Soon as AIDS started to affect the straight world things changed. If you were a straight woman or a child born with HIV, you became infected with HIV through a blood transfusion then you* *were a victim and got sympathy, but if you were a gay man with HIV you got condemnation from everywhere.' (T 6: L148-51).*

Interview reflections from an ethics perspective:

In Chapter 3 I discussed the ethical dilemmas often faced when interviewing participants in counselling psychology. As part of this, I referred to Duncombe and Jessop (2002) and their warnings of the *'commodification of rapport'*; utilising one's skills as a practitioner to essentially create a sense of affinity and rapport for the purpose of eliciting 'good' data. It was certainly my hope that the participants would engage in the research interviews as fully as possible and to this end, it would be disingenuous to suggest I did not invoke my relational skills as a practitioner, in order to facilitate my aims as a researcher.

Firstly, it was vitally important that the participants could be assured that this was a responsible, professional and safe environment; something which in my view is conveyed by how the researcher conducts both them self and the actual process. Furthermore, I did experience a genuine sense of affinity with my participants which I accept could have been conveyed at times, for example, in prompts and comments. However, this was not 'manufactured' for my progressing my researcher aims and instead I suggest this was an inevitability of authentic relatedness when two people are engaged in a meaningful exploration such as this research project. Moreover, and of the upmost importance, I was transparent throughout regarding both the purpose of interviews and my role as a researcher.

As Brinkmann and Kvale (2008) argued, research such as this involves a degree of acceptance that there will be some tension and conflict in terms of researcher-practitioner aims and potential effect for the participant. In other words, it is not necessarily about attempting to eliminate these tensions, a task which in itself could simply paralyse the entire research endeavour. Instead, the primary ethical duty is to monitor and recognise dilemmas and risks when they do arise, identify where the associated dangers might exist for the participants and manage these accordingly.

To this end, it was extremely important that each participant had been made aware and felt assured that they were being asked to disclose only to the extent that they felt comfortable and willing to do so. Therefore, I purposely reminded all the participants before and during each interview that they could stop at any time. It was also crucial that the opportunity to debrief both with me as an accredited practitioner immediately after the interviews was offered, as well as making sure they were fully aware of the option of alternative counselling support should they wish to access it.

More specifically, it emerged how the participants experienced the interviews as being in themselves an important component of their journey to understand their experience of living with HIV. This was mainly because the interviews provided the participants with a defined space in which they able to reflect, take stock, clarify and articulate their experience of living with HIV. In other words, the interviews gave the participants the opportunity to feel heard and understood regarding their experience of living with HIV. Furthermore, it is my view that the interviews gave the participants a platform for their voices to be heard. I would argue that it also gave participants the opportunity to reflect on what it means to be someone living with HIV and experience themselves as a whole person and not just a diagnosis or a cluster of symptoms.

Obviously, the participants' experiences of this research process portray a somewhat different purpose and effect than mine as a researcher. My intention has been to produce robust data from which to develop a specific contribution to both counselling psychology knowledge and practice. This was made explicit in both the Participant Information Sheet (PIS) and in the initial email and subsequent telephone communication which each of the participants, as was the possibility that engaging with this subject could provoke uncomfortable feelings for the participants. Therefore, it is reasonable to assume that the participants were cognisant of both the intention of the research as well as the potential impact of participating in the interview process from the outset.

I now turn, in the following chapter, to a detailed evaluation and discussion of the findings presented in this chapter by way of commenting on the contribution to counselling psychology knowledge this research offers.

5. Discussion

5.1 Chapter scope and objectives

In the following chapter sections, the research findings presented in the preceding chapter will be evaluated within the context of the existing literature and the implications for clinical practice will be made explicit. While it is not my intention to repeat what has already been discussed in the previous, I do make reference to some of themes throughout for the purpose of transparency and clarity of argument. This chapter concludes with an assessment of the research limitations as well as offering some thoughts and ideas for future research.

I begin by summarising the rationale that has underpinned this project. My primary concern which was borne out by the conversations I had with clients during their counselling sessions with me was that they did not feel heard or understood by HIV clinicians. In the past people with HIV were able to access a range of support through their HIV clinic. However, due to the current economic climate the NHS is having to look for ways of saving money. The impact this is having on services such as Sexual Health and Mental Health in particular has meant that a lot of people living with HIV no longer feel cared by their HIV clinicians in the way they once did. The focus for HIV clinicians is prevention of the spread of HIV. Therefore, clinicians are keen to identify who might be most at risk of becoming infected with HIV and making sure they do not become infected. In other words, the focus is now on prevention and treatment of those infected appears to have been reduced to a minimum. Also third sector services providing support for people with HIV have seen large reductions in their fundings and are struggling to stay open. What this means for people living with HIV is that although their basic medical needs (such as regular appointments to assess patients' CD4 counts and their viral loads) are still being met, people with HIV appear to feel less able to give voice to their everyday concerns. The purpose of this project has been to give, albeit, a small number of people living with HIV the opportunity to voice some of the ways their lives have changed since becoming infected with HIV.

The primary aim has been to gain an understanding, through first-hand reflections, of the defining features of it is like to live with HIV. I have also sought to identify some of the main concerns people living with HIV have. From the analysis of my findings I identified several key themes which were common to all the participants who took part in my study.

The themes that emerged from the analysis of the findings which were common to all my participants are discussed below. The themes were:

5.1.1 Disclosure of a person's HIV Positive status

A concern that was shared by all the participants disclosing their HIV-positive status with others. They were anxious and fearful of how other people might react towards them. The tension between the need to maintain control over personal information and the moral and ethical obligation to warn others of the potential for HIV-related risk is at the core of the debate concerning the use of criminal law to encourage or punish non-disclosure of an individual's HIV positive status.

For example, what should you do in a work situation? Should you inform your line-manager? What should do about telling family and friends? Should disclose your HIV-positive status to a new partner?

Thinking about disclosing that you are HIV positive can feel like a daunting or even frightening thing to consider having to do. When thinking about disclosing your HIV positive status the two most important things to consider are: who you are going to tell and your motivation for wanting to tell them. Once someone has disclosed their HIV positive status to another person they cannot undisclosed it. A further concern that needs to be thought about is what the person who has been disclosed to will do with that information. How much control does a person infected with HIV have over who might know that have HIV? The issue here is how confidential information is handled by organisations, such as the NHS or a person's employer, and how this information is both stored and shared.

5.1.2 Practicalities to consider when thinking about disclosure

There are several things to consider when thinking about disclosure. A person living with HIV needs to think carefully about what they are going to say, and how, where and when they are going to make the disclosure. Further considerations are to think about how the other person might react and be prepared to answer questions that they might have about what has been disclosed to them. There is also a conversation to be had around who the person disclosed to can share the disclosure with and how much information can be shared. It is what might happen to the disclosed information once it has been disclosed that causes the most anxiety for individuals living with HIV when they think about disclosing their HIV status. Informing someone you are infected with HIV can trigger a range of reactions and anxieties in the person being disclosed to. For example, the disclosure might tap into prejudices they have about sexuality, illness, disability, race or HIV itself. Sometimes it is difficult for the person making the disclosure to know how to respond to the other person's reaction, particularly if it is hostile. Is it because they are upset or is it because they do not understand? After masking the disclosure some people who are HIV positive feel they have to reassure the person they have made the disclosure to, for example, that HIV is no longer a death sentence. In addition, the person disclosed to might feel under pressure to offer or provide support to the person infected with HIV, but not be able to or know how to.

Disclosing one's HIV positive status to a partner, family and friends can be both a frightening and liberating experience for the person who makes the disclosure and the person disclosed to.

Another dilemma surrounding disclosure for someone living with HIV is whether to inform work colleagues. This is becoming an issue for individuals who are still well enough to remain in employment. Although there is no legal requirement to for someone living with HIV to inform an employer of his or her HIV positive status, an individual might feel under pressure to disclose the reason why they have so many doctor's appointments or why they have had so many days off sick. The Equality Act 2009 makes it illegal for an employer to discriminate against an HIV person in the workplace because of their health status

Disclosing one's HIV positive status to healthcare professionals is another area of anxiety for individuals living with HIV. It is not just about making the initial disclosure that causes most people lining with HIV anxiety, but what happens to that information once it has been disclosed to the healthcare professional. Major concerns are how is the information being stored and who has access to the information. Concerns about confidentiality of patient information in healthcare settings can have a detrimental impact on HIV testing, and treatment and also reinforce the stigma surrounding HIV.

The second theme which is related to the theme discussed above is stigma. The stigma of having HIV makes disclosing you have HIV. If you have another disease, such as cancer or heart disease you openly disclose that and also you will a sympathetic response from other people. This tends not to be the case for people living with HIV. There is still fear around disclosing one's

HIV-positive status because of the judgements other people might make about your lifestyle choices. Shame is also experienced by people living with HIV because they often blame themselves for becoming HIV-positive. They may even internalise the stigma of having HIV in the form of self-stigma. This phenomenon of self-stigma is discussed in more detail in the section below.

5.1.3 Stigma

The World Health Organisation (WHO) in 2001 estimated that 25 percent of the worldwide population was affected by a mental or behavioural disorder at some time in their lives. This issue is thought to contribute to 12 percent of the worldwide burden of disease and projected to increase 15 percent by 2020 (Hugo, Boshoff, Traut, Zungu-Dirwayi and Stein, 2003). Further research has shown that individuals who are in need of care often do not engage with services and those who do initially seek help frequently do not complete the recommended treatment (Corrigan, 2004). It has been estimated that less than 40 percent of individuals experiencing severe mental illness receive consistent mental health treatment throughout the year (Kessler, Berglund, Bruce, Koch, Laska, Leaf, et al, 2001). Why might this be the case? There are several potential reasons why there is lack of participation in treatment. One likely explanation is that individuals suffering from mental health conditions are so disabled by their conditions that they are not able to seek treatment. Another explanation is that many individuals experiencing mental health issues are not able to identify that they have issues that require treatment. However, there is another explanation that has been identified in the research literature. Both the U.S. Surgeon General (1999) and the WHO (2001) have identified stigma as a barrier to successful engagement in treatment. Stigma can also prevent seeking and sustaining participation in appropriate services.

To understand how stigma might prevent individuals who are in need of treatment for mental health, behavioural and medical conditions seeking treatment it is necessary to examine the definitions and dimensions of stigma. Stigma can be experienced on numerous levels. There is social stigma, self-stigma, stigma by association and health professional stigma.

Stigma is defined as “an attribute that is deeply discrediting” that reduces a person “from a whole and usual person to a tainted, discounted one” (Goffman, 1963: p.3). An individual who is stigmatised is perceived as having a “spoiled identity” (Goffman, 1963: p.3). Dudley (2000) further defined stigma as stereotypes or negative views attributed to an individual or group when their characteristics or behaviours are perceived as different from or inferior to societal norms. This definition, which is derived from social work literature provides a vantage point from which to develop an understanding of stigma. Most conceptualisations of stigma focus how individuals from a variety of backgrounds, including race, ethnicity, gender and sexual orientation are discriminated against by others. However, these conceptualisations do not specifically focus on the impact of stigma on mental health. Therefore, is necessary to establish a definition of mental disorders so that its relationship to stigma can be better understood. The Diagnostic and Statistical Manual of Mental Disorders 5 ([DSM-5]; American Psychiatric Association [APA], 2013) defines mental disorder as a *‘clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that associated with present distress or disability or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom’* which comes from *‘a manifestation of a behavioral, psychological or biological dysfunction in the individual’* (APA, 2013, p: xxxi). This definition can also be used to form the basis of how stigma impacts on the lives of people living with HIV through exploring the underlying constructs that constitute the concept of stigma.

Jones et al. (1984) identified six dimensions of stigma. These include concealability, course, disruptiveness, peril, origin, and aesthetics (Feldman and Crandall, 2007; Jones et al., 1984). In addition Corrigan et al. (2001; 2000) identified stability, controllability and pity as further dimensions. These dimensions can present independently or simultaneously in the creation of stigma. Furthermore, stigma is more than simply a combination of these elements impacting on each person as an individual because stigma is believed to be widespread in the structure of society (Feldman and Crandall, 2007).

The first of dimension of stigma is peril or dangerousness. This is considered an important aspect in the development of stigma because it is how the general public perceives others. In the case of people living with HIV/AIDS they are perceived as being dangerous because HIV can be transmitted to other people through sexual contact or contaminated blood products. Corrigan (2004) also argues that fear and discomfort arise as a consequence of the social cues attributed to individuals. Social cues include psychiatric symptoms, changes in physical appearance and through labels (Corrigan, Markowitz, Watson, Rowan and Kubiak, 2003). In the early days of people living with HIV changes in physical appearance, such as lipodystrophy, were particularly distressing and stigmatising. This also highlights the role of aesthetics or the displeasing nature of the condition (Jones et al., 1984). When society attributes to a person or group behaviours that do not adhere to the expected societal norm discomfort may be experienced. This often leads to labelling and avoidance of the identified individual or group. Certain characteristics such as being gay can be generalised to being an identifying characteristic of people who are most likely to be infected with HIV and, therefore, other groups such as heterosexual men and women are less likely to be perceived as being at risk of being infected with HIV. This has further increased the likelihood of certain groups, such as men being demonised and blamed for having and spreading HIV.

Another dimension relating to stigma is origin. This is particularly relevant in the case of HIV where the origins of HIV are hotly debated and certain groups of people and particular parts of the world have been identified as being the most likely origins of HIV.

Controllability can also lead to certain individuals or groups becoming stigmatised because they are perceived as being responsible for their condition or behaviour and, therefore, they are to blame not only for becoming infected with HIV, but also for the continuing spread of HIV within the general population (Corrigan, et al., 2001). There is more sympathy for individuals suffering from conditions that are perceived as less controllable (Corrigan, et al., 2001).

Concealability or visibility of the illness is a dimension of stigma that parallels controllability, but also provides further insight into stigmatisation. Crocker (1996) argues that stigmatised attributes such as race can be readily identified, and less concealable which allows society to discriminate and stigmatise on the grounds of the visibility of the individual. This conclusion is supported by research which found that society attributes more stigmatising stereotypes towards like such as schizophrenia which have more visible symptoms than other disorders such anxiety or depression (Angermeyer and Matschinger, 2005; Lundberg, et al., 2007). One of the most visible signs of HIV is lipodystrophy which can include a buildup or loss of body fat or both. Since the widespread use of antiretroviral therapy, HIV, lipodystrophy occurs in 30 to 50 percent of people infected with HIV.

Course and stability refer to how likely someone living with a disability is to recover and/or benefit from treatment (Corrigan, et al., 2001). The dimension of disruptiveness assesses how much a disorder or disability may impact on relationships or success in society. While disorders and disabilities are often to be associated with an increased of poverty, lower socioeconomic status and lower levers of education (Kohn, Dohrenwend and Mirotznik, 1998), the stability and disruptiveness of the conditions have implications as to whether someone will be able to get and maintain employment and engage in healthy relationships, as evidenced by the differences in stigma based on social class status. This suggests that where disorders are less disruptive, in which case they may be perceived as being more stable, they are also less stigmatised (Corrigan, et al., 2001).

Social Stigma

Social Stigma is structural in society and may create barriers for individuals with a mental or behavioural disorders. Structural implies that stigma is a belief held by a large faction of society in which persons with stigmatised conditions are less equal or are part of an inferior group. Stigma is embedded in the social framework and creates inferiority. This form of stigma may result in unequal access to treatment provision or the creation of policies which disproportionately and differentially affect the population. Social stigma can also result in further disparities in an individual's ability to access basic services and needs.

Researchers in social psychology have suggested that here are three specific models of public stigmatisation. The socio-cultural model suggests that stigma forms a justification and rationalisation for social injustices (Crocker and Lutsky, 1986). An example of this might be that individuals suffering with mental and behavioural disorders are identified and labelled as unequal. The motivational model emphasises the importance of the basic psychological needs of the individual (Crocker and Lutsky, 1986). An example might be that since people with mental health or behavioural problems are often in lower socio-economic groups, they are also perceived as inferior. The social cognitive model tries to make sense of basic society by using a cognitive framework (Corrigan, 1998). A person identified as having a mental illness would be given a label, placed in a category and differentiated from individuals not suffering from a mental illness.

Psychologists tend to favour the social cognitive model to explain and understand stigma (Corrigan, et al., 2001). One perspective that is derived from this understanding is Attribution Theory and is related to three specific dimensions of stigma, which are stability, controllability and pity (Corrigan, et al., 2001). A study found that the general public often stigmatises mental and behavioural conditions to a greater extent than physical conditions (Corrigan, et al. 2001).

Self Stigma

Stigma is not only held among others in society, but can also be internalised by the person with the condition (Crocker, 1999). Moreover, the continued impact of social and public stigma can influence an individual to experience guilt and feel inadequate about their condition (Ccorrigan, 20004). Collective representations of meanings in society, such as, shared values, beliefs and ideologies can act in place of direct social and public stigma in these situations (Crocker and Quinn, 2002). Therefore, in self-stigma, the knowledge that stigma is present within society, can have an impact on an individual even if that same individual has not already experienced being directly stigmatised. This can also have a serious negative impact on an individual's self-esteem, and self-efficacy, which in turn may lead to changes in how that person behaves (Corrigan, 2007). However, Crocker (1999) argues that individuals may internalise stigma differently according to their situations and this suggests that personal self-esteem may or may not be as affected by stigma depending on the application of coping mechanisms (Crocker and Major, 1989).

Other theories have provided further insights into self-stigma. For example, labelling theory argues that the expectation of becoming stigmatised, in addition to actually becoming stigmatised, can be factors that influence psychosocial wellbeing (Link, Cullen, Straining, Shrout and Dohrenwend, 1989). A study by Weiner (1995) found that stigmatised beliefs can provoke an emotional response. For example, an individual who feels stigmatised may react with shame, anger or feel marginalised by society.

Stigma by Health Professionals

In one study involving psychiatrists, nurses and psychologists found that health professionals did not differ from the general public on their desired social distance from individuals with mental health conditions (Nordt, Rössler, and Lauber, 2009). Other studies have down similar conclusions (Lauber, et. al, 2006; Tummala and Roberts, 2008; Sriram and Jabbarpour, 2005). Clients have also described how they have felt 'labeled' and 'marginalised' by health professionals (Liggins and Hatcher, 2005).

Another aspect of HIV is how it has changed from a terminal illness into a chronic disease.

5.1.4 HIV as a Chronic Condition

In June 1989, Samuel Broder, the then head of the National Cancer Institute, declared in a speech at the international AIDS meeting in Montreal, Quebec, that AIDS was a chronic disease and that treatment should follow the model of cancer (ref). This public statement marked a shift in the social definition definition of AIDS from an acute to a chronic illness, a shift with economic and cultural repercussions for the treatment and understanding of AIDS at the national, local and individual levels (Fee, Fox, 1992). However, it was not until the advent of protease inhibitors in 1996, which ushered in the era of highly active antiretroviral therapy (HAART), that the view of HIV/AIDS as a chronic illness became widely accepted. These medications were often described by the mass media as 'miraculous' because they reduced the risk of opportunistic infections and extended survival rates by suppressing viral replication and boosting CD4 counts. The availability of HAART was said to have given hope back to patients infected with HIV for the first time in over a decade of treatment (Kobayashi, 1997) and offered those infected with HIV a 'second life' (Rabkin and Ferrando, 1997).

While in the Western world recent treatment advances have had a profound effect both on the illness trajectory and the life expectancy of many infected individuals (Centers for Disease Control, 1997). AIDs-related mortality is still an issue in parts of the world where access to the newer medications is limited. The prohibitively high cost of antiretrovirals coupled with inadequate and inefficient health delivery systems have enable AIDS to reach catastrophic levels in many developing countries (UNAIDS and WHO, 2001). Even in North America not all those infected with HIV have access to or choose to take the new treatments. Some doctors are less likely to prescribe HAART to patients they assume to be at risk of low adherence, such as those with a history of drug abuse, the homeless and the mentally ill (Bassetti, Battegay, Furrer, et al, 1999; Maisels, Sternberg, Tobias, 2001; Gerbert, Bronstone, Clannon, Abercrombie, Bangsberg, 2000), although the evidence supporting these views remains inconclusive (Chesney, Ickovics, Hecht, Sikipia, Rabkin, 1999; Fogarty, Roter, Larson, Burke, Gillespie, levy, 2002). Further research indicated that women, African-Americans and those with low levels of education are less likely to have ever tried the new medications (Cook, Cohen, Grey, et al, 2002; Jacobson, Gore, Strathdee, Phair, Riddler, Detels, 2001). These finding have been attributed not only to a lack of access to HIV medication amongst these socio-economically disadvantaged groups, but also to their own reluctance to take these more effective medications due to factors such as fear of adverse side-effects and a general distrust of doctors.

What is a Chronic Illness?

Chronic illnesses are typically incurable and, therefore, the goals of medical care take the form of containment, slowing disease progression and symptom management rather cure. Chronic diseases tend to share a variety of characteristics (Cordin, Strauss, 1991; Royer, 1998). Frequently, they have an uncertain disease trajectory which is often characterised by alternating periods of remission and relapse, or stable periods interrupted by episodic outbreaks of symptoms (Lubkin, Larsen, 2002). Most require adherence to a treatment regimen, although these are likely to differ significantly across different diseases both in complexity and efficacy. Chronic diseases often require considerable self-care, such as self-monitoring of symptoms on the patient's part, because much of the daily management of chronic illnesses occur outside health institutions or medical facilities. As illness could be described as a form of deviance, it is an undesirable state and carries a degree of stigma. However, this stigma can vary greatly and depends on a variety of factors, for example, whether the individual is deemed responsible for having acquired the illness, whether the illness is contagious and whether there is visible disfigurement. Lastly, chronic diseases often bring about identity changes as the patient attempts to integrate the illness into his or her life and self-perception in the long term. Psychological distress is often experienced by individuals living with chronic conditions, because of the inherent uncertainty which is common to many of these illnesses. Each of these aspects of living with a chronic illness pose an adaptive challenge to the individual. These challenges include tolerating uncertainty, managing stigma, and adhering to treatment regimens. How well a chronically ill individual adapts to his or her disease will depend to a large extent on his or her ability to master, or at least successfully manage, these tasks. While available treatments can render a patient's viral load undetectable, HIV can not be fully eradicated from the body and, left untreated, the viral load will rebound. Consequently, there is no cure for HIV. Also while the natural history of the disease has been delineated, the course of HIV disease progression varies considerably amongst individuals (Hogan, Hammer, 2001). Furthermore, the drug treatments for HIV are not equally effective for all patients (Friedland, Williams, 1999). It is also recognised that living with HV can have a profound impact on intimate and social relationships. The fact that the disease can be transmitted through sexual behaviours renders intimate relationships fraught with anxiety and ambivalence. Infected adults often feel that others unwilling to enter into long term relationships with them for fear of having to assume care-giving responsibilities when the disease progresses.

In addition, self-care is a component of living with HIV. Many patients engage in self-initiated strategies, for example diet, relaxation exercises, stress avoidance, which are aimed at managing illness or treatment-related symptoms, boosting their immune system, or reducing stress. Davis et al. (2006) argue that a type of post-HAART fatalism has begun to emerge as a way of defining the limits of personal responsibility. This fatalism can be characterised as a failure of the reflexive self, in the form of giving up. They further argue that fate has value for patients because it give a freedom to exist without blame. Chronic illness self-management discourse is often critiqued because it mobilises moral judgement of those who are seen to fail to act to care for themselves in a responsible manner. In this discourse, fatalism is regarded as a type of denial or failure of reflexivity. Davis et al. (2006) state that the chronic illness discourse can be overly blaming, particularly where a lack of reflexivity could be also understood as an act of freedom. People living with HIV need to be free to settle on fatalism as way of existing within the limits of HIV treatment. Pre-exposure prophylaxis (PrEP) has also changed the way HIV is conceptualised. The introduction of PrEP has change the focus of clinicians from treatment to prevention. There has also been a reduction in funding of support for people living with HIV in the voluntary sector. This has become a further area of anxiety for individuals living with HIV.

5.1.4 Pre-exposure prophylaxis (PrEP)

Pre-exposure prophylaxis (PrEP) is the preemptive use of drugs to prevent disease in individuals who have not yet been exposed to the disease-causing agent. More specifically, the term is used to refer to the use of anti-retroviral drugs that interrupt the life cycle of HIV as a strategy for the prevention of HIV infection. PrEP is an optional treatment which may be taken by individuals who are HIV negative, but who have a substantial, higher than average risk of contracting HIV infection.

currently, the only drug which any health organisation recommends for HIV/AIDS PrEP is Truvada, which is a combination of tenofovir and emtricitabine. The Centers for Disease (CDC) says that PrEP is a powerful HIV prevention tool can be combined with condoms and other preventative measures to provide even greater protection than when used alone'. However, individuals who are given PrEP must commit to taking the drug every day and seeing his or her health care provider for follow-up checks every three months (CDC, 2014).

Approval for use

The CDC's HIV prevention guidelines were amended on 14 May 2014. It was recommended that PrEP be administered to high infection risk populations due to research indicating that PrEP effectively prevented transmission from mother to child (15). Prior to that date PrEP was only approved to treat existing HIV infections (CDC, 2015) In 2012, the World Health Organisation (WHO) issued PrEP guidelines which stated that PrEP may be considered as possible additional HIV prevention intervention for the uninfected partner in couples where one partner is HIV-positive and when additional HIV prevention choices for them are required (WHO, 2012;). The WHO made similar recommendations for men and transgender women who have sex with men. It was further stated that international scientific consensus is emerging that antiretroviral medication, including PrEP, significantly reduce the sexual acquisition and transmission of HIV regardless of population or setting (WHO, 2012; 8 10 11). Also in 2014, on the basis of further evidence, the WHO updated their recommendation for men who have sex with men to state that PrEP is to be recommended as an additional HIV prevention choice within a comprehensive HIV prevention package (WHO, 2014; Celum, 2011). This advice by the WHO was expanded, on the basis of more evidence, and stated that it had broadened the recommendation and advice to include all population groups at substantial risk of HIV infection. The WHO emphasised that PrEP should be an additional prevention measure in an already comprehensive package of services (WHO, 2014).

The IPERGAY study (Molina et al, 2015) investigated the efficacy of an alternative strategy of 'on-demand' PrEP where Truvada was taken between two to twenty-four hours before sexual activity and only continued for two days afterwards. In a clinical population of gay men in France and Canada at hight risk of becoming infected with HIV, this strategy lead to a drop of 86% in HIV infections over the average nine month followup in the study. As of December 2015 non-continuous PrEP methods have not been endorsed by WHO or national guidelines (United States Public Health, 2014; WHO, 20150.

Moves towards the widespread adoption and acceptance of PrEP has proved divisive, politically, and within gay culture. It has lead to a perception in some quarters that PrEP is likely to be misused, and undermine existing safer sex policies (McNeil, 2014).

Young et al. (2015) identified how deeply entrenched forms of HIV-stigma and homophobia can shape and obfuscate the consumption of PrEP. Furthermore, rather than seeing PrEP as liberating through reduced levels of infectiousness or risk of transmission, social and legal requirements of responsibility in relation to HIV risk reinforced unequal forms of biomedical self-governance. The research of Young et al. (2015) also highlights how responses to PrEP are grounded not solely in an expert/lay divide or economic inequalities per se, but in a sero-divide that is perpetuated through the emergent dividing practices of the very biomedical practices themselves. The uneven patterning of biomedicalisation is amplified by and further manifested in the nexus of traditional lines of inequalities such as sexual identity, ethnicity, migration/mobility, gender and geography. Young et al. (2015) suggest there is a potentially growing gulf between HIV-positive and HIV-negative communities in terms of health expectations and experiences of negotiating biomedical prevention. It also raises a number of questions about what equitable and fair HIV prevention looks like, how this might manifest across diverse communities and who is or will be implicated in the increasingly biomedical moral imperative to prevent HIV.

5.2 Research contribution and recommendation for practice

As well as being a key requirement of my doctoral training, at the core of this research has been the intention to offer a meaningful contribution to the knowledge-base of counselling psychology; and in particular to our understanding of what it is like to be living with HIV.

In sections below, and for ease of cross-reference and wherever practicable, I present the clinical implications systematically in the order in which they been so far discussed.

In terms of specific concerns and issues that emerged in this research, the findings strongly endorse the importance of giving people living with HIV the opportunity to be able to freely express what it is like for them. In other words, allowing their voice not only to be heard, but their experience of living with HIV to be understood from their perspective. I evaluate below this central implication from the perspective of both theory and practice.

To reiterate and as discussed in 5.1.1: all participants presented with anxiety which, I have argued, was directly associated with being infected with HIV. This principally manifested in a sense of isolation; social withdrawal; discrimination; stigma; fear of rejection persecution.

From a theoretical perspective the objectives were closely aligned to the defining characteristics of Counselling Psychology, which as shown in Chapter 2, is a pluralistic profession underpinned by key phenomenological concepts. These include a fundamental acknowledgement of the subjective lived experience - the participants wanted their *reality* to heard and understood - and our inherent relatedness in the world and with others. At the heart of their distress was isolation and a yearning for acceptance and meaningful relating.

Further, and as '*encouraged'* in the BPS (2012) Professional Practice Board guidelines for working with sexual minorities, based upon the participants experiential accounts I suggest it is necessary for all practitioners working in the field of HIV to be sufficiently conversant with the wider issues and the socio-political context for people living non-heterosexual lives. This includes common assumptions made, pejorative stereotypes and their associated impact on both the mental health and general wellbeing of people living with HIV. Without practitioners equipping themselves with this knowledge, clients (such as service users attending HIV support groups) are likely to feel misunderstood and which participants in this research identified as vitally important.

Cooper (2009) argued that practitioners need to develop an attitude of '*welcoming the Other'* and this was an *'ethical imperative'* for counselling psychologists. Having feared and experienced both persecution and rejection in their lives individuals living with HIV need to feel safe enough to able to ope up and show their vulnerabilities to others.

As stated above, and in line with the current BPS guidelines, an important aspect of this would be ensuring practitioners are fully aware of the specific challenges sexual minorities experience. Given the ever evolving nature of this area of work, this may well require an element of continuing professional development to ensure working in this field keep abreast of the current socio-political situation and its potential implications.

This is especially important for anyone working in this field who does not identify as belonging to a similar sexual minority and cannot expect to convey a genuine understanding or empathy of their service users experience of living with HIV unless they have fully familiarised themselves with some of the key issues encountered by people living with HIV. Far from a demise in social stigma and persecution, in some sections of society there has been an increase of discrimination of people living with HIV. For example, Stonewall commissioned *Gay British Crime survey* in 2013 found that hate crimes continue to be a very present and serious problem in the UK, reporting that *one in six lesbian, gay and bisexual people experienc(ed) a homophobic hate crime or incident over the past three years…suffering wide-ranging abuse, from physics assaults and threats of violence through to harassment, verbal insults and damage to their property'* (Guasp et al., 2013: p.4). This complicated current socio-political situation and the potential profound implications for people living with HIV needs to both acknowledged and understood.

Taking stock

By offering a forum to subsequently reflect, process, review and appraise, the research interviews were welcomed by all participants and deemed to be an integral part of their coming to terms with living with HIV. Therefore, in terms of clinical practice, providing service users living with HIV with an opportunity to review and evaluate what works for them in terms of coping strategies and making healthy lifestyle choices. Returning to some of the core characteristics and intentions of Counselling Psychology (i.e. individual empowerment and facilitating a focus upon wellbeing and potential); and for us as practitioners to comprehensively attend to these opportunities to encourage service users to share their experiences of living with HIV.

Furthermore, there is significant value in providing opportunities for individuals living with HIV to be able to talk openly and freely about their experiences in safe space, provided by someone other than a therapist. There is also a need for professional care and support that takes into account the needs of the individual living with HIV rather than a *'one size fits all'* approach.

5.2.1 Clarification of research contribution scope

When considering the overall contribution of this research project, it is important to also be clear on what claims *cannot* be made from the findings. Firstly, and to repeat the point made above in the Method chapter (section 3.3); and given that this an ideographic study, there has been no attempt to produce generalised conclusions or develop theories attributable to the wider population. Rather, this investigation has been about providing an arena for a small group of service users and giving them the opportunity to give voice to their experiences of living with HIV.

The findings show how the participants fear of stigma, rejection, persecution and discrimination and a general sense of isolation as well as a need for acceptance and relatedness were all associated with living with HIV.

However, and again reflecting on the fact that this is an idiographic study, I cannot draw any such conclusions about what it is like to living with HIV from these findings in terms of the wide clinical population.

Having outlined the research contribution in terms of counselling psychology theory and practice, I now turn my attention to an appraisal of the design limitations of the current research as well as offering some suggestions for future related research studies.

5.3 Design clarifications and ideas for future research studies

My primary intention throughout this research process has been to offer a robust contribution to the knowledge-base of the discipline of counselling psychology. As part of this evaluation, I have identified a number areas that might be deemed worthy of consideration for future investigation and which are detailed below in section 5.5.2.

However, first and possibly something that is inevitable with most research, during the planning and implementation stages some design issues emerged. For the purposes of research transparency as well as to assist future researchers in the design of their studies, I will outline each issue below (in no particular order).

5.3.1 Design implications and clarifications

Based the research literature and identified gaps in the knowledge-base, I approached the design stage of this research with clear ideas about what I wanted to explore. Specifically, I had distinct areas of the experience of people of living with HIV that I had concluded were worth focusing upon. However, I accept that this could be perceived as running counter to the central feature of descriptive phenomenology, which is the research should be participant-led, characterised by semi-structured interview questions intended to facilitate a non-directive exploration of the participant's experiential world. A key aspect of this is the minimising of any pre-conceived notions or assumptions of researcher.

I agree that these fundamentals of a descriptive phenomenological research design to be crucial. I consider my actual interview questions to have been appropriately open and facilitative of whatever the participants wished to explore - albeit within pre-defined parameters.The intention has been to conduct a non-directive enquiry of specific phenomena within a wider phenomenon. Without doing so, the specific objectives of the research may not have been satisfied and the potential opportunity afforded by my research participants giving so generously and courageously of both their time and knowledge for the purpose of enhancing our knowledge could, I believe, have been lost. For example, I wanted to understand what it was like to be living with HIV, so I began my investigation by asking a question about what is it like to be living with HIV. I would argue that this is an open and phenomenological question rather than a specific question such as *'What has been your experience of stigma?'* I wanted the question to encourage each participant to describe their experience of living with HIV without them feeling they had to address any specific issue such as stigma. In this way, I would argue that I can reasonably suggest my data contributes to the gap in knowledge. My view is that greater depth and focus upon the gaps in the knowledge-base was achieved by the research questions I asked. Whilst acknowledging this inevitably a researcher-led element to the interview design, my view is that Colaizzi's (1978) descriptive method as described in section 3.3.1 allow for this as well as protecting against it being over-reached by way of analysis transparency.

Following on from the above, I turn to what I would argue is a strong ethical argument for allowing each participant to see my analysis of their interview and give them the opportunity to give me feedback on my analysis, particularly when the research participants were service users at the HIV charity where they were interviewed and so were disclosing and engaging with potentially distressing or affecting issues. The rationale for asking for feedback was to ensure that the analysis of the data and the subsequent reporting of my findings were based on a robust and comprehensive understanding of the participants' experiential accounts. As I stated in Chapter 3 (section 3..4), Flowers (2008) argued that the potential for lost opportunities is high due to the elevated 'cognitive load' for the researcher when so much is demanded and expected from an 'one-off' interview. This is especially true for the novice descriptive phenomenological researcher.

6. Conclusion

Early in the AIDS epidemic, the public understanding of HIV infection was that it was a highly fatal disease which result in an early death. Medical advances, such as anti-retroviral medication, mean a person infected with HIV can now hope to have a normal life span. However, there are still challenges faced by people living with HIV such as stigma and discrimination which prevent many people living with HIV from being open about having HIV. Many people living with HIV also experience being rejected by others who fear stigma by association. These experiences can lead people living with HIV to feel socially isolated and some may even choose to isolate themselves to minimise the impact being rejected can have on them.

One area of further research might be to explore the experience of people living with HIV since HIV became classified as a chronic condition to see how their experience might differ from individuals diagnosed HIV-positive at a time when becoming infected with HIV was considered a death sentence.

Another area of research might be to explore why some groups that are HIV-positive, such as women and children receive more sympathy compared to Gay men. It would be interesting to explore where these prejudices come from and why they are so resistant to change.

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Appendix 1

AIDS defining clinical conditions

AIDS defining clinical conditions is the terminology given to a list of diseases published by the United States government run Centers for Disease Control and Prevention (CDC) . This list governs the U.S. government classification of HIV disease. This allows the government to handle epidemic statistics and define who receives US assistance.

According to the US CDC definition (1993), a patient has AIDS if he or she is infected with HIV and presents with one of the following:

A CD4 T-cell count of less than 200 cells or CD4 T-cell percentage of total lymphocytes less than 15 or the patient has one of the following AIDS defining illnesses:

1987 definition:

1. Candidiasis of bronchi, trachea or lungs
2. Candidiasis oesophageal
3, Coccidiodomycosis, disseminated or extra pulmonary
4. Cryptococcosis, extra pulmonary
5. Cryptosporidiosis, chronic intestinal for longer than one month
6. Cytomegalovirus disease (other than liver, spleen or lymph nodes)
7. Cytomegalovirus retinitis (with loss of vision)
8. Encephalopathy (HIV-related)
9. Herpes simplex: chronic ulcer(s) for more one month; bronchitis, pneumonitis or oesophagtis
10. Histoplasmosis, disseminated or extra pulmonary
11, Isopsoriasis, chronic intestinal (for more than one month)
12. Kaposi's sarcoma
13. Lymphoma, Burkitt's
14. Lymphoma, immunoblastic
15. Lymphoma, primary, of the brain
16. Mycobacterium avium complex or Mycobacterium kansasaii, disseminated or extra pulmonary
17. Mycobacterium, other species, disseminated or extra pulmonary
18. Mycobacterium tuberculosis, any site (extra pulmonary)
19. Pneumocystis jiroveci pneumonia (formerly Pneumocystis carnii)
20. Progressive multifocal leukoencephalopathy

21. Salmonella septicaemia (recurrent)

22. Toxoplasmosis of the brain

23. Tuberculosis, disseminated

24. Wasting syndrome due to HIV

Added in 1993:

1. Cervical cancer (invasive)
2. Mycobacterium tuberculosis, any site (pulmonary)
3. Pneumonia (recurrent)

Appendix 2

Transcripts

Maria (Not her real name) 38

HIV Positive 15 years

1. Researcher: Good morning Maria.

(I gave the consent form to sign and the question sheet. She signed the form and took a moment to read the question sheet.)

2. Maria: Most teenagers are pretty savvy about boys, but 20 years ago, I was you
3. know what you might call naive. I grew up in a small village in a big, traditional
4. and staunchly Catholic family. We were a family of nine children.
5. I'd never even had a boyfriend, let alone had sex, so er during the um summer

break from college. I went to visit my sister in a nearby town, and Charlie, who was a good looking guy who looked like he was in his mid to late twenties, made a fuss of me. I guess you could say I was ripe for the picking. At the time, I had no idea about safe sex. We spent the whole of the summer together and at the end of the summer when it was time to leave, I went straight back home to continue my studies and didn't really think about him again after that. A few years later, I was sitting in a cafe with Michael who a young boy I had met at college. Having been together a few months, we having were the standard "previous relationships" conversation and I innocently brought up the subject of my summer romance. Michael'sface went suddenly white and, after a pause which seemed to go on forever he said to me 'I think we need to go for an HIV test.' Although Michael didn't know Charlie, he said that it was an open secret amongst the locals that Charlie was a drug user and also HIV positive. Hearing Michael say that well as you can imagine it hit me like a being run over by a truck. It was strange though I didn't feel angry or sad, in fact that all came later. At the time the images that I had in my head were falling tombstones from those scary HIV adverts that were all around in the early 1980's. My one and only thought was "I'm going to get sick real quick and die." Michael was really good and took control cause I wasn't in a fit state to think clearly anymore. He did some asking around and found a clinic where we could get tested. He booked an appointment for both of us and we went together for the test. I didn't know what to expect. I gave a blood sample and was told to wait outside in the waitng room until my test results were ready. The doctor said it would not take long. It seemed like forever as we waited to be called back into the room to be given our results. I don't know how long we must have been waiting. Then I heard my name being called out, at first I didn't respond, then Michael nudged me and said “They’ve called your name.”I got up and slowly walked towards the Doctor’s door. Everything was happening in slow motion. I knocked on the door and went in.The doctor told me to sit down. The doctor didn’t even look at me as he read out my test results. “You’re HIV positive” he said, before asking “What drugs have you been using?” I was so stunned. I was in total shock. I could barely answer. “I don’t do drugs” I told him, but he refused to believe me. I just sat there and cried. Michael was given his result and it came back negative. He knocked on the door as he wondered what was taking so long. He came in and sat next to me. I will never forget the coldness of the doctor’s words. I felt judged by him. The doctor then said “You can never have unprotected sex, so you probably wont get married, you will never be able to have children and you’ll maybe live another 10 years if you don’t get sick.” I had been HIV positive for 3 years without even knowing it. The next two years were a bit of a haze. I felt so dirty and ashamed and I somehow became convinced that be coming HIV positive was all my fault. All the talk around HIV/AIDS at the time revolved around prostitutes, injecting drug users and gay men. If even my doctor wouldn’t believe I was none of those, then why would my family or friends, who know much less about the disease believe me. As a result, I couldn’t bear the thought of telling my family and friends. So I ended feeling depressed and isolated. It was an awful time for me. I’d tell my flatmate that I was going swimming and just go walking and walking. I’d be out with friends in a cafe and all of a sudden I would burst into tears for no reason. Michael was my only source of support, but eventually even he stopped wanting to touch me, let alone have sex with me, and we broke up. Strangely, enough although I felt I couldn’t discuss my HIV with my family I felt it was compulsory to tell all the men I dated after

56. Michael as it seemed only fair or I would be as bad as the guy who had infected 57.
me. Their reactions ranged from quietly drifting away to downright callous. I was 58.
going out with one guy for a short time and after I told him he we split up. I don’t 59.
who he told, but one afternoon I was sitting in my local cafe and one of his friends 60.
came up and said to me “Is it true that you have AIDS?” It was then that I began 61. to
face the possibility of being on my own forever. One night I was out dancing 62. with
a group of friends from work. I’d trained as care assistant and was working 63. in a
nearby hospital at the time and I met someone I really liked. He was Alberto. 64. We
just danced together all night and after that we became friends. I didn’t feel I 65. wanted
to take it further. But, after a couple of months I began to think he wanted 66. more and
cause he was so good-hearted and kind I couldn’t bear the thought of 67.him developing
feelings for me without me telling him the full complicated story.

68. He seemed such a lovely guy, but so had others and had just disappeared after
69. being told. After the initial shock, Alberto just looked at me and said “Well we can
70. take precautions, so let’s try and see how it goes. If it works out there’s no reason
71. why we can’t get married, maybe have a child. So let’s see it how it goes.” I was
72. gobsmacked. I mean not only did he want to continue seeing me even after I’d
73. dropped a bombshell on him, but he was serious about having a relationship with
74. me. The real me. Alberto and me. We were married 2 years later. Despite all the 75.
happiness I felt on my wedding day, I knew that by refusing to tell my family and 76.
close friends that I had a disease that could kill. I was living a lie. One sister I was 77.
particularly close to lived in North London, so on a visit to see her, well, it I just 78.
blurted it out that I had HIV. Her fear about what would happen to me soon turned 79.
to anger that I hadn’t told her before. Eventually she did calm down and we were 80.

able to talk about my fears. She was convinced there was a better chance for me to get the medical help I needed if I came to live with her in London. So with Alberto we came to London soon after. At the hospital where I was being treated in London I was given a leaflet about a support group which was for heterosexual adults and their families as most of the groups were for just for Gay men. The welcome I got was unbelievable. Everyone made me feel so comfortable and for first time in years I felt I could relax and be myself.

R: What was that like?

M: I began to feel normal. I took to going most weeks when there were meetings on. I also took the opportunity to join in some of the other activities that were being offered. It was a great way to start meeting other HIV positive people. I did yoga classes and was offered counselling which I had never really thought about. Slowly I began to feel safe enough to let my guard down. It really helped being with other people who were in the same position as me. They knew what it was like to be HIV positive without me having to keep explaining myself. Until then I felt I was the only one. Now I knew there were others like me and I have learned alot from talking to other women about their experiences of having HIV and being in relationship with someone who is HIV negative. What really surprised me the most, though, was seeing HIV positive mums coming in with babies, who looked healthy. “Is he okay?” I couldn’t help asking one woman about her baby boy. “He’s perfect.” she said. “You know you can have children and they will be fine.” I couldn’t take it all in. I thought this is too good to true.

R: In what way?

M: I went to see my HIV consultant and asked him how it would be if I wanted to have a baby. He explained about the new treatments for HIV given to

105. expectant mothers during pregnancy and labour and as long as I didn’t
106. breastfeed, the chances of passing my illness to my baby were less than one per
107. cent. It took awhile to sink in. I’d given up any dreams I’d had of having
108. children long ago. But my doctor at the time confirmed what I’d heard at the
109. time was true. Nine years after after my first doctor had told me I’d never have
110. children, my son was born. He looked healthy and happy when he was born, but
111. because HIV takes time to show up in tests, we had to live in anguish until we 112.
got the all clear. The time the waiting was awful. I kept wondering thinking I was 113.
being selfish bringing a child into the world. At 18 months my son got the
114. all-clear and today he’s active and cheeky and loved football. He’s just like any
115. other seven year-old boy. Still I knew deep down that because of me my child 116.
would never be able to have a normal life. For example, once after I had done an 117.
interview for our local paper, one of the mothers from my son’s school stopped 118.
talking to me..I remember seeing her cross the road when she saw me coming.
119. It really hurt to feel that someone who I knew and trusted was avoiding me just
120. because I had an illness that I could not do anything about. I was still the same
121. person she had been speaking to all along. I felt it was me in wrong not her.
122. Things like that happening still hurt, still upset me. I try not to let it matter or that
123. I’m upset by it. I feel I have to be strong for my husband and child. Then there’s
124. the possibility I might die. I’ve had the virus for 20 years and luckily I’ve kept
125. pretty well, but I know I could get really sick and have to start taking medication.
126. Anything could happen. Where one person lives 30 years after diagnosis, another
127. will get sick and die much sooner. By far the biggest issue for me though was 128.
telling my son. Disclosing to him that I had HIV. I did not want it to be some 129. dirty

secret or him finding out from anyone else. I did not want to keep it a secret 130. from
him. I didn’t want him growing up feeling and believing that HIV was
131. something terrible we couldn’t talk about. It was difficult to judge when it would
132. be a good time to tell him about my HIV. After all he is still quite young. But 133.
one day he asked me why I had so many hospital appointments and so I told him 134.
that Mummy was sick, that I had an illness. That seemed to satisfy him. Slowly, 135.
we will filter little bits of information to him. The shock of breaking it to him 136. when
he gets to being 14 would be too much for him to cope with. I want my son 137. to
grow up knowing that he never need be ashamed of anything about himself or 138. his
family. I am slowly coming to terms with the fact that I have HIV and it is 139. nothing
to be ashamed of. That’s why I chose to give you this interview. I want 140. to be able
to tell my story and maybe how I have lived my life since testing
141. positive will inspire others you know give that hope perhaps reassure them that it
142. is possible to still have a life after testing positive to HIV. I mean you see so
143. much publicity for diseases like heart disease and cancer, but the image of
144. HIV is still swathed in secrecy and shame. It’s unbelievable really when you
145. think that the number of people getting infected and living with HIV is on the 146.
rise. We need the same kind of care and compassion, the same as anyone with a 147.
terminal illness, but if no-one will talk about it you know discuss having HIV it 148.
will always remain a dirty secret. And if someone bullies my family as a result of 149.
me having this disease I feel stronger now and I’m ready to take them on the
150. bullies. I’m tired of hiding. I’ve become much more open with friends too. A few
151. years ago I felt able to disclose my HIV status to my family. I went back home
152. and told my family that I had HIV. At first my siblings were in denial and tried

to stop me telling my Mum. They said that she was too old and frail and would not be able to handle me telling her. But I had to. My reasoning was that if I couldn’t accept myself having HIV, how could the world ever accept me? Although when I did tell my Mum at first she did think it meant I was going to die. But once she began to understand she came around to being accepting of me having HIV and still being her daughter. Now my family see how healthy I am and see my gorgeous little boy and my wonderful husband and they see a loving healthy family HIV or not. For that I will always be grateful

Mark 51

HIV Positive 22 years

Mark: Comparing things to when I first tested Positive in 1994 as someone who is a long-term survivor, one of the first problems I had was accessing clinics, particularly as I still working at the time. Just getting a test was difficult in itself. I took a test on a Tuesday and the next time I could get back was a month later to find out the results as that was the only way I could get tested so I working the whole time with the uncertainty, the not knowing of the test result. When I did find out I had tested Positive it was a complete shambles as the clinic I went to was a GU clinic. I just went into a room and someone opened a folder and said “You’ve tested Positive”. I was told to wait for a doctor to come and explain what it meant to be HIV Positive. The doctor kept being interrupted by nurses all the time he was trying to explain to me. That evening I had to go to work so I did not have any time to think about.So from then to now I think there are a lot more services available for people and obviously the testing technology as moved on, now there is rapid testing with counselling which is a big difference and across different Boroughs you can get tested at any time. So there isn’t a particular worry, As

16. regards Stigma I didn’t have that problem with my parents as my Mother died
17. when I was 21 and my Father who became an alcoholic so I didn’t see him and so
18. didn’t to tell him my diagnosis, but I did need to tell my Sister and her family. I
19. went up where they were living specially to tell in person. They weren’t hostile to
20. me when I told them so I relieved that they took it on board so well, but the one 21.
thing that did happen was my Sister then phoned up all my other relatives without 22.
first letting me know, but luckily my relatives were supportive so I didn’t get any 23.
hostility from my relatives which was rather surprising because that was the one 24.
thing that really worried me. At work the one problem I had was that when I
25. became unwell, I couldn’t tell anyone in senior management or my immediate
26. colleagues at work.I couldn’t go to the Personnel Department because even if it 27.
was only said to someone in Personnel believe you me when I say it would get
28. around the office, around the building like wildfire and everyone in the building 29.
would know. So when I was feeling ill which was a lot of the time I had to
30. disguise it as best I could by taking days off as holiday and also the drug available
31. at that time AZT which I declined to start taking and my consultant at the time did
32. not offer any alternative drug treatments when they became available so I was 18
33. months before I could even get treated properly by which time I had stopped
34. working as I was needing to have too many days off when I was feeling ill. In
35. those days it was a death sentence so I was signed onto benefits and so that was it,
36. which has all changed round now. Funnily enough, one area where I did get some
37. prejudice, which surprised me, was from some Gay friends who I would have
38. thought they would have known better. They suddenly dropped me like a ton of 39.
bricks. I used share lifts with them, sometimes they would drive, sometimes I
40. would drive. We would car share. Once I stopped working because I was HIV

41. positive my friends disappeared. I didn’t see them after that for dust. Why do
42. think that was? Probably they didn’t want to be associated with someone who was
43. HIV positive at that time because there was prejudice around having HIV and to
44. have HIV was an instant death sentence. They didn’t want to be seen around with
45. somebody who would perhaps reflect on them that hey might be associated with 46.
something like that and also in a mercenary sense you find out who your friends 47. are
when things start going wrong, but it did surprise that it was in the Gay friends 48. I
had, close friends. So that was a real hurtful setback for me or particularly
49. regarding certain people it hurt me. Also at that time there were a lot people dying
50. of AIDS, so I was attending a lot of funerals. It was a totally different atmosphere
51. to what it is now.When I was first HIV positive and um because it was seen as a 52.
death sentence I was really, I did not have that much time to think about it because 53.
I was still working I had to get on with it, I was always a very self-sufficient
54. person anyway and as I mentioned earlier I did not have parents to fall back on
55. and so I had to look myself financially and everything else. I really didn’t have the
56. luxury of being able to think and wallow in fact that I was dying in that sense so 57.
perhaps that helped to get through it, but emotionally I was in completely different 58.
place, I thought “Oh this is the end” and in fact what I did when I gave up my job, 59.
I handed in my notice and went with some friends to Australia, I used up my life 60.savings because at that time I thought “Well if that’s going to be the end of it then I
61.might as well see something of the rest of the world”. I did that two years running.
62. Um (laughs) I wished I saved the money now. So um it did affect me for quite a
63.long time but because I’ve positive for such a long time now and with the
64. advances in medication now, the way that medication doesn’t so many

side-effects, they've worked out which ones do and which ones don't because I've been so 12 different combinations and during that time I've so many ups and downs with different problems from the medication. Luckily, the stuff I take on a regular basis now does not affect me in that way. But I have had side-effects that are long lasting and which I am still dealing with, but in another I am in a much better place now and this time last year to give you an example when I changed medication my T-cell count went up from 68 to 88 continued to rise and by the middle of this year my T-cell was 200 which is still not ideal, but a lot of my energy has come back and I felt able to start volunteering here at this organisation which had helped so much in the past and I'm trying to rebuild things against a background of lots of other things going on such as the economy as a whole.

That's important point you are making and so I am wondering how you now maybe see your place in the world now? There are two ways of answering that question. Um, I've always worked, worked for 26 years so I know what the workplace is like. I come back here to basically to upgrade my skills, but I've got to point where after a year my T-cell counts are on the increase after a really rough time of it for the past 15 years and against a big backdrop of a lot of younger people looking for work and people of my age 55, 56 are all on the scrap heap and now the added stress of now having my benefits, having been transferred, benefits which were not even at the higher grades to the Employment Assistance Allowance which means I have to see a so called Specialist Advisor at the Job Centre now. But the Specialist Advisor doesn't exist so it is a complete sham, they don't know anything about anything and basically I have to go through all this rigmarole and although I have been given an action plan and I'm volunteering and I'm upgrading my skills when I ask if I could go on a computer course to upgrade my skills I'm told “We don't do them.”, they're not available. When I asked about other training they didn't know and they told I would need to find out for my self, I would need to go round the local colleges and find out for my self. This week I have be called for an interview by the Job Centre as they have sanctions if you don't attend so I'm going this Friday to show them what I have been doing to look for work even though we all know there is nothing out there for someone of my age and with my health record, my medical history. The next step is for me to be off loaded by the job centre onto a private service provider to be taught confidence building, employability, and skills which without bigging myself up I think I already have and so it is up to me whether I decide to go on it or not, but it is all that is on offer contrary to what you're told in the media and I have to miraculously find myself a job by the 19th July or my benefits will be stopped because there is an Act of Parliament going through at the moment which which will give them the power to stop your benefits if you have been claiming for a year. So that's the wider picture. So being a realist I mean it's totally ridiculous because by the time I have completed any further training I will nearly retirement age. So who'll be interested in taking on a 60 year old with my medical history, well frankly I don't think so.and what about the 16-25 age group to need to get the jobs? Whereas what I want to be thinking of is taking early retirement and taking whatever pension I've got. So that's the political side (laughs). Sorry.

But you are making an important point here about how having HIV is impacting on your life on many different levels not just health, but economically and socially as well.

It's no just affecting me it's affecting everybody in this situation. I'm saying I'm a special case because I'm not. I don't believe that just because you have all sorts of problems in your life that you should get special treatment

115 or exemptions from doing things. I'm not saying that, in fact, I don't think you 116.
should receive benefits for nothing. I believe that you should contribute some
117.thing in return so that's the other point of view. I don't there is a good enough
118. understanding of the HIV virus in the wider community at large. I think that
119. most people think it is only something that affects gay men and that we are
120. responsible for spreading the virus, transmitting it. So you often get the reaction
121. from someone who is heterosexual and is having unsafe sex that they can't get
122. HIV. It is not something that can ever affect their community. It is not widely 123.
understood that it is a blood virus and it can equally be caught from sharing
124. needles if you are an injecting drug user. But because the faster route of
125. transmission is sex they seem to think of it as only a sexual disease and so a
126. moral argument comes into play from some quarters as a result, that it's dirty, not
127. nice you know all those things that people might think about. So it does make it
127. difficult if you have an illness and it difficult when you might try to compare
128. illnesses, but supposing I said that I had cancer I could more openly talk about
129. that in a freer way and would probably get a more sympathetic reaction, more 130.
understanding and a kindly response from other people, whereas if I were to tell 131.
people in the wider community, excluding health professionals and doctors, that I 132.
have HIV then I would not be able to predict the reaction, even today, even with 133.
all the information available today and the fact that it is no longer a death
134. sentence so even that fear has been taken away there is still a huge prejudice in
135. all sorts of areas of the community, particularly from certain religious groups, 136.
where you might think there would be compassion, but there is often isn't. You 137.can
get you're an evil type of person reaction or you're a sinner and it's against 138. God's
will and all that kind of thing. It creates all kinds of problems. So is the 139. prejudice

because it was Gay sex or just that it was sex? Probably because it was 140. sex because if you look at the African community they also get a lot of prejudice 141. particularly if one of their sons or daughters is gay, but that's for a different
142. reason, but there would be a prejudice there even though the transmission routes 143. might be different because the heterosexual husband might go of with prostitutes 144. on the truck stop and that sort of thing and then give it to the wife, doesn't tell 145. the wife then they have children who are born HIV positive. So it isn't just gay 146. prejudice, it is prejudice right across the board from all different parts of society.

147. R: So based on what you've been saying about HIV now being more of a chronic 148. condition and that given that there are now Expert Patient Programmes where 149. everyone with a chronic condition is put all together in the same group, would 150. you feel comfortable discussing having HIV with people who might have cancer 151. or heart disease?

152. M: I would be very reluctant to openly share that I had HIV in a group like that, I 156. also know that it says more about my fear and anxiety about how others are
157. going to react rather than possibly the reality. I would be guarded about my dis158. closure until I had got to know the others in the group and felt safe in the
159. knowledge that I would not be judged, but there is the need to protect one's self, 160. but it also about challenging one's own inbuilt prejudice about others and what 161. they might be thinking. But I don't know whether I would get that opportunity to 162. get to know the others well enough because if you have a condition like diabetes 163. or a heart condition you would not even have to think twice about disclosing 164. what you were feeling, whereas I would be reluctant to take the risk just in case I 165. got a negative reaction from someone in the group and if I was newly diagnosed 166. and still coming to terms with getting the diagnosis I don't think I would be

comfortable disclosing my positive status to a group of strangers even though others might be having to come to terms with their issues of being diagnosed with for example cancer and having been told that it is likely to be terminal.

R: So are you saying that some of the prejudice and a sense of isolation comes from inside the person?

M: I think it depends on the individual, but as you can’t what someone else might be thinking, you are likely to be reticent about what you disclose given the innate prejudice that is ever present when considering HIV. People still have the misunderstanding that you can pick up HIV from a toilet seat or touching somebody so there is a big fear still there in the general population. So it’s a question of educating people about the illness and changing other people’s perceptions and I don’t think that that has happened as yet.

R: And do you think it will happen in time or do you think there is a resistance within the general population to even be made more aware?

M: I don’t think that it’s even on most people’s minds to be honest. It’s not necessarily there in their lives so they wouldn’t automatically think about it. A lot of people are too busy with their own lives, have their friends, doing their own thing to give it a second thought. It’s not necessarily something most people will be thinking about and there isn’t the push in different areas to make people aware of this particular illness, but that is also can be said to be true of other conditions as well. Particularly where there is a lack of money, funds to provide the level of care needed. So the actual education and improvement of services isn’t happening.

R: So over the time you have been HIV positive and it is has become seen as more of a manageable chronic condition it doesn’t mean to say that that the psychological factors have gone away?

M: Well it works in two different ways, people of my generation at least will still remember that government advert with the iceberg and the death warning and a lot of people of a certain age will remember it as a death sentence, but perhaps not be so aware of the improvements treatments unless they are directly affected by HIV either personally or through having a family member or friend living with the virus. Where it works in a different way is there will be a lot of younger people particularly young gay men or African families who will know about the medication that is available and that has a reverse effect because HIV is no longer seen as a death sentence and because they think the medication is there long term they don’t consider things like having to take the medication regularly, building up a resistance to it over time, that the medication can be toxic to them, what health effects it might have in terms of side-effects. It’s like they think they can have unprotected sex if they’re under 21 and it’s not going to matter because they just go and get medication and everything is going to be fine and all right. So there are different ways of looking at it, but the general understanding isn’t there because most people don’t even think about it much.

R: So HIV has dropped off the radar in terms of being something that’s out there.

M: I think so unless you’re actually positive yourself or know someone is positive or if you’ve had unprotected sex and you think about going to get a test, otherwise I don’t think most people give it a second thought like they would other things.

R: Have you noticed a difference in level of support offered?

M: Compared to when I first tested positive I think there is a lot more support available now, a lot more. But um it depends because a lot of the support that is now on offer has broadened in lots of ways. Um but then again the funding for those same services is now under threat and also much of the medication that is effective is now ring-fenced by the new commissioner and you're being told that pressure from above, because basically the new commissioner is putting pressure on consultants who in turn are putting pressure on GPs who likewise are putting pressure on their patients to give the more expensive HIV medications and to be put on a particular drug that has been costed both as a way of ring-fencing that treatment and bringing down the overall cost of providing treatment whether or not that particular drug is effective for that particular patient and there is a lot going on behind the scenes by the Government to push people off medication and onto more cost-effective treatment whether they like it or not even that is not supposed to be happening. So there are lots of different things going on. So the whole way HIV is being managed is shifting now. The clinic I go to used to have money ring-fenced for HIV but now that money is no longer ring-fenced so that money is now just part of the clinics overall budget and so it can be spent on things in other departments instead of just HIV. So clinics are having to find ways of still providing the same level of service to their patients but at the same time also have to bring down the overall cost of providing that service. So you have a situation where even though the demand for services might be increasing the amount of funding available to provide adequate service provision is being cut all the time so you get a back log of people waiting to access services or simply get information from the very start. So now much of the information is being given by other organisations outside of the HIV sector such as the Citizens' Advice Bureau, but this leads to additional problem which is these organisations have also had their funding cut so they are struggling to cope with the extra demand themselves.

R: So based on your own experience what have you found most helpful?

M: Well initially um being able to still get money on which I could live because it is all very well being able to take medication but if you haven’t got any food or any heating or even anywhere suitable to live it is not much good to you is it? (laughs). So initially having a benefits structure sorted for me have given me some form of stability and that would the thing that has been most helpful to me.

R: So it has been having the practical support in place that you feel has been the most helpful to you?

M: Yes because I needed that as a backdrop because as I said earlier I did not have parents I could run back to so I was on my own when it came to dealing with being HIV positive and given that at one stage I was too ill to stay working I nevertheless needed money from somewhere to enable me to keep a roof over my head, buy food and try to keep me myself warm as best I could. At the same time none of these things are taken into consideration by your HIV clinician when you go to see them for treatment even though on a health basis it does because if you are freezing to death over the winter when you are taking your medication it not going to help very much is it. (laughs). Also if you don’t have the money to buy the right food with the right nutritional value then you are not going to benefit from any treatment you might be getting because it is not just a case of taking the tablets, it also about having that daily structure in place.

R: So are you saying that when you go to see your Consultant they are only interested in your CD4 count and your viral load and don’t consider the wider context?

M: Yes because that is not their concern as their primary concern is to look after your CD4 count and monitor your viral load so they are only interested in your blood results and nothing else. So if you have any other problems they might refer you to a specialist you could deal with those things, for example you might get to see a social worker. I know from personal experience that whenever I have tried to bring any of those wider issues up with my Consultant they have not wanted to know as it is not part of their remit, it is not something they want to know about. However, they will refer you onto to others you can provide that support as part of a social care network, but those networks of social care are having their funding and budgets cut so it is not always possible to get access to support you might need. So it is getting much more difficult to access those services and if you are on benefits and you become unwell whereas in the past your GP could sign you off so you could get Disability Living Allowance instead of Job Seekers it is now not that easy because the people who are assessing the benefits people get aren't medically qualified anyway so when you go to be assessed by ATOS as whether you are fit enough for work the assessment takes the form of ticking boxes on a form. The assessment is not based on any medical criteria so if you try to discuss CD4 counts with them they wouldn't know what you are talking about. That is also why there is such a backlog of appeals going on at the moment and it is costing the Government a lot more money than they might be saving because they haven't looked at it from a proper point of view. A proper point of view would be to look at it from a medical point of view and the assessment to be undertaken by a medically qualified professional such as a Consultant or at the very least your GP. But that doesn't come into to it.

In fact I don’t know how most people manage to access the help and support they need when they become chronically, I have absolutely no idea.

R: So in terms of staying well what has worked best for you?

M: I have always tried to take responsibility for my health, always looked after myself and tried not to let things get to me. But um part of that is working out strategies to survive, but um I mean at the moment the thing that would worry me the most is that I have been assessed as being fit for work and I’ve been attending a jobclub which is fine and if my CD4 count was higher I might feel well enough to consider applying for jobs in an attempt to get back into employment and also I’m getting older so there are a number of factors that impacting on me so I can’t really see how being made to jump through all these hoops is likely to do me any good. What I really need is time which is something I don’t really have in order to plan what I want to do regarding getting back to work, what decisions I need to take, what courses I go on, what I do. I don’t want the threat of having to attend a jobclub at a particular place on a particular day because I’m already doing voluntary work as way of keeping myself occupied and staying in touch with others. The last thing I need or want is to be sent on spurious courses where I am taught how to wash my hands properly as part of a food hygiene certificate. I want to left alone to manage my own life and I don’t want the added sanction of someone threatening they are going to take away my money because quite frankly I would then be out on the street. I don’t want that worry hanging over my head like the sword of Damocles and my time is focussed on what I am doing because as of next July I don’t know where I’m going to be or what I will be doing. So, I’m trying the best I can to get myself into a place where I’m well and able to look after myself by whatever means I can do. I might be getting the support from the medical profession, support in the form of the benefits that I'm on at the moment which are at a level which enable to get by and keep going, but I'm not being given the time to get back into the work situation and so those are the problems I face and there's no-one who listens and no understanding as it is all politically driven. It's all a tick box culture, it is where you have to do this and do that and if you don't then this will happen to as a consequence.

R: So, there are demands being placed upon which you feel are unrealistic.

It is legislation which has been rushed through not by this Government but by the previous one, driven by Civil Servants and Mandarins in Whitehall who don't think things through and there is no groundswell in the Country to make things happen to change anything, everything is done simply on a cost to the consumer basis so everything is on a short-term basis and never properly thought through with regard to the longer-term. We'll make a fast buck today and forget about tomorrow and to justify it all they produce paperwork and statistics to demonstrate that it is working and of benefit when in reality I think we know what is likely to happen is that the shit will hit the fan in a few years time and someone else will be left to pick up the pieces. In meantime services are being cut so there is not the support in place that people with HIV need to stay healthy emotionally which to my mind is as important if not more so than simply being kept alive and healthy. I also think that it is true to say that there is no longer any distinction made between what someone who has been living with HIV long-term might need to carry on their daily lives and someone who is newly diagnosed with all the new treatment that are available to them. It is two very different situations we are talking about here.

478. R: In terms of your own situation would you say that your HIV Consultant is 479.
more concerned about you staying physically healthy than looking at how you 480.
might be coping emotionally with having HIV?

481. M: When I was first diagnosed I had counselling to help me come to terms with
482. my diagnosis and at that time those services were more widely available and 483.
easy to get access to. Of course now with all the funding cutbacks right across 484. the
HIV sector it is not so easy to get emotionally support, it is out there out, and 485. most
HIV clinics provide information about the services such as support groups 486. and
counselling that is being offered, however, it does require a lot of effort to 487. get it
and this is perhaps something that is not always going to happen when you 488. are
feeling down and on the point of giving up. Staying well is more than
489. keeping healthy physically, emotional well-being is vital to staying well and to
490. stay emotionally healthy there needs to be the psychological support in place 491.
along the provision for looking after someone's physical health. I also see that 492. now
HIV is now thought of much more in terms of a chronic condition or disease 493. people
living with HIV are no longer being treated in specialist departments, but 494. are instead being treated along side other chronic illness such as asthma and
495. diabetes.

Tina 40

HIV Positive 19 years

1. Researcher: Good morning Tina. Thank you for agreeing to be interviewed for my
2. research.

3. Tina: I was 18 when I arrived in London from the South Coast in 2001. I'd only
4. had two short-term boyfriends and was very conscious of my lack of sexual

experience compared to some of the others. I felt under pressure to catch up, but I always practiced safe sex. I studied social anthropology and was interested in welfare, so I took a job on the university's helpline, advising other students about issues such as drugs, debt, STIs and HIV. It's naive, but despite growing up with the terrifying Government campaigns that warned that HIV kills I still didn't think I could catch it. Didn't think HIV was something I could catch myself. Halfway through my final year at university I had a one-night stand. We did use a condom, but it split. The morning I got my final university exam results, I got two letters in the post. One told me I had passed my degree course and the other was the health clinic. I felt elated about my exams, but was curious and anxious about the clinic's letter. A few weeks before I had had an HIV test as part of a general checkup and the clinic was writing to tell me to see my doctor straight away. I'd only ever had unprotected sex once in my entire life and two sexual partners, so I was really confused about this letter. I was only really worried about getting pregnant so after my period came the following month I completely forgot about it. Later that same year in September 1994 I met Pete. He was three years older than me. He was tall and really laid-back. I fell head over heels in love. We'd been together about nine months when the following summer and feeling exhausted by exams and felt really run down I went to my doctor for a gynaecological MOT at my local health centre. One of the many tests I had was an HIV test. I was told that it was routine and there was nothing to worry about. We'd always used condoms so I expected everything to be fine, you know. I didn't even bother to tell Pete, as he'd just left for a three month trip backpacking around Europe and I was about to go to India with some friends and had the time of my life in India and by the time I arrived back in London in August I'd forgotten all about my check-up. I moved in with a friend and prepared to start my new job as welfare officer at my university. Peter wasn’t back until October, but I was already looking forward to it. A few days later after plucking up the courage to go back to the health centre I made an appointment and went in on the morning of my first day at work. What happened next well it was all a bit of a blur I mean it all happened so quickly. I was ushered into the health advisor’s office She started talking and then suddenly I heard her saying “I am sorry to have to tell you but you are HIV positive.” As you can imagine this came as a massive shock to hear her say that. It was such a shock I could hardly breathe. I could not take it all in. I was only 23 with what I thought was my whole life ahead of me. What I was being told. It just didn’t register with me. All I could think of, think about was I’m going to die. Was it going to happen tomorrow, in three years or in ten? I felt so utterly alone, numb and sick and I asked if I could phone my Mum. She was incredibly strong and supportive. She held back the tears and planted a seed of hope in me that helped me through from the very start. All of a sudden I felt sick it was as if I had been handed a death sentence. This might sound a cliche, but it’s true my life just literally flashed before my eyes. I kept going over it in my head over and over again. “What am I going to do? How can I live with HIV?” These thoughts kept going round in my head.

R: What were some of those thoughts?

T: I was terrified of having to tell Pete, my mum and my younger sister Sandra. I also had no idea how I was going to tell my friends, how they would react or if I would be able to have any children. What was terrifying at the time was that the health advisor couldn’t even say how long I might have to live. She explained that the virus kills white blood cells that protect body from infection. She informed me my CD4 count was still high at 800 and a normal count is about 1,000. This meant I wasn’t ill so I would not need to take any medication to boost my immune system and prevent the HIV infecting more cells. Apparently from what I was told was that I would only have to start taking treatment for HIV if my CD4 count fell below about 300 and the disease had progressed to AIDS I think she said. By that stage I would also be at risk of secondary infections like pneumonia. But for now I still felt healthy with no symptoms. But how was I going to cope. That was the big question for me. Pete was still away, so I called my mum from the health centre. We have a good relationship and talk on the phone most days. It was just such a relief to be able to speak to her. She tried to be optimistic but when I put down the phone I burst into tears. Mum later told that she too had wept buckets. Suddenly I felt like I had a big secret half of me wanted to tell everyone but at the same time I was also too frightened of the consequences. Being HIV positive felt like a massive stigma too taboo no-one talks about it. It is not something you can speak openly about. So I went to work like nothing had happened you know like nothing was wrong. After all it was the first day of my new job. Looking back that it might seem strange that I seemed more concerned you know worried that I would be letting people down if I didn’t show up for work, but that was what I felt. I had to go to work and carry on as normal. I did not want anyone to know.

R: You didn’t want anyone to know?

T: I didn’t even tell the friends I was living with when I got home from work. My diagnosis had left me shell shocked and apprehensive. That afternoon I went back to work as a student welfare officer and lost myself in problems about housing and student loans. I effectively put on a mask and basically went into denial.

It wasn’t until I went swimming a couple of days later that the fear enveloped me. I was in the pool and I suddenly felt convinced that people could tell I had HIV. All those negative government slogans and adverts with tombstones filled my mind. I felt so scared, so frightened. I didn’t want to tell my friends or anyone else in my family. I realised I needed to find help. So within weeks of getting my diagnosis I forced myself to seek help. A few weeks after my diagnosis I went to a support group. I found a support group I could go to after work. The first time I went to place where the group was being held I felt really nervous and and anxious. I hesitated as I got to the door of the venue. I nearly turned back, but there was another women right behind me. We looked one another and she smiled and said “You here for the group? Not seen you before.“ Is it your first time?” Before I could answer I found myself in the room where the group was.

R: What was that like for you?

T: I was amazed to see so many people chatting and laughing. It was incredible. I was introduced to some of the other women in the group. I was amazed at all the people that were there. Not only were there men and women who were like me HIV positive, but there were others there too, grannies, babies and teenagers who came to the group for support because they had a partner or family member with HIV. Some were like me newly diagnosed. Other were long term survivors I remember speaking to one woman who had had HIV for 18 years. At first I couldn’t believe it take it all in. Some of the conversations were about medication and I saw a few in group that looked quite sick which did frighten me a bit at the time. The most common thing that I heard was how difficult it had been for many of those attending the group to tell their family and friends about their diagnosis.

103. Finding the group has been a real life saver for me as it has stopped me feeling
104. so alone and isolated. It made a huge difference. Meeting other HIV positive 105.
men and women. We chatted over coffee and they were all so friendly. I was also 106.
struck by their honesty and compassion towards me. I felt like I wasn't the only 107.
one anymore. I felt like I wasn't the only person in the world who was feeling 108. the
way I did. I began to realise that I was not alone. All this time I hadn't said 109. anything
to my boyfriend. He was travelling through Europe and I didn't want to 110. tell him
over the phone. We'd been together for nearly two years and I'd
111. assumed he'd given me the infection. I didn't know how to feel or what to say.
112. As the time got nearer for when Pete was due to return I began to really dread it.
113. What was I going to do? What was I going to say to him? This was the man I 114.
loved with all l my heart so how I could I tell him something as awful as this you
115.know being HIV positive. My head was full of other questions too. How would
116. me having HIV affect our life together? Would we even have a life together? I
117. felt so scared. I was hardly able to sleep the night before Pete was due to get
118. back to London. When he got home, I told him and he was terrified. Almost as
119.soon as he got in through the door of the flat I just blurted it out. He looked so so
120. stunned and then he burst into tears. After that we talked and talked and talked
121. some more. Pete was brilliant the way he handled it. He reassured me that he 122.
would not break-up with me, that there was no chance of us splitting up. But he 123.
wanted to understand HIV fully before he was ready to take the test himself. Of 124.
course I was worried that Pete could be HIV positive as well. We'd never had 125.
unprotected sex, but I still began to question how careful we had been. I
126. wondered if we might both end up HIV positive together. At the end of what had
127. been a most eventful month Peter and I moved into together. We went to couples

128. counselling to air our feeling about HIV. I had to confront you know deal with 129. the fact that I was HIV positive through having unsafe sex with a broken split 130. condom. It was hard to accept that I'd caught a life-threatening disease through 131. such a brief meaningless sexual encounter. I felt it was my fault the condom had 132. split, but I didn't want to find the man who had given me HIV. It was much more 133. important for me to figure out how to live with it. At first he refused to take the 134. HIV test himself. He just couldn't face the idea of it. Pete finally went to be
135. tested in December. But when he did finally take the test it came back negative. 136. When he got the all clear we were both so relieved. We were both so relieved, 137. but then I thought that him testing negative would be the end of our relationship. 138. Luckily I was wrong. We sat down and we were able to talk about everything. 139. We talked about our hopes and dreams, our fears, life and death. In a strange way 140. it brought us together. Made us both stronger. Last year Pete and I got married 141. got married in a registry office, with friends and family all present. It was such a 142. wonderful day. When I met Pete in the beginning I knew he was the one I was 143. going to marry. There was never any doubt even after my diagnosis. I feel I am 144. so lucky to have found him he has been my anchor. We do want to have children, 145. but not just yet. But it took us a long time before we felt ready and able to think 146. about having sex again. We couldn't be spontaneous and it was difficult having 147. to be so careful. We avoided sex altogether during my period as that is when the 148. risk of infection is greater than at other times.We still enjoy sex. For a while at 149. the beginning we used two condoms when we made love. Pete had the idea of 150. using two condoms as he thought it would make it safer but my GP told us that 151. condom was actually more likely to split and tear that way. But my doctor told 152. me that the friction could cause the condoms to split. Now we just use one. We 153. are getting on

with our lives like any other married couple. Things obviously had 154. to change.
Having HIV made me more likely, left me prone to infection. The first 155. time I got
a bad cold I was really petrified. I soon recovered and now know not 156. to panic. I
go to the doctor every six months to have my blood measured for the 157. viral load
and at the moment I don't need to start on medication. I try to take care 158. of myself.

159. R: In what way do you try to take care of yourself?

160. T: I try boost my immune system holistically with plenty of healthy food,
161. massage and exercise. I always try to stay optimistic about the future. One day I
162. would like to have a family, but I can't forget about HIV. It's not like a nine to
163. five job where you can switch off at home time. I try to look after myself. I make
164. sure I get plenty of sleep every night. I've cut down on alcohol and changed my
165. diet to include plenty of organic fresh food as possible. I became really health 166.
conscious and I suppose you could say I adopted a holistic lifestyle. I use lots of 167.
herbal remedies, aromatherapy and massages. It took over a year before I felt 168.
strong enough to tell my friends I had HIV. It goes without saying that it was a 169.
huge shock to them, but in the main they have been very supportive. Whenever 170.
there was anything on EastEnders about one of the characters, Mark Fowler, who 171.
had HIV, my sister she'd call me in tears. I suppose I have been really lucky as I 172.
have heard some real horror stories about the reaction some people with HIV had 173.
when they disclosed their positive status to family and friends. However, one 174. person
did react quite badly and banned me from visiting their house and seeing 175. their
five year old daughter as he was so frightened. I was devastated. I tried to 176. explain
to him that HIV can only be passed on through blood, semen or breast 177. milk, not
from kissing or toilet seats as people think, but he would not listen. He 178. just did not
want to know. I decided I wanted to learn as much as I could about 179. HIV, so I quit

my job, left Pete at home and went backpacking around South Africa, Australia and Japan. I worked on HIV volunteer projects and met some amazing and inspirational people on my travels. When I got back home I enrolled on an MA and became a regular volunteer at the same support group that had been so good to me when I was first diagnosed. I've lived with HIV for a little over 19 years and the discrimination and ignorance surrounding this disease can still be very upsetting. There are days when I break down crying on a crowded bus or tube because I suddenly feel so alone. The uncertainty of living with HIV is that you don't know how the disease is likely to progress. I've already written a will as I don't know when I might start to become really sick. But so far my CD4 count is holding up. I get my bloods done every six months so it is really encouraging that my CD4 count is staying quite high. I want to start a family. I know it is a conversation I need to have with my HIV doctors at some point as there are loads of things to be considered and it is not without it risks. But I have met many wonderful mothers who have HIV and have proved to me that it is possible and the way they have all coped is a real inspiration to me. My hope is that through speaking to you and helping with your research into what it's like to have HIV I can maybe help to change the view people have of HIV. To begin to change people's prejudiced view of HIV. I sometimes think that the stigma of having HIV is worse, perhaps far worse than having the illness HIV itself. I believe you can live positively with HIV. I am lucky to have so much love and support and despite my uncertain future I remain full of hope.

Gary 52

HIV Positive 25 years

Researcher: How would describe having HIV now compared to before you tested Positive?

Gary: How would I describe it now as to before I tested HIV Positive, after HIV Positive? It was easier, more outgoing, socially more outgoing and I had a better outlook on things. I think now as positive sort of see it as a closure sort of end you don't see a future so I didn't plan ahead so to speak.I expected to die years ago so I'm still surprised I'm still here now. I was diagnosed in 87/88 quite a long time ago so with the treatments and combination therapy things have changed so I have to readjust to start planning ahead again. So I like I feel I stopped for 20 years and now I've restarted and I'm much older now.Everything has changed really. I carried on working that was the shock factor then I got ill so I had stop working so I could start looking after myself then there was a phase of hibernation so it has been like hibernation I think that's a brilliant word for it where you just look after yourself and just keep well because that's all you could do 10/15 years ago as nobody know was round the corner at that stage. I had amazing CD counts still in the thousands so I was very lucky very good immune system, but still there was that mortality thing going on in the back of my mind as well so there was a detachment and isolation that comes into it as well as you didn't want to hurt family members my family don't know.Well my mother is a nurse so she's not stupid, but she hasn't approached me about it and I haven't told them cause HIV is to do with race and ethnicity being a positive and black guy from a Jamaican family and and being gay is 3 dilemmas 3 stigmas stigmatised in three ways really.

R: Is stigma from outside or do you feel you have internalised it as well?

G: I have internalised it, but it is from outside as well because obviously certain groups being a black gay man in a black community is still very stigmatised there’s a lot of homophobia because in Jamaica they believe it is a western disease and being positive on top of that is a retribution for doing the wrong thing so you get that as well so you get from 3 directions which you have to deal with a well so I isolate myself rather than deal with the noise if that makes sense.

R: Can you say a bit more about that?

G: Um because in my community they want you to do the right thing which to be straight have a family that sort of thing and as you get older you get more isolated from the family because they don’t want you they don’t include if you’re gay because they want their kids to look up to a certain model certain way of life so you become excluded my uncle excluded me from his wedding simply because of sexuality so you get a lot of that and what they do in terms of what I do is to pull away and isolate myself from my family. I still see my sister, my nephews and my mum three times a year. My mum comes down to see me, but I’m detached from my family. I’ve consciously done that to protect myself from further stigma and to protect them, protecting myself also. I lost a sister when I was sixteen so I’ve experienced loss so when I found myself positive I decided I needed to protect them as well because it was quite a traumatic time for everybody really so I didn’t want to be a problem to anyone so I thought just detach myself and get on with my life.

R: So how do you cope then with being HIV Positive, what sort of coping strategies do you have or ways of managing?

G: Volunteering is a way of coping, dealing with your situation, having a social outlet and creating a different family and making new friends. You have friends to help you cope and that's a bit limited because you don't want to spend your entire life in the HIV environment you want need other things to continue really um, but I do have friends to help me cope. I have worked in different areas. I've worked in a sex cinema so that gave another outlook as well I saw another side of life that was shall we say interesting and colourful you could say and I've met interesting people along the way. I've seen some different things as well. It makes you realise that it's not that bad actually. It's no longer the death sentence it once was. Some people are going through a lot worse than I am.

R: So you feel that you don't allow HIV as diagnosis to be all consuming?

G: I don't think you should allow it to consume you, you should live with it, learn to deal with it, treat it not quite as a friend, but treat your body as a temple in a way, don't burn the candle at both ends give yourself time to recover that sort of thing because it's always there, but never let it consume you. I've seen it consume some people. I've had people who've phoned and been given all their pills by their doctor and they've said 'That's it, I'm going to end it all right now'. I've know two people who have committed suicide, this before the therapies were getting to be more successful. People didn't have an end game, so people did commit suicide mainly because of the stigma.

R: In what sense the stigma?

G: Um one guy committed suicide, he was adopted and found his parents, but I think he couldn't cope with being HIV Positive cause on the gay scene being HIV Positive ten years ago was still very stigamatising, it was seen as being a leper really cause other people would reject you if they found you were positive like being at the cinema I've people who would reject people, but I would know they were positive themselves so there is a whole cycle of fear going on as well.

They're rejecting because they don't want people to suspect that they might be positive because of the association. There are a lot of those games that go on on the scene as well. It's quite horrible actually so you do see certain things, so my coping strategies are volunteering, try to keep a positive outlook and just keep going really.

R: So you don't think of having to do anything differently now?

G: Um I do think about getting back to work and reclaiming my life, that's my main objective so that's why I volunteer to get some life skills and contribute towards the community, but that's been very hard because time has passed I'm much older now and there are younger chickens on the scene so to speak. So it's been quite competitive to get back to work so that will keep me getting back to work and to be part of life again. I do feel like that now, that I do feel like I can move on. I've got a good prognosis that's quite good. My coping mechanism right now is to be a volunteer and keeping busy.

R: And in terms of your coping what helps you the most knowing that you are physically healthy or is it emotional well-being you consider as well?

G: I think it is a bit of both, I'm physically healthy, I'm very well and can also help others and can contribute towards helping other people. That can help with your self esteem and gives you some sort of realism, you can become really isolated, you can get trapped in your own little world really, become completely delusional and that's the worst thing you can be, so it's nice to volunteer, it keeps you grounded, it keeps you in touch because I think the other thing is that from being positive in the past a lot of people became isolated not through choice, but because of becoming ill or they're having really bad days when they can't get out or just not coping. So, I'm quite lucky that I'm not in that situation.

R: So there’s a danger of becoming self-absorbed?

G: Oh yes quite easily in fact I know quite a few people who are self-absorbed and that is mainly because of the isolation. When you get detached you can slip into your own world quite easily if you don’t have friends around to challenge you. I know some people you are home all the time, wont go out, don’t see the point of going out and if they do think about going out perhaps to a sauna then they expect to have everything laid on for them you know the ‘pills’ and the guys should be there. It is all very delusional. My attitude is go and see what happens, but they don’t want to do that. They just want a result and that’s really delusion. So people like that need to be realistic about what could happen, but that’s also the case with one person I know who was only diagnosed five years ago. I think the fear for him is that if he gets that contact he could easily slip back into those hedonistic ways which was how he got HIV in the first place. Taking ‘pills’ you get off your face, do all sorts of silly things and he’s really scared of going down that road again as he nearly died, so it was quite touch and go for a while with him.He’s well, but now he’s gone into reverse, super safe, locked in even got food for three months ahead in the house, that sort of thing. It’s quite funny really, he can’t see it, but I think it’s quite funny actually. We tried to get him to go out but he won’t take a chance, he wants it all set out on a table for him, which is why I find it quite funny, and the reason he won’t try to sort out his problems is because it gives him something to think about, to talk about. So he will never resolve them, he likes to have them as it’s something that keeps him going, something he can keep going on about. He just keeps on and on and on like a broken record. I decided enough is enough and decided to pull away and let him get on with it.

R: So you have noticed that some people get so that they identify with HIV in such a way it becomes a ‘badge’ that they wear everyone who comes into their orbit has to know about.

G: Yes, some are like that, some don’t need to wear ‘badges’, but it does take over their lives. I’ve seen it happen but what’s nice now is that with treatments that are available now is that people are being encouraged to carry on with their lives, get back to work, form friendships. It’s not the death sentence it was before. It has moved on, my generation didn’t have this choice, so now we are trying to make this change, to get back and reconnect which is the difficult bit.

R: And is that adjustment the hardest part?

G: I think yes to reconnect make that adjustment is the hardest part. If you’ve been out of it for ten to fifteen years it hard to reconnect the world’s moved on people have moved on with their lives, maybe they’ve moved to a different part of the country. I’ve got friends who want to move out of London because it has changed so much. People do change and move on.The whole thing of adjusting to things changing is very difficult.

R: Were there particular decisions you made when you were first diagnosed which now with hindsight you think you could have done things differently?

G: Um, when I was first diagnosed I just carried on working. I suppose I was in shock when I found out my diagnosis, it was in a portacabin at the back of a GUM clinic. It was a really horrible time to get diagnosed back then um I didn’t deal with it really, I just go on with life, it was only when I started getting ill that I started to deal with it. I’d reached rock bottom and then I came here (to the support group) and they helped me out. They organised my hospital appointments, that sort of thing, and everything started to stabilise. But I think it was really the shock of it, it is quite hard to find places to turn to, I was quite lucky that I had a good GP who referred me to Barts.

R: So right from the start you benefited from structure and direction.

G: No not direction, but certainly structure in terms of medical help. It was only when I got to go to the Globe Centre that I felt I got some direction. I was able to be around other positive people and for the first time felt comfortable being around them. It helped me feel less isolated. Back then you were very isolated when you got given your positive diagnosis. You were scared, especially in the black community, you got stigmatised, it was horrible and it still is horrible now to some extent. I don't think it has completely gone away, it's still there, that's still a hard thing to deal with, the stigma.

R: What do you think could be done to change people's attitudes?

G: I don't think people's attitudes can change, it's all to do with the survival of the fittest, people will do anything to survive, they will stigmatise a group or put a person down just to feel better. I don't think people will change, they will only change if it affects them or they can relate to something.I mean, for example, when I was at the sex cinema I saw of a lot of prejudice, lot's of racism in there and that's because they didn't want to mix with other groups. Once you got different groups of people in there then attitudes did start to change, but once you got HIV then it was still a No No down there. It's the fear of the unknown. The worst thing about HIV is that it's very visible and that's what scares people. It's so visible and that's what causes all the anxiety, you know. and so compared to other illnesses like cancer, for example, Cancer if you've had cancer you get more sympathy even those who might have been smoking sixty a day can still get that sympathy you know it’s like “You poor thing”. In some quarters with HIV you can still get that same amount of sympathy as well. Certain groups, I’ve been with some people where someone has died of HIV and their families have put ‘Cancer’ on the death certificate because the family didn’t want others to know it was HIV.

R: Are you aware of there being a hierarchy with HIV in terms of it being more acceptable if for example a woman or a child has it? Are some groups with HIV more worthy than others?

G: Well I mean a haemophiliac would definitely get more sympathy because it wasn’t there choice it wasn’t a sexual thing, likewise a child would probably get more sympathy because they are born with it – it wasn’t their fault – Gay men on the other hand have it rough still have a hard time of it because some people think that they are the cause of it not realising that there are monkeys out there that have the virus and then people who eat the meat get infected. So that’s still out there, it’s still there. But I think the more it moves into the general population people’s attitudes will slowly change. Having access to testing clinics is a good idea because that also helps to deal with people’s anxieties around having HIV. We have a testing clinic here. In there you see all different groups coming to get tested. You also see some of the old issues as well. A man who had been to his friend’s house where his friend’s wife was HIV positive, this man came in to be tested because he had sat on a chair in the house and was worried he might have got infected. This was in 2016 so it’s still there this ignorance, this fear.

R: I experienced something similar when someone asked me about the work I do and when I told them it was with groups who have HIV this person said to me

"Aren't you scared of catching it? You know from being in the same room as 199. them."

200. G: Well that's to do with education.

201. R: But don't you think that some people just don't want to know, they put up 202. barriers?

203. G: At the same time those barriers are the worst thing for them because that's 204. when risk happens. I've seen it happen in clubs where someone will hook up 205. with a gorgeous guy and take them downstairs and bareback them and I've know 206. that that same guy is positive. How do I tell them to use condoms? That's the 207. dilemma because people often think that they know what's best for them when it 208. comes to protecting themselves, but then on the second they will go out there and 209. take a risk and just hope they haven't caught it.

210. R: There is what's called cognitive dissonance.

211. G: Yes, then there's the thing about being an autonomous adult and you can't tell 212. me how to live my life and then when something does happen, they often don't 213. deal with it very well either.

214. R: You say that you think people's perception of what it means to have HIV is 215. changing?

216. G: Yes I will change over time, the younger generation, the kids are becoming 217. more informed now and they also seem for tolerant. It may not be true for all 218. groups, but overall it is getting better. It's not fantastic, but things are moving in 219. the right direction even those you will still get pockets of ignorance amongst 220. some people, that will always be there. But the kids are informed and of course 221. the internet have a big part to play in that as well depending on where you access 222. your source obviously, but kids can now get information without their parent's 223. consent

‘cause kids are quite smart when it comes to the internet and they can actually get data that they need and access it really. It’s the same here with the testing clinic loads of kid’s teenagers come in and they seem to be relatively well informed.

R: At the same time have you also seen people getting more blasé about getting HIV based on the fact the drugs work?

G: Yes in particular with PrEPS (Post-Exposure Prophylaxsis). They have sex, the condom bursts and they go along to the hospital for PrEPS within 72 hours and that will always be there as for some it will always be the case that they think that the drugs are working. I don’t think this generation saw what we saw, when twenty years ago people were dying, people in wheelchairs, could hardly walk, the lypodystrophy. You don’t see it anymore, you just don’t. If you go into the pub you don’t see it, whereas I remember when I used to go into a pubs and I see at least one person with lypodystrophy or that’s quite ill with friends. People are just not dying anymore, it sounds awful, but people just aren’t dying anymore. So people don’t see that, so people take more risks, they think oh well there are drugs out there and I’ll be ok and so they don’t take it seriously, or take in consideration the things that come with it as well, you know the side effects, lack of appetite, diarrhoea and all the other things that come with it, anxiety, impotence, all the things that come attached to it but which you don’t see until you are further down the road, but you are right that people can becoming a bit complacent.

R: Also over the time you have been positive the definition of HIV has changed from being seen as life threatening terminal illness to being seen as a long-term chronic condition, so I am wondering if that has affected you in anyway?

G: Yes the definition back then of HIV was AIDS because it wasn't HIV, there was never any talk of HIV it was always just AIDS. Yes so you are right it has changed, people now know that you have HIV before you have AIDS, before it turns into AIDS and yes you are right it has changed how people understand HIV nowadays.

R: And some clinicians now refer to Early Stage and Later Stage HIV infection, they don't even use AIDS as a diagnosis at all anymore do they?

G: AIDS is such a horrible word anyway. But oh yes, now someone can have had an AIDS-defining illness, but now no longer have it whereas in the past it was a one-way street where once you had an AIDS diagnosis you could then not have it whereas now people can have what amounts to a reverse in their diagnosis, but still their life will be shortened. It also depends on how far your CD4 count drops really as well, but they now still have 20 or 30 years extra compared to what it was like in the early days. It all depends on how you deal it as well really.

R: So has the way you cope changed knowing now that HIV is more manageable as condition?

G: No not really, for me I was able to cope because my CD4 count has always been really good, it has always been in the thousands, sixteen hundreds. So that gave me more confidence in myself that I could would be able to cope. I would sometimes have tantrums at the hospital if my CD4 count dropped to like eleven hundred, I know that in reality my immune system is as robust as a lot of HIV negative people. Overall I keep really healthy, I catch the odd cold now and then, but for the part I keep really well. I don't drink, I gave up smoking over a year ago and cut out drugs as well now so I think I am doing all I can to do the right think regarding my health. So I just want to get back to work as I was a workaholic. You could say it has always a coping mechanism of mine, work to you drop (laughs), I am one of those. So I miss it as I do like the structure of work and also the social side to work. There is a social structure to working as well. In terms of our physical and mental health it is the quality of our social network that makes a difference and when you’re working you experience a pride in what you do and it gives you confidence which you can lose if you are out of work for any length of time. Working means your’re not dependent on handouts from others or the State. Being unemployed is still a social taboo for many people. Another thing about HIV is the dependency, the dependency on State Benefits and other handouts. It can become habitual, like you’re in a bubble really. That can be a problem, being part of the dependency culture. So you don’t have to think about anything as it is all done for you. All your bills get paid and so all you have to do is your own shopping, but everything is pretty much done for you, but it can give you a false sense of security. It isn’t like real living, your life is really in limbo. I’ve got a friend who calls just that “living in limbo” he just gets up when he feel like it or sometimes stays in bed all day. At weekends it worse, he stays at home not answering the phone, not talking anyone, not doing anything. It is so easy to get like that, in fact I could feel myself slipping into that way of being awhile back, like “Groundhog Day” the film. You know just the same thing every single day and that can become a problem really. But once you are weaned off the Incapacity Benefit and are put on Job Seekers Allowance it all changes because you are having to engage in job search, attending a job club and it all helps to get you motivated and interacting with the World again. It is about getting your life back. But of course it does depend on how motivated you are to engage with it so although it has been good for me I have certainly seen others really struggle as they have found it all too demanding, too much pressure. I’ve seen some people who are quite dependent as people go into meltdown, it just gets all too much for them. But you have to learn to adapt, it is hard out there, you have to find a way otherwise you go under. It is very tough out there. I know of people in terrible situations having had their benefits cut, but you have to deal with as best you can. See it as something that’s inevitable.

R: In terms of Psychological support what sort of thing do you think is most helpful to personally?

G: Group Support, it’s the isolation, that’s the worst thing. I have found being able to access a Support Group where I could talk openly about my experiences, my anxieties and concerns without the fear of being judged. For me it was the isolation, that was the worst thing about HIV, it still is, it can be a real effort sometimes to come here and attend a group, I am always glad I have managed to do because I feel so much better for having done it both mentally and strangely I find I have more energy after I have been to a group. It also gives me a focus, something outside of myself, it stops me becoming self-centred, self absorbed. In fact, you can I become really selfish, I know I can so being around others in a similar situation as myself and being able not only to get support for myself but give support to others in the group is a big thing, in fact it’s huge. It has made a huge difference to me in my life, it has given my life meaning, made me feel a part of something again, a sense of belonging which is strange because I didn’t always really feel I belonged even before I got positive. In a one sense I feel I belong to the HIV Community now, because it like being part of something, something everyone who is Positive can relate to and be a part of. But it can be harder for some ethic groups to access services because again they are up against

325. the stigma so for example are a very West Indians coming along to groups, so I
326. don't want they do for support.
327. R: What you think is reason for this? Do you think some ethnic groups don't see
328. a need to provide support or is it that people from certain ethnic groups who are
329. positive don't access services because of the stigma of having HIV?
330. G: Yes, it is about not wanting people to know. Some people might travel two 331. hundred miles to get a test because they don't want anyone in their local
332. community knowing they are going to have a HIV test. Some people go across
333. London to a different hospital and use a different name to get tested because they
334. don't want anyone to find out. There is a real sense of paranoia for some people
335. who are from certain ethnic groups. But it is also a realistic fear. It can happen, it
336.does happen where you go to a group and someone knows someone and when 337. that happens it's horrible, really horrible. It is quite scary, quite scary. That is 338. why some groups do not access services because of their fear of being identified.
339. There is the stigma from their community if they are found out as having HIV.
340. That makes some groups hard to reach and even harder to get to engage with 341. services. They won't go anywhere where they could be identified or where they 342. might be an association with HIV. Even though the building might be
343. anonymous, in your mind you think because you know what goes on there, you
344. think other people do as well whereas of in reality most people in the community
345. don't know or even if they do they probably don't care.
346. R: Do you think that stigma comes from what someone has internalised about 347. having HIV?
348. G: Well in one sense yes, but feeling stigmatised comes from experiences of
349. being judged, the prejudice of others and when you see others also being

discriminated against. I think that’s what creates stigma. Stigma works on so many different levels, in so many different ways. It is how you experience it as well. Having HIV makes you feel stigmatised anyway.There are members of my family who expect me to talk using street slang, for example my young nephews. So I get stigmatised because of the way I speak and the words I use, the way I dress. Anything can be used to stigmatise someone. It can have many different layers. It can also be a way of trying to protect yourself from getting HIV by identifying certain groups who are more likely to be at risk and stigmatising those individuals and those groups so you can say “I’m not one of those. That’s not what I do.”That way you can think yourself safe. It’s quite sad really. It can be a way of thinking I’m special, different, that it can’t happen to me, but of course it can and it does. It can be a real wake up call. That’s why testing positive is such as shock for a lot of people. They think that they can’t be at risk unless they are in one of the obvious at risk groups. For me, I did not have that attitude, but it still came as a shock when I did test positive as I thought I would be safe if I took precautions, practiced safe sex, used condoms, but accidents still happen. Condoms splitting, that sort of thing. That’s what happened to me, a condom split, the thought went through my mind that it could be this time as I’ve had condoms split before, but I’ve always been okay.I suppose I thought my luck had to run out eventually, but it was still a shock. Now I accept it, but for a while after I did think to myself “Why me?” When I was first diagnosed I was given five years maximum, but that was twenty five years ago. The hardest thing was not dying after 5 years, I know that might sound strange, but I had spent all that time preparing myself and my family and friends for the inevitable and then

374. when it didn’t happen, it initially felt like a let down. Then I started to live again, 375. think about having a future, dare to have a future. Learn to live with HIV. Not 376. make it the whole of my life, my identity. I am someone living with HIV, but that 377. is only one aspect of my life. Some people identify with HIV. It becomes them, 378. who they are, their identity. They say “I am HIV” when talking to friends and 379. family.That’s when having HIV can become all consuming. Then your whole life 380. revolves around HIV, having HIV, that is really not healthy. That is why I try to 381. do as much as I can even if it is only volunteering and training courses so that 382. hopefully I can get back to doing some work even if it is only part-time, I feel 383. more optimistic now compared to when I was first diagnosed. A lot has changed, 384. in terms of HIV medicine, the understanding of what HIV is has increased. It’s 385. not the death sentence it once was, at least that’s true for most people who are 386. newly diagnosed today. Of course attitudes and prejudices still need to change, 387. but will take time. Most importantly, I’ve got my life to live, thats what I need to 388. focus on most of all.

Nigel 48

HIV Positive 22 Years

1. Researcher: Good morning. Thank you for agreeing to be interviewed.

2. Nigel: Being gay and living in London I knew all about this thing called HIV that 3. had been around the gay community since the eighties. If you were part of the gay 4. scene back then you knew about what had happened to Terry Higgins. Those were 5. scary times. Before then being gay was all about clubbing and partying. At the time 6. no-one knew what it HIV was. It didn't have a name, but you knew it could kill
7. you. Those government campaigns only helped to scare you even more. There was
8. very little information. Only rumours and scare stories coming out of America. A

lot of my friends went into hiding, stopped going out. Others I knew went into denial and went partying even more. It became an act of defiance for many in the gay world. We had had to fight for our rights as gay men so we saw AIDS as just another thing to stand up and fight against. At the time none of us knew how big a thing HIV/AIDS would become or how it would affect us in the gay community in the future. Looking back it was like a war zone people getting sick and dying. We were all wondering who was going to be next. I suppose I was one of the lucky ones as I didn't get positive until 1994. I didn't have any symptoms at the time, but I had starting going for regular HIV tests since 1992. Looking back I had had a bit of a fever and a cough I couldn’t get rid of, but I didn't give it any thought. I just thought it was the flu that was going around. Anyway, I went for my HIV test. I hadn't had one for several months. I would normally only go if I had had lots of unprotected sex. I didn't go out a lot, but when I did I would make the most of it, if you know what I mean. So, anyway, I’d been out partying and made quite the weekend of it so to speak. So, I thought I had better get tested, just to be in the safe side as it were. I don’t .know what I was expecting. In fact, I never gave any thought to whether it would be positive or negative, you know. So when I tested positive it was a case of oh well shit happens. That was it .really. I didn’t think any more about it until I got home. I was living on my own at the time, so I got home I had taken a few days off work and made myself a coffee and lit a cigarette. I was numb. The guy who had given me my test results had had a brief conversation with me and given me some leaflets about HIV. I had just nodded and stuffed the leaflets into my jacket pocket. I had also been given a follow-up appointment to discuss what happens next. Back then whenever you went for an HIV you were given a pre-test counselling session and then had another counselling session after your test to discuss the result even if it was negative there was 30.stuff to discuss about how to practice safe sex and stuff about minimising risk. Perhaps, I should have paid more attention to what was being discussed, you know about safe sex, but I didn’t. Like most people, I only started to pay attention and listen when I got positive. When it was too late. Bolting the stable door after the horse had bolted, so to speak. My follow-up appointment was a month later. Testing positive wasn't meant to happen. I kept repeating it over and over in my head. Life was for living as you’re too long dead. That’s what I’d always believed. That’s how I’d lived my life. Work all week and then party all weekend. You only live once. The gay scene is all about youth, being attractive, having lots of sex and having lots of fun like there’s no tomorrow. You don’t think about consequences or the future when you’re young. Being gay is all about living life to the full and having no regrets. Sounds foolish now, doesn't it, but when you’re young you don't think about getting old or getting sick. So getting positive was massive, more than just a wake up call, you know. Everything was going to have to change. But where to start. I went for my follow-up appointment, but I don't think I was ready to engage with anyone. Not ready to have the conversation about being HIV positive. I wasn't something I discussed with my friends, even those that had HIV. It wasn't really a conversation I ever wanted to have, to be perfectly honest. Once you get HIV you can’t un-get it. That was my logic. So, how would talking about it, you know about HIV, change anything. I was never one for talking about feelings. Typical bloke, you could say. I have to say that my attitude has changed over the years..I can see the value now in being open about what you're feeling. Maybe, it’s also about getting older. Would I have changed my attitude to life had I not got HIV? Well, you know, that’s a difficult, perhaps almost impossible question to answer. What I do know, what I do see is that there are still a lot of people within the gay community who are still carrying on in the same hedonistic way I used to behave. There is a lot of immaturity amongst gay men. Now I’m older I see it for what it is. Many of friends think I’m boring, but I feel I’m done with it. You know, I do .miss the fun times, the care free times, but nothing lasts for ever. Don’t get me wrong, I’m not saying I regret my life. I had good time, but now I want something more substantial, more fulfilling, more worthwhile. That’s what being positive had done. It has made me more reflective. It has made me think more about what’s important. It has stopped me being superficial and shallow. That part of the gay scene holds no interest for me anymore. Having HIV has made me grow up, take responsibility. It has forced me to and I’m grateful for that. It’s an opportunity. At least, that’s how I see it now. I can see now how self-centred I was and how little I really cared about anything other than having a good time.

R: So what changed?

N: I stopped going out. I went to work and then went back home. The only time I went out was when I went shopping to the supermarket to buy food. It was such a dramatic change that my friends starting asking me what was going on. It took me nearly a year to tell anyone, my family and friends, that I was HIV positive. I suppose I thought that if I didn't say anything, you know, tell anyone, then it would not be real. I could still believe, or at least pretend I was still HIV negative.I mean, how foolish is that? It’s nonsense isn't it? But it was how my thinking was at the time. I don't think I was depressed, but I did sort of go into hibernation. I withdrew from the world. I didn’t think it through, you know say to myself “You need to take care of yourself. No more crazy late nights, burning the

84. candle at both ends and the middle as well”. However, common sense did prevail.
85. Some of my friends did ask me if there was anything wrong. I wouldn’t answer 86.
the question and would often just change the subject. I don’t think it was because I 87.
didn’t think that they would understand. At the time it more to do with with not 88.
wanting to talk it, HIV. Maybe, by not talking about I thought it would go away. 89.
Once you test positive, you have to go for regular tests to see how your immune 90.
system is responding. I’m sure you know all about viral loads and CD4 counts.
91. Anyway, each time I went for a test, I would ask the nurse taking my bloods if I 92.
was still HIV positive. I mean, how mad is that? The nurse would just look at me. 93. I
think she thought I meant “am I undetectable?” I took me a long time to
94. understand that being infected with HIV was not reversible. When I say it took a
95. long time for me to understand I mean on an emotional level. At time the only
96. way I could deal with having HIV was to spilt off 81.my emotions. I dealt with 97.
everything on a purely intellectual cognitive level. I convinced myself it was
98. because I was man. You know, men don't do emotions. All that touchy feely
99. nonsense. That’s what I told myself. That was what put me off having counselling.
100. I mean, the thought of to talk feelings to a complete stranger. I don't think so. I
101. don’t even talk feelings to family and friends. I know it works for a lot of people,
102. but I just can’t imagine doing it myself. I’m more of a practical person. Someone
103. who likes to know what can be done to solve the problem. I’m a problem solver.
104. It’s how I make sense of things. I like to fix things, but having HIV is different.
105. It’s not something you can fix. It’s not problem you simply solve. That was what
106. was hardest for me to get my head around. I only started to come to terms with
107. having HIV when I started to engage with it on an emotional level. I realised I 108.
had to start to embrace having HIV. BY that I mean accept it as part of you and 109.

what I am, but at the same time not allow it to define me. Does that make sense? I’ve seen lots of people with HIV be consumed by it. It becomes their life. They make career out of having HIV. It’s all they seem to think about and talk about. I think that’s a mistake. You need to have a life that’s not just about having HIV. Admittedly, in the past, when HIV was a death sentence the only way to survive even in the short term was to focus on having HIV and getting the most out your life in the time you had left. Now, HIV is a chronic condition and there are many treatment options it’s not like it was. I mean, there is a lot less anxiety, but it’s still a challenge. You still have to keep on top of it. There is no room for complacency. I see myself as one of the lucky ones who got positive at a time when there were few options treatment wise and has been able to stay healthy long enough to benefit from the advances in HIV treatments that are available today. Not all my peer group who got HIV were so lucky. They got infected, got sick and died. That’s what’s hardest for me to bear. AIDS wiped out a whole generation of people. That was the darkest of times. It’s still raw in the memory. It’s so different now. The kids don’t know they’re even born. For them HIV is almost an irrelevance. I mean, it’s not something they even think about. I hear the kids saying things like “HIV won't kill you” and “The medication works so no need to worry”. What they don't seem to understand is that the medication might be effective, but it is also highly toxic and the side-effects are very unpleasant. Coping with HIV is one thing and bad enough, but having to deal with the multiple side-effects of the medication is another thing all together. For me having HIV is about choosing how to live with HIV. As I’ve already said you can choose to allow HIV to consume you or you can embrace it. I don't really like

the word “embrace”, but I think you know what I mean. Perhaps, acceptance 134. is a
better word. You have to become proactive. When I go to see my HIV
135. clinicians I engage with them and ask about staying healthy, explore what
136. options are available to me. I don't like being told what to do. Ive got a good HIV
137. consultant who likes me saying what I want. I know from conversations I’ve had
138. with friends that I’m lucky to have the consultant I’ve got. Many of my friends,
139. who also have HIV, have had bad experiences with consultants who don’t listen
140. to their patients’ concerns and are not willing to discuss treatment options with
141. patients.
142. R: Has that been your experience?
143. N: No, I’ve been lucky that I’ve been able to keep working and not had to have
144. much time off sick. It would be very different if I was on benefits. I’ve heard 145.
some real horror stories from people on DLA having to go on Back to Work
146. schemes, having their money stopped and losing their hosing benefit, being
147. scared they would lose their home if they couldn’t pay the rent. There isn't the
148. safety net that there used to be. I’ve seen people diagnosed the same time as me
149. and get sick and because they couldn’t keep working ended up becoming
150. suicidal. You can’t live on benefits, you can only just about survive. Worst of all
151 you can become very isolated. Without social contact you can easily lose touch
152. with reality. I’ve seen it happen. That’s why I’m so grateful to be able to keep 153.
working. I think it’s what’s kept me sane. Don’t get me wrong it’s not been easy. 154.
There are many challenges to faced. I’ve mentioned isolation. In the beginning, 155.
when I was first diagnosed I did feel isolated, but to be honest I isolated myself. 156.
That I mean I needed to spend time away from people in order to come to terms 157.
with my diagnosis. As I said I still went to work, but stopped going out at

weekends to clubs, that sort of thing. Going out to clubs had lost its attraction for me. It was like I had grown up over night. I wanted more from life.

R: That’s interesting, can you say more about that?

N: I also didn’t want to face having to keep explaining myself to people about having HIV. One of the hardest and most difficult things about having HIV is having to disclose your HIV status to other people. You can imagine the conversation can’t you? Hello, my name is….. and I’m HIV positive. Not exactly a good chat up line, is it? I know it’s different now. HIV is almost commonplace in the gay community at least, but back in the day when I was newly diagnosed things were very different.

R: What is different, what has changed?

N: The stigma around having HIV was huge. There was so much fear. I could understand why there was such a hostile reaction at the time from the straight world and how people in the gay world became the target for so much anger and hostility from the straight community. The straight world has always been hostile and AIDS gave them the reason and justification for how they felt towards us. We were to blame and the cause of AIDS. We deserved to suffer. Of course, soon as AIDS started to affect the straight world things changed. If you were a straight woman or a child born with HIV, or you became infected with HIV through a blood transfusion then you were a victim and got sympathy, but if you were a gay man with HIV you got condemnation from everywhere. Even the gay community turned on itself. Again I think was fear that made a lot of gay men reject someone as soon as they found out that person was HIV positive. Friends would suddenly stop speaking to one another and blank each other in the street or in a club. It was the fear of being seen with someone who was known to have HIV

in case you were thought to have it as well. It was this stigma by association 184. that
made having HIV almost unbearable for a lot of my friends who were
185. diagnosed around the same time as me. Again I think I was lucky, I only had one
186. friend stop talking to me when they found out I was HIV positive. He was very
187. angry when I told him I was HIV positive. I was quite shocked by his reaction.
188. To this day I don't really understand what made him react the way he did? He 189.
was so irrational. Again, I think it was fear as much as anything. In contrast, my 190.
colleagues at work have been really good. They don't treat me any differently to 191.
how they did before I told them I had been diagnosed with HIV. They are really 192.
supportive and it has made it much easier for me to stay in work knowing that 193. I’ve
got an employer that is on my side. Living with HIV is a challenge in so 194. many
ways. Even when you are well you have keep thinking about what you
195. need to do to stay healthy. You can’t take your health for granted. Something 196.
could happen where your CD4 count drops really low and your viral load spikes. 197.
Then you get an infection which you can’t get rid off. So, you have to get used to 198.
living with uncertainty. At same time, you have to live life as though HIV wasn't 199.
important. You can’t ignore it, that you've got HIV, not make the focus, your
200. focus if you get what I’m saying. What I’m saying is this. HIV cannot be the
201. focus of your life otherwise you can easily become consumed by it. You let it, 202.
HIV, define you. If you do it can take away your choices. I am still the same
203. person I was before I tested HIV positive. I may have changed my attitude to life
204. as a result of testing positive, but I am more that my diagnosis. My diagnosis is
205. not what defines me. That to me is a healthy attitude to have. I’m not saying it 206.
would work for anyone else. I can’t speak for anyone else, all I know is that it 207.
works for me. At least so far it has anyway.

R: Can you say more about your healthy attitude?

N: I try to eat healthy food. I go to the gym and get plenty of exercise and not have too many late nights. I still like a drink now and then, but I don't do the party scene anymore. That’s not so much about having HIV as much as it is about getting older. The clubs are so full of young people these days and I feel so out of place when on the rare occasions I do venture out into a club. I don’t like the music, don’t do the drugs anymore so there’s no reason to go clubbing. I’d much rather stay at home or invite a few friends round to watch a dvd or maybe go a meal with a few close friends. That may sound boring. I know that’s what I used think when I was younger, but now I’m older I appreciate things more. Quality not quantity as they say. As long as I can stay healthy that’s all that matters. I have some really good friends, all of whom were diagnosed around the same time as me. So we have that in common. I think it makes it easier because although my experience of having HIV might be different from theirs in some respects, there is enough common ground for us to understand each other without having to keep explaining ourselves. I try not to think too far ahead. I try to live more for today. I’ve always been like that anyway. My friends say I’m impulsive which I suppose I am to a certain extent. I’m not good at planning ahead. Of course, I do think about the future, but I don't worry about it. Getting older has its challenges, so does getting older and living with HIV, but it’s not the death sentence it once was. If you were to ask me now if I could turn back the clock and not have HIV I don’t think I would choose that option. Having HIV in a strange way has proved to be an immense gift for me. It has made me think about my life, what’s important, what matters, what doesn’t matter, what I want to achieve before I die. I don't want to have regrets. Before I got HIV Positive I was hedonistic, selfish and self-centred and quite immature. HIV made me grow up and take responsibility for how I lived my life. It has made me reflect on my choices and what I want from life. This may sound like a cliche, but I think having HIV has made a better person I mean I hope it has. I used to be quite judgemental, look down on people. Having HIV makes you realise that you're not that special after all. The gay world is full of people who think they're special, God’s gift, that sort of thing. I was like that, I still can be, but I try to catch myself when I do it. I’ve found myself judging others who have HIV. It’s not something I’m proud of admitting to as I’ve felt judged myself. I know friends, well they used to be friends who started to avoid me once I became positive.

R: Why do think that was?

N: I’m not sure. Maybe it was that they didn't want to be associated with me because I was positive. A lot of them were doing the same things I was anyway. So maybe, it scared them when I got positive. You know, if it could happen to me then it could happen to them. So maybe it was fear that made them behave the way they did towards me. Maybe they didn't want to be associated with me because of the association of having HIV. Which I think is strange because HIV is everywhere now. Having HIV divides people. Younger people on the gay scene will do everything to avoid even thinking about HIV. I think they think HIV is no big deal anymore, but at the same time they don't want to get it. It doesn’t make sense does it. It’s a real contradiction. I think PrEP has had a lot to do with it. I think it has given a lot of people a false sense of security. They seem to think that if they are taking PrEP they can’t get positive. It may significantly reduce the risk, but the risk is still there. I don't see any of these people really thinking about how they are behaving. I think if anything it has made them think they can just.carry on as normal and getting HIV just wont happen to them. I think someone of them are in for a big shock. I know how much a shock it was me when I got positive. Even now I have days when I really struggle. I do the best I can, but it can be hard. I worry about getting sick and having to start on medication. I’ve heard all the stories about side-effects. I’m hoping to stay healthy for as long as I can. I try not to think about it too much, you know getting sick. When the time comes I know it’s a conversation I will need to have with my consultant.

Claude 38

HIV Positive 15 Years

Researcher: Good afternoon. Thank you for agreeing to be interviewed.

Tom: HIV was a game changer for everybody in the gay world. It was non-stop partying, sex and drugs. I was young and single. I had just come to London from a small market town to go to Uni. Up to that point I’d been the only gay in the village (laughs). Of course I’d heard about AIDS, we all had, but it’s not something you think about or at least try not to. When you're young and out to have fun, you don't think about the risks you're taking. It’s about getting laid, simple as that. You really don’t think. Every weekend it was clubbing, partying. It was beyond imagination what was on-offer. As I said I had grown up in a small market town and there wasn’t a gay scene to speak off, so when I got to Uni in London it was mind blowing. When you're young you don't think about the risks, the dangers. As I said, I knew about AIDS, but I blocked it out of my mind. I kept telling myself it wont happen to me. My gay friends kept saying to me that I should get tested, but

I kept putting it off and making excuses whenever anyone asked if I’d been for a test. I suppose I thought if I didn't take the test then I could I could convince myself that I was ok. You know what I mean HIV negative. Most of the time I used condoms, but I did slip up from time to time. Even when I did slip up and didn’t use a condom I didn't think about going for a test. It was like, what was I thinking?

R: But you did eventually go for a test?

T: Yes. Eventually, I did go, for a test, I mean. I actually went to support a friend who was going for an HIV test. He’d been a few times. of all my friends, you could say he was the most sensible when it came to looking after myself. He liked to party like we all did, but knew the risks and always tried to stay safe. He’d had a friend who had got HIV and got really sick quite quickly, so he knew how real it was. What could happen, or perhaps I should say can and does happen.

R: What happened when you went for your test?

T: Anyway, one of my friends told me he was going for an HIV test and suggested I went with him. When we got to the clinic, he went for his test and I waited for him in the waiting room. When he came out after his test, he said to me “Now you’re here, why don't you ask to be tested?” Without thinking I agreed and said “Yes, okay”. I went in and the nurse asked me some questions and told me what to expect. She took a blood sample and told me she would tell me the result straight away. She looks at the result and said “It’s a positive result”. I said to her “Are you sure?” She said that she was. I just sat there and said “Oh well”. I didn’t know how to react. Did I feel anything at the time? I’m not sure. I felt numb. I couldn’t take in what I was being told. Didn’t really process it. My friend who was with me could see something was wrong. I just showed him my result. We

37. both looked at, the test result with our mouths open. We both just sat there in the
38. waiting room not knowing what to do. My friend had tested negative, but had
39. other friends that were positive so he knew what to do. He took me home. I lived
40. on my own. He 38.made me a cup of coffee and sandwich. He tried to act normal,
41. you know, carry on as normal. I think if I had been on my own that day I would 42. have panicked, gone into meltdown, become hysterical. All my friends say I can 43. be a real drama queen over the littlest thing. You know, like having a bad hair day. 44. So having someone there who knew what to do, how to deal with it for me.was 45. really massive. He was able to reassure me that I wasn't going to die. Nowadays 46. having HIV is survivable, When I'm having a bad day I have to keep reminding 47. myself that having HIV is survivable. Having HIV just wasn't something I gave 48. any thought to. I wasn't expecting it to be positive. Sounds a daft, doesn't it given 49. what I've just told you about my lifestyle at the time. Anyway, I was given some 50. leaflets about support groups, you THT and the like. I was given a follow-up
51. appointment with a doctor and had to go back for more blood samples to be taken.
52. It was all explained to me about viral loads and CD4 counts. I don't know when I
53. got positive, but from what I was told it was probably quite recent. In other words,
54. I was probably only infected a month or so before I had the test. So, I was really 55. lucky. My viral load is quite low, not quite undetectable, but good enough. I've 56. also got a high CD4 count so I am pretty healthy. As soon as I got the positive test 57. I knew things had to change.
58. R: What were some of those things?
59. T: .I knew the partying had to stop. I think, you could say I grew up over night. I
60. know I'm lucky to have tested positive when I did. I mean, now there's lots of

treatment options available compared to how it used to be. Still, I don't want to be taking medication unless I have to. I go to the gym and eat healthy. I only have a drink now and then. I’m a hermit or monk, but I am much more careful now, if you know what I mean. It’s not easy living with HIV, but it’s not the death sentence it once was. I can't begin to imagine what it must have be like in the early days of AIDS. I mean, no-one knew what was going on, what it was, there was no treatment. People were dying and nothing could be done to stop it happening. So, I suppose I’ve got a lot to grateful for. Don't get me wrong, I do get down sometimes. I go for regular tests and always get anxious the night before. I think to myself will this test be ok or will I need to start treatment. I know the pills work and the combination treatment is simply to take. I remember seeing people on medication back in the early days, you know, when HIV patients were interviewed in documentaries and they were taking loads of different pills several times a day. Thank God It’s not like that anymore. I know that if and when the time come for me to start on medication I will only need to take one or two pills a day. I try to live my life as best I can. I try not to think or worry too much about the future. I keep telling myself “It’s doable, It’s survivable”. My family know I’ve got HIV. I told some of my gay friends. I thought there was not point keeping it a secret. You hear a lot about stigma. I know some people have had really bad experiences when they have disclosed their status to others. You can let fear and anxiety get the better of you, but I thought I’ve nothing to ashamed of, I will tell people if I think they need to know and let them deal with it. I work in web design, it’s a small company and so I had no problem telling my work mates. Everyone’s been really supportive. I know it’s not an experience shared by everyone. I’ve heard some real horror stories about people who have disclosed their HIV status to friends and family and been totally rejected as a result. There is still fear around HIV, maybe not as bad as it once was, but I know it’s still there. You can’t predict how someone is going to react when you tell them. The way I see it, think about it, is that if someone can’t handle me telling them that I’m HIV Positive, then I don't want that person in my life period. I guess you soon find out who your real friends are. The Gay world is quite shallow or at least some aspects of it. I have to say that since I got positive I’m not sure whether I really relate to the Gay world in the way I used to. I mean, I think it is all a bit superficial or maybe what I’m really trying to say is that I began to realise how superficial I was. Getting HIV made me think about what really mattered. You know, what did I want to achieve in life. I didn't suddenly find God and get all spiritual, but it did make me question my values. I used to be very driven at work, very materialistic, very hedonistic, but not now. I am much more reflective and I’m more considered in how I approach life. When I was a younger, anyone who knew me back then would’ve described me as being really angry. I struggled coming to terms with my sexuality. Growing up in a small market town was bad enough without feeling different like I did. I did not have any reference points for what I was experiencing where I lived. So when I left home to go to Uni I saw it as an escape route from all the boredom and small mindedness. I needed stimulation, intellectual and emotional. I wanted to live life. I’m lucky that I have a supportive family. I know from talking to gay friends that my experience is perhaps may not be the norm. A lot of gay men I know are damaged psychologically. They are very ashamed and full of self-loathing. For the ones that are also HIV positive it’s the worst thing ever. I see how depressed they are and how some of them have just given up. For them it’s the end of the world to

111. be HIV positive. I've heard some of them say that they deserved to get HIV. It
112. was like they believed they deserved to be punished. I supposed it's a form of 113.
what psychologists might refer to as internalised homophobia. The Gay world is 114.
really messed up like that. I know some of friends find it hard, you know,
115. difficult to understand how I can be so accepting of my situation. I mean, I have
116. good days and bad days. I get down, I get anxious, but, to my mind, I think that's
117. normal, don't you? I'm not sure whether it's true to say that I'm accepting or 118.
simply that I'm a pragmatist. You know, I don't believe in fate, but I believe that 119.
life is for living. You only get out of life what you put into it. So, perhaps, It's 120. true
what people who know me say when they say I'm driven. I am certainly
121.focussed as a person. For me having HIV is a gift, although saying it like that 122.
sounds like a cliche, but if it hadn't been for HIV I would have carried on being a 124.
party animal. Looking back on it I suppose I was heading for an early grave.
125. Sounds quite dramatic, doesn't it, but I was living close to the edge back then.
126. Getting HIV was a wake-up call. I've seen what getting HIV does to some
127. people. Some people never seem to come to terms with having HIV. I'm not sure
128. whether they go into denial or what it is that happens, but I can see that they are
129. not coping. Their reaction, their coping strategy is to go over board, over
130. compensate, do everything to max, party, drugs and sex. I've also seen other
131. people go into hiding, just disappear. Not go out, not answer the phone, not reply
132. to emails. I've never understood what that is all about. For me, it was about
133. taking stock. It was about saying to myself "What are my choices?" I asked
134. questions, found myself a good consultant and took charge of my situation. I 135.
don't allow myself to have self pity. I'm not one or self pity, never have been. I 136.
always try to face my challenges and learn from them. I try not to preach about 137.

how to live healthily with HIV. I know people who seem to see as their mission 138. in life to preach about living with HIV. I don’t think you can tell another person 139. how they should live their life, especially when they aren’t exactly walking the 140. talk themselves. I think it is up to the individual to figure it out for themselves. 141. You know, figure out what works for them. I only know what seems to work for 142. me, if anyone asks me I will share my experience with them, but it’s up to them 143. whether or not they want to take it on board. You can’t live another person's life 144. for them can you? I want to stay well and have a long life. I try to look after
145. myself as best I can. Everything in moderation. I don’t always get it right.
146. sometimes I fail, but I tell myself that I’m only human. Emotionally, I’m in a 147. good place, I have my down days like most people, but I keep focussed on
148. what’s important. I have my goals, the things I want to achieve personally and
149. professionally. I like my own company, my independence. I dip in and out of the
150. social scene. As I’ve said I find a lot of what happens on the gay scene shallow
151. and superficial. I can only tolerate it for so long then I have to take a break from
152. it all. I like to do my own thing. I don’t let HIV rule my life. That’s a mistake 153. I’ve seen too many people with HIV make. I’ve seen how it consumes them. 154. Every waking minute is dominated by HIV. They define themselves by having 155. HIV. HIV becomes their identity. HIV is their life. That’s not for me, no thank 156. you. This is not a dress rehearsal. You only get one chance at life. Having HIV is 157. still a big deal in lots of ways for many people, but it’s not the end of the world. I 158. have HIV, but that isn’t who I am. There’s more to me and my life than HIV. For 159. some there is the stigma of having HIV, but I think there are still some people in 160. the Gay community who feel stigmatised for being gay. So for them having HIV 161. is an additional thing to feel bad about. I think it’s those people who find it

hardest to cope with having HIV. They are more likely to experience it as a punishment. I don't think it's about acceptance as such. I think it's about making the best of things. You know, when we are born we are dealt a set of cards. You can bitch about it all you like, but it wont change anything. Life is what you make it. Like I say I know people who like to play the victim. I suppose it's a way of getting attention, being a drama queen. Having HIV is a gift for those sorts of people. They seem to use it, having HIV, as a way of making other people feel bad, feel guilty. I don't think that way of behaving is very attractive. I think the way to live with HIV is to be strong, single-minded. No point dwelling on the past. We all make mistakes, make bad choices, but that's how life is. At least I try to liv each day as it comes point having regrets. I've maybe made some bad choices along the way, but then again who hasn't. Hindsight's a wonderful thing isn't it? The only way I know to live healthily now I am HIV positive is to take responsibility for my life choices and not seek to blame other people for how my life has turned out. Would I rather not have HIV? I'm not sure. I've often thought about what I would do, how I choose, if I turn back the clock, you know, go back in time.

R: Would I choose differently?

T: HIV is a part of life now for everyone. We live in a world where there is HIV, just like there is cancer, heart disease, diabetes, dementia. You can go into hiding, become a monk, but I don't see why you would want to do that. It might be a choice for some people, but I suppose I'm more of an extrovert. I left where I grew up and came to London to experience life. I want to do more travelling, see more of the world. Life is short enough as it is. I want to make the most out

186. of the life I have whilst I’ve still got the energy and the health to enjoy it. I don't 187. do sitting still. I get bored too easily. I need constant stimulation. I no longer 188. take things for granted. By that I mean, life, friends, I try to stay focused on 189. what’s important. I don’t want to waste my time and energy on anything that's 190. not really important. I want to do everything to the best of my ability. Having 191. HIV has given a focus I didn't have before. I try to make my health a priority 192. now. Staying well is the key to living with HIV. What I mean is I have become 193. much for health conscious now that I’m HIV positive. It may not be life-194. threatening anymore, but you can still get some nasty infections which can make 195. you really ill. You have to know your body. Anything that’s not right needs to be 196. checked out straight away. Better to go and get it checked out than to leave it, 197. thinking it will go away or that it’s nothing and then be told you should have 198. come sooner because it’s actually something serious and could even become life-199. threatening if left untreated. Having said that, I’m actually really positive about 200. the future, my future, I’ve got a good job, great friends, friends who are really 201. supportive. That’s important, support, I mean. It’s easy to become discouraged, 202. especially when you feel down and then you can get to feel scared, feel all alone. 203. So, for me, having a good support network is really the most important thing. To 204. stay healthy you need to have a good HIV consultant, a good GP and be 205. proactive in your relationships with your healthcare professionals. To maintain 206. good physical health you also have to look after your mental health as well. I 207. know a lot of messed up people, both gay and straight, messed up 208. psychologically and emotionally. I’m sure you’ve heard about Chemsex. 209. Crystal meth is something I keep well clear off. It makes you do crazy things, 210. take risks, put yourself in danger. I know people who are so heavily into that

scene, the whole Chemsex scene and those guys are totally on another planet 24/7. They end up paranoid, delusional and unable to function and take good care of themselves. I’ve do some crazy things in the past, some things I’m frankly not proud of, but I’ve had my wake-up call. As I’ve said, getting HIV made me wake-up and smell the coffee, you know what I mean. I’m more reflective and a lot less impulsive now. I know how to take care of myself, at least I hope I do.

Appendix 3

Paperwork submitted for Ethical Approval

MIDDLESEX UNIVERSITY
SCHOOL OF HEALTH AND SOCIAL SCIENCES

HEALTH STUDIES ETHICS SUB-COMMITTEE

APPLICATION FOR ETHICAL APPROVAL OF CATEGORY A PROPOSALS

This form must be completed for all research projects carried out by staff or students of the School that conform to the category A definitions.

Title of proposed study:

An Existential-Phenomenological Investigation into the Experien infected with HIV (not having AIDS)

Name(s) and qualifications of supervisor(s) / principal investigator (s):

Professor Digby Tantam BA (Open) BM BCH (Oxon) MA (C (Havard) Phd (London)

Name(s) and qualifications of researcher(s):

Alan Palamountain BSc (Hons) Psychology/Philosophy MA Psy
and Counselling MSc Counselling Psychology UKCP Registere
therapist

Is the proposal linked to a programme of study? If so, please identify:

DCPsych in Existential Counselling Psychology and Psychother

Indicate the start and end date for the proposed study:

Start date: November 2011
End date: June 2018

Is the proposal externally funded? If so, name the source of the funding:

No

Identify under which of the criteria in category A of the guidelines this proposal can be classified:

For information only ☐

A1 ☐ A2 X A3 ☐

A4 ☐ A5 ☐ A6 ☐

NB: If A6 is ticked you will also need to tick A2, A3, A4 or A5 as appropriate

You should submit one hard copy (signed by the research supervisor in the case of a student submission) and an electronic copy to

Christine Constantinou, HSESC secretary, at Enfield (c.constantinou@mdx.ac.uk). This should be submitted at least **two weeks** before the date of the HSESC meeting.

Students must remember to keep a copy of this form for inclusion in their project/dissertation report.

Declaration:

- As supervisor or principal investigator for this research study I understand that it is my responsibility to ensure that researchers/students under my supervision undertake a risk assessment to ensure that health and safety of themselves, participants and others is not jeopardised during the course of this study.
- I confirm that I have seen and signed a risk assessment for this research study using standard university forms and to the best of my knowledge appropriate action has been taken to minimise any identified risks or hazards.
- I understand that, where applicable, it is my responsibility to ensure that the study is conducted in a manner that is consistent with the World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects (see http://www.wma.net/e/policy/b3.htm).

- I confirm that I have reviewed all of the information submitted as part of this research ethics application.
- I agree to participate in committee's auditing procedures for research studies if requested.

………………………………………………………..

Signature of Supervisor or Principal Investigator
Date

INDEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT FRA1

This proforma is applicable to, and must be completed in advance for, the following fieldwork situations:

1. *All fieldwork undertaken independently by individual students, either in the UK or overseas, including in connection with proposition module or dissertations. Supervisor to complete with student(s).*
2. *All fieldwork undertaken by postgraduate students. Supervisors to complete with student(s).*
3. *Fieldwork undertaken by research students. Student to complete with supervisor.*
4. *Fieldwork/visits by research staff. Researcher to complete with Research Centre Head.*

FIELDWORK DETAILS

Name Alan Palamountain……………………………………………….

Student No
Research Centre (staff only)…………

Supervisor Professor Digby Tantam………………………………….

Degree course …DPsych in Existential
chotherapy……………………………

Telephone numbers and name of next of kin who may be contacted in the event of an accident	**NEXT OF KIN** **Name** Avideh Shahsavani ………………………………………………… **Phone** 0208 8869347……………………………………
Physical or psychological limitations to carrying out the proposed fieldwork	None……..………….………….………..…… …… ……..………….………….………..………… ……..………….………….………..………… ……..………….………….………..…………
Any health problems (full details) Which may be relevant to proposed fieldwork activity in case of emergencies.	None……..………….………….………..…… …… ……..………….………….………..………… ……..………….………….………..………… ……..………….………….………..…………
Locality (Country and Region)	London UK………………………………………………… …. ……..………….………….………..…………
Travel Arrangements	Public transport…………………………………………… ………. ……..………….………….………..………… ……..………….………….………..…………
NB: Comprehensive travel and health insurance must always be obtained for independent overseas fieldwork.	……..………….………….………..…………

Dates of Travel and Fieldwork ……..………..………..…………..…………

……..………..………..…………..…………

PLEASE READ THE INFORMATION OVERLEAF VERY CAREFULLY

Hazard Identification and Risk Assessment **PLEASE READ VERY CAREFULLY**

List the localities to be visited or specify routes to be followed **(Col. 1).** Give the approximate date (month / year) of your last visit, or enter 'NOT VISITED' **(Col 2).** For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern **(Col. 3).**

Examples of Potential Hazards :
Adverse weather: exposure (heat, sunburn, lightening, wind, hypothermia)
Terrain: rugged, unstable, fall, slip, trip, debris, and remoteness. Traffic: pollution.
Demolition/building sites, assault, getting lost, animals, disease.
Working on/near water: drowning, swept away, disease (weils disease, hepatitis, malaria, etc), par
Lone working: difficult to summon help, alone or in isolation, lone interviews.
Dealing with the public: personal attack, causing offence/intrusion, misinterpreted, political, ethni
ences/problems. Known or suspected criminal offenders.
Safety Standards (other work organisations, transport, hotels, etc), working at night, areas of high
Ill health: personal considerations or vulnerabilities, pre-determined medical conditions (asthma, a
disabilities, persons suited to task.
Articles and equipment: inappropriate type and/or use, failure of equipment, insufficient training f
Substances (chemicals, plants, bio- hazards, waste): ill health - poisoning, infection, irritation, bur
Manual handling: lifting, carrying, moving large or heavy items, physical unsuitability for task

If no hazard can be identified beyond those of everyday life, enter 'NONE'.

Give brief details of fieldwork activity: Interviews…………………………………………………………………………………………………..

…….

…….

…….

1. LOCALITY/ROUTE	2. LAST VISIT	3. POTENTIAL HAZ

Postive East – Stepney **159 Mile End Road London E1 4AQ**		**Ill-health HIV**

The University Fieldwork code of Practice booklet provides practical advice that

should be followed in planning and conducting fieldwork.

Risk Minimisation/Control Measures PLEASE READ VERY CAREFULLY

For each hazard identified **(Col 3),** list the precautions/control measures in place or that will be taken **(Col 4)** to **"reduce the risk to acceptable levels",** and the safety equipment **(Col 6)** that will be employed.

Assuming the safety precautions/control methods that will be adopted **(Col. 4),** categorise the fieldwork risk for each location/route as negligible, low, moderate or high **(Col. 5).**

Risk increases with both the increasing likelihood of an accident and the increasing severity of the consequences of an accident.

An acceptable level of risk is: a risk which can be safely controlled by person taking part in the activity using the precautions and control measures noted including the necessary instructions, information and training relevant to that risk. The resultant risk should not be significantly higher than that encountered in everyday life.

Examples of control measures/precautions:

Providing adequate training, information & instructions on fieldwork tasks and the safe and correct use of any equipment, substances and personal protective equipment. Inspection and safety check of any equipment prior to use. Assessing individuals fitness and suitability to environment and tasks involved. Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.). Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances. First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements). Working with colleagues (pairs). **Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility.** Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations. Checks on Health and Safety standards & welfare facilities of travel, accommodation and outside organisations. Seek information on social/cultural/political status of fieldwork area.

Examples of Safety Equipment: Hardhats, goggles, gloves, harness, waders, whistles, boots, mobile phone, ear protectors, bright fluorescent clothing (for roadside work), dust mask, etc.

If a proposed locality has not been visited previously, give your authority for the risk assessment stated or indicate that your visit will be preceded by a thorough risk assessment.

4. PRECAUTIONS/CONTROL MEASURES	5. RISK ASSESSM

Health and Safety I will be using an office building at Positive East – Stepney to conduct my interviews. I will only conduct the interviews when the building is staffed.	Conducted with the Centre Manager

PLEASE READ INFORMATION OVERLEAF AND SIGN AS APPROPRIATE

DECLARATION: The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.

NB: Risk should be constantly reassessed during the fieldwork period and additional precautions taken or fieldwork discontinued if the risk is seen to be unacceptable.

Signature of Fieldworker (Student/Staff)	……….……………..……….………..……………	**Da**
Signature of Student Supervisor	……….……………..……….………..……………	**Da**

APPROVAL: (ONE ONLY)

Signature of **Curriculum Leader** (undergraduate students only)	……….……………..……….………..……………	**Da**
Signature of Research Degree Co-ordinator or **Masters Course Leader or** **Taught Masters Curriculum Leader**	……….……………..……….………..……………	**Da**
Signature of Research Centre Head (for staff fieldworkers**)**	……….……………..……….………..……………	**Da**

FIELDWORK CHECK LIST

1. Ensure that **all members** of the field party possess the following attributes (where relevant) at a level appropriate to the proposed activity and likely field conditions:

? Safety knowledge and training?

? Awareness of cultural, social and political differences?

? Physical and psychological fitness and disease immunity, protection and awareness?

? Personal clothing and safety equipment?

? Suitability of fieldworkers to proposed tasks?

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2. Have all the necessary arrangements been made and information/instruction gained, and have the relevant authorities been consulted or informed with regard to:

? Visa, permits?

? Legal access to sites and/or persons?

? Political or military sensitivity of the proposed topic, its method or location?

? Weather conditions, tide times and ranges?

? Vaccinations and other health precautions?

? Civil unrest and terrorism?

? Arrival times after journeys?

? Safety equipment and protective clothing?

? Financial and insurance implications?

? Crime risk?

? Health insurance arrangements?

? Emergency procedures?

? Transport use?

? Travel and accommodation arrangements?

Important information for retaining evidence of completed risk assessments:
Once the risk assessment is completed and approval gained the **supervisor** should retain this form and issue a copy of it to the fieldworker participating on the field course/work. In addition the **approver** must keep a copy of this risk assessment in an appropriate Health and Safety file.

Alan Palamountain
144 Warwick Road
London
N18 1RT

3 November 2011

Dear Alan

Re: Research Proposal Resubmission & Ethics Approval

We held an Ethics Board on 7 October 2011 and the following decisions were made.

Research Proposal Resubmission
Resubmission of Research Proposal has been approved.

Ethics Approval
You have been granted this approval.

Yours sincerely

Dr Gordon Weller	**Prof Digby Tantam**
Programme Leader DProf (Health)	**Chair Ethics Committee**
Middlesex University	**NSPC**

MIDDLESEX UNIVERSITY
SCHOOL OF HEALTH AND SOCIAL SCIENCES

HEALTH STUDIES ETHICS SUB-COMMITTEE

PARTICIPANT INFORMATION SHEET (PIS) AND CONSENT FORM

Study Title
An Existential-Phenomenological Investigation Into The Experience Of Being Infected with HIV

This study is an exploration of the impact being HIV positive has on an individual's life.

Invitation to participate in the research study

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

Thank you for reading this.

What is the purpose of this research study/

This research study is an attempt to explore what it is like to live with HIV. By using semi-structured interviews I will attempt to discover more about how HIV impacts on the lives of individuals. The aim is to give individuals living with the opportunity to share their experience of living with HIV.

Why have I been chosen?

After my presentation to the group you approached me and indicated that you would be interested in finding out more my research study. You offered to be interviewed as part of this research study. It is my intention to interview a maximum of six individuals living with HIV aged 18 and over. Anyone with a learning disability or a psychiatric disorder will be excluded from this research study.

Do I have to take part?

It is up to you to decide whether or not to take part, but it will not affect the service you receive from this agency if you decline to take part. If you do decide to take part you will given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if i take part?

Only you and I will know what you have said. Information will be stored confidentially and not made available to any other agency.

What do I have to do?

I will conduct the interview and it will last for approximately one hour. It will be conducted at a time and place convenient to both of us. The interview will be an opportunity for you to describe to me what it is like to be living with HIV and the different ways it impacts on your life.

What are the alternatives for diagnosis or testament/

Not applicable.

What are the possible disadvantages and risks of taking part?

If any part of the interview makes you feel upset you can ask to stop the interview. You can also have the opportunity to talk about how you felt during the interview with either me or a counsellor if you so wish.

What are the benefits of taking part?

There are no direct benefits from taking part.

Will my taking part in this research study be kept confidential?

All information that is collected about you during the course of this research study will be kept strictly confidential. Any information about you which is used will have your name and contact details removed so that you cannot be recognised from it and replaced with an identification code. All information relating to this research study will be kept in a locked cabinet in the office at the venue where the interviews are conducted. All data will be stored, analysed and reported in compliance with the Data Protection Legislation.

What will happen to the findings of this research study?

This research study will be published as part of my Doctoral Thesis. I would be happy to send you a copy of my completed research should you wish to have a copy. You will not be identified in any report or publication relating to this research study.

Who has reviewed this research study?

This research study has been reviewed by both the Research Ethics Committee of the New School of Psychotherapy and Counselling also Middlesex University, School of Health and Social Sciences, Health Studies Ethics Sub-committee.

Contact for further information

Alan Palamountain

Email: alanp144@yahoo.co.uk Mobile: 07773127902

Middlesex University

School of Health and Social Sciences

New School Of Psychotherapy and Counselling

NSPC

Written Informed Consent

Title of study and academic year: 2011

An Existential-Phenomenological Investigation Into the Experience of Being Infected with HIV

Researcher: Alan Palamountain

Supervisor (only for students): Professor Digby Tantam

I have understood the details of the research as explained to me by the researcher, and confirm that i have consented to act as a participant.

I have been given contact details for the researcher in the information sheet.

I understand that my participation is entirely voluntary, that the data collected during the research will not be identifiable, and I have the right to withdraw from the interview at any time with no obligation to explain my reasons for wishing to do so.

I understand that the interview will be recorded and transcribed.

all data will be stored in accordance with the Data Protection Act (1998).

I further understand that the data I provide may be used for analysis and subsequent publication, provide my consent that might occur.

Name: Signature: Date:

To the participants: Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Social Sciences Ethics committee of Middlesex University, if required buy institutional audits about correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits: ——