Abstract

HIV AND HUMAN BEING

Greg Madison

Abstract – Few of the studies of psychological adaptation to an HIV+ diagnosis have inquired into its existential dimension. Existential enquiries contribute valuable insights into lived experience without pathologising that experience. In the present research, the experiences of six HIV+ gay men were assessed using semi-structured interviews and Focusing, a method of intensive self-reflection. The transcripts of these sessions were analysed phenomenologically and the results were compared to previous existential studies with special emphasis on the process of adaptation to HIV. These men’s experiences are then presented as aspects of the general modes of human being described by Heidegger. This highlights the commonality of the ‘healthy’ and HIV situations. The question is asked whether we will take the opportunity to learn from the existential insights of HIV+ gay men.
TABLE OF CONTENTS

Introduction .................................................................................................................................................. page 1
The Research Context ................................................................................................................................. page 5
Aims of the Present Study ............................................................................................................................ page 14
Research Methodology .............................................................................................................................. page 17
Interpretations ............................................................................................................................................ page 26
Discussion of Existential Themes ................................................................................................................ page 43
Process, Experiencing, and Meaning .......................................................................................................... page 48
HIV and the Being of human beings .......................................................................................................... page 53
Concluding Remarks .................................................................................................................................. page 66
References .................................................................................................................................................... page 70

LIST OF FIGURES
Table One ...................................................................................................................................................... page 42
Appendix ...................................................................................................................................................... page 73
Chapter 1
Introduction

Throughout human history, societies have been called upon to respond to threatening crises. Temporarily, each crisis looms large in our concerns only to gradually shrink away as the threat fades and time passes. Yet, in the closeness of the present these crises have the potential to impact in a profound and transforming way. Our response to these events can determine whether they disengage into the past as once-threatening challenges, or whether they have long-lasting repercussions for our way of living and our view of life itself. The former Director of London Lighthouse, Christopher Spence, said in an address in 1994,

These are the events which bring both unimaginable crisis and great challenge; events that expose the fabric of society where it is worn out or rotten through and through, and in doing so stir the human spirit out of its habitual complacency to insist on, and fight for, a response that is focused on fundamental and far-reaching change. I believe that in our time, AIDS is such an event and that history will judge this generation by the quality of our response (pp. 9-10).

AIDS was first recognised among gay men in America. Its aetiology, the HIV virus, was identified in 1983 but its spread, in retrospect, likely began in the late 1970s. In the western world, the impact of HIV/AIDS has been most profound in the gay community and the following study will focus on the experience of HIV+ gay men.

The AIDS crisis has produced a dramatic change of life for those affected. Most HIV+ gay men have had their careers cut short because work is too exhausting. They therefore become financially dependent upon the same community that marginalises and stigmatises them. They regularly rely upon strong prescribed drugs with disturbing side effects and
subsequently acquire the label of ‘disabled person’. They face the trauma of rejection by family and friends when feelings of inadequacy, isolation, and loneliness may already be heightened by their disease. In the prime of life, their sexual expression can be deeply affected and their prospect for future life itself significantly foreshortened.

The gay community has responded courageously to this onslaught, creating ‘... a new group of bereaved care-givers: gay men who are in early middle age and primary relationships that are not legally recognised and whose partners have had an illness that is stigmatised and with which the caregivers may themselves be contending’ (Folkman et al., 1996,p.343). Even in the six participants for this study, one of them copes with the grief of having lost all his friends, symbolically a generation of gay men, to AIDS. Outside of wartime and genocide, such experience of mass death has been rare in our society. It can be difficult for repeat survivors to remain engaged in life ‘... because the AIDS epidemic still looms large; many fear they will start new relationships and that these too may succumb to AIDS’ (Blechner, 1993, p.74).

HIV has many distinct features: There is a long and variable interval between infection and the onset of symptoms, with fifty percent of people infected becoming ill within ten years and subsequently dying of AIDS in another one to three years¹. Belonging to a discriminated group makes one particularly vulnerable (gay and bisexual men, injecting drug users, men and women with multiple sex partners). ‘A multitude of disease-specific psychosocial stressors, including stigmatisation, discrimination, loss, and isolation, interact to create considerably more psychosocial problems and needs among AIDS patients than among patients with other fatal diseases’ (McCain and Grambling, 1992, p.271). HIV embodies many taboo subjects which our culture prefers not to discuss ‘... sexuality,  

¹This prognosis seems to be changing drastically with the introduction of ‘combination therapies’.
particularly homosexuality; disease and disability, particularly in younger people; and death’ (Hildebrand, 1992, p. 457).

As part of society’s response, HIV/AIDS has acquired a set of unique meanings and myths. Susan Sontag, in *Aids and its Metaphors* (1988) describes the ‘age-old process whereby diseases acquire meanings’ by becoming associated with our deepest fears (p. 94). HIV has come to stand for sexual excess and perversity (ibid. p. 29-31). The HIV test has created a group of ‘... lifetime pariahs, the future ill’ (p. 33). Sontag suggests that the public response to HIV/AIDS expresses a desire for stricter limits to the conduct of personal life.

The academic community has responded by making AIDS and then HIV the subject of countless studies (as cited in Davies, 1995a, b, c; Schwartzberg, 1993; Viney and Bousfield, 1991; McCain and Grambling, 1992; and many others). The medical effects, social factors, psychiatric diagnoses, efficacy of various psychotherapies, and psychoanalytic case studies have all been investigated in an effort to contribute to our understanding of the unique situation of HIV+ gay men.

However, with few exceptions, these studies place HIV+ gay men ‘over there’, across from us, as the objects of research. It may be significant that the angle that has largely remained unexamined is the existential aspect of this disease. This aspect can call the researcher to identify with the experience being studied. It contemplates how the HIV+ situation symbolises the general human condition. It emphasises both what is unique and what is common about living with HIV, and therefore provides an opportunity to tap at our awareness of our own lives. It is our social and individual reaction to *this* awareness that could produce fundamental and far-reaching change. In the words of ‘Sebastian’, one of the participants in the present research,
Greg Madison, PhD unpublished MA dissertation, 1997, University of Sheffield

... AIDS isn’t about AIDS ... AIDS is about everything. It’s not just AIDS, it’s about living. It’s about facing suffering, everyone suffers. It’s about facing death, everyone dies, the death rate remains the same. It’s about looking after people; everyone’s got to do that. It’s about coping with prejudice, it’s about standing up for yourself. And I don’t know a single person alive who doesn’t have these issues, you know? It just so happens that HIV makes it all very focused (Interview, Question 3, P4).

The present research was originally designed to be a comment on previous research and an investigation of Focusing as a phenomenological method with HIV+ gay men. However, as the interviews proceeded, it became evident that the existential impact of living with HIV has salient relevance for us all. Sebastian’s comment, echoed by other participants, invites us to identify what we can learn for ourselves from the HIV experience.

The following paper will proceed by setting the research context, presenting the aims of the current research, describing the methodology and analysing the participant’s material. The discussion will begin by commenting on the other main existential studies of HIV+ gay men (Davies, 1995a,b,c; and Schwartzberg, 1993). These studies have emphasised how HIV+ gay men adapt to their diagnosis. However, the more original aspect of the current paper is the presentation of experiences of six HIV+ gay men as expressions of various aspects of human being in general. By applying concepts from Martin Heidegger’s ontology, I hope to contextualise the HIV experience within the general experience of ‘human being’. Thereby not only does our view of these men’s process lose its implicit judgement of ‘successful’ or ‘failed’ adaptation, but also their orientation to HIV reveals ‘modes of being’ that are as applicable to our situation as to theirs. Comments about the relevance of Focusing to this view will also be included.
Chapter 2

The Research Context

Before discussing existential studies, it is relevant to give the broader context of HIV research, and indications why existential studies seem especially appropriate. The psychological effects of living with HIV have been described from a variety of perspectives with differing emphases. The efficacies of psychotherapeutic, psychoanalytic, and psychiatric interventions have also been the subject of research\(^2\). These studies, in their own way, distance the researcher from the object of research. When the object of research is human experience, this distancing can alienate the researchers from themselves.

Psychiatric intervention is based upon the premise that ‘disorders’ will stem from an HIV+ individual’s difficulty in coping with their new life situations (Treisman et al,1993, p.432). The assumption is that it’s quite OK (normal) to be a little demoralised by one’s impending death and all the associated indignities of dying, but a more extreme reaction is pathological;

We have seen an increased incidence of major depression late in the course of HIV infection, and the emergence of this syndrome is correlated with low CD4 counts and the development of AIDS. Although the demoralisation related to the awareness and progression of illness might be mistaken for major depression, the correct diagnosis is usually clear when these classic symptoms cluster into a full syndrome of major depression (ibid.p.433).

These psychiatrists are convinced by ‘good response rates’ to ‘become more aggressive in the use of medications’ and ECT (ibid,p.444-6). They warn not to be ‘too understanding’ and thereby convey the mistaken attitude that depressive symptoms are a consequence of terminal pain, stigmatisation, living with the uncertainties of HIV in the prime of life, loss of friends and lovers, rejection, and the progressive deterioration of all functional abilities. Rather than a meaningful

\(^2\)This includes incorporating psychotherapeutic models into health advisor HIV prevention
response, depression signifies ‘manifestations of a treatable affective disease’ (ibid, p.437).

Markowitz et al (1995) also assert that ‘depression is never normal’ and that HIV+ depressed patients appear to be ‘highly motivated and appropriate candidates for brief psychotherapy’ (p.1508). Bor (1991) comments that ‘... an HIV diagnosis can reactivate or exacerbate psychological symptoms which pre-date the diagnosis’ (p.405). He concludes that psychotherapeutic and psychiatric interventions have little impact on the nature, severity, or course of these ‘psychological symptoms’ (ibid, p.406-7). He suggests that perhaps time is the great healer in the face of the distress of a HIV+ diagnosis. This implies that adaptation to HIV may occur gradually but seems to negate the possibility that this is a meaningful process rather than a simple shedding of symptoms. Depression may reveal a meaningful response to the reality of living with HIV and pathologising this experience cuts us off from understanding its meaning (see Simon, Laurence, 1994; Svensson, Tommy, 1995; for critiques of the medical model in psychiatry, psychoanalysis and psychotherapy).

The few psychoanalytic studies of living with HIV follow the above trend to diagnose and pathologise. In this case, a relevant aspect of these studies is the preconceived attitude to homosexuality in psychoanalysis,

When psychoanalytic researchers have attempted to study the individual homosexual or homosexuality in general, they have entered the process with definite biases and preconceived notions about the study’s outcome (Cornet and Hudson, 1986, p.103).

The way in which psychoanalytic theory leads researchers and analysts to prejudge gay men as pathological because they are homosexual rather than because they exhibit any symptoms has been examined by various researchers (see Lilling and Friedman, 1995; Bleckner, 1993, p.61). In stark contrast to psychoanalytic theory, other studies have not counselling (Grace, 1994).
found any basis for labelling homosexuality as a ‘maladaptive orientation’ (Cornett and Hudson, 1986, p.104).\(^3\)

The psychoanalyst Peter Hildebrand believes HIV+ gay patients are like Macbeth, ‘... in that their desire has lead them to being overtaken by an extraordinary fate’ (Hildebrand, 1992, p.460). This is an interesting, almost puritanical, substitution of sexual desire for the virus which causes the disease (Sontag’s analysis seems pertinent here). Hildebrand describes his own reactions to a HIV+ gay patient as ‘dissociation’, ‘a fierce assertion of my own life’, ‘some numbness’ and ‘intense feelings of depression and despair’ (ibid, p.462-4). He directed the focus of his work towards the patient’s life concerns ‘... rather than accepting the fact of his death which perhaps in some senses it would have been appropriate for me to do’ (ibid, p.462). When this patient was on his deathbed, Hildebrand shook his hand and told him to ‘keep fighting’ though it was clear that death was imminent (ibid, p.466). Hildebrand himself admits, ‘... [psychoanalysts] do not have any real body of experience or practice with dealing with the dying’ (ibid, p.467). He says that when patients like this come with their ‘existential problems’, it is difficult for the analyst to maintain their ‘inner standards’ (ibid, p.467).

These problems are echoed by Mark Blechner (1993) who says that working with AIDS patients places a burden on analysts because the patient’s emotions are ‘contagious’ and can cause an existential crisis for the analyst and his/her beliefs (p.68-70). Dealing with HIV seems to require the psychoanalyst to re-orient to the situation in a way that is unsettling. Their patient’s existential reality, and subsequently their own, seems to conflict with the traditional analytic role and emphases.

\(^3\)For example the study cited earlier in which bereaved gay carers were shown to have the same depth of commitment to relationships as ‘traditional caregivers’ who’ve lost a spouse or child (Folkman et.al., 1996, p.345).
Diane Sadowy, a psychoanalyst with a HIV+ woman patient, recalls feeling ‘very clumsy and awkward’ around death (Sadowy, 1991, p.205). As she works with the patient Sadowy begins to ask herself ‘Where do transference, countertransference, resistance and such have a place when the realities of the situation are so overwhelming’ (ibid, p.205)? She also emphasises the confrontation with mortality and physical frailty that occurs within her during the process. Sadowy addresses the situation by leaving her purely analytic role to help in caregiving tasks with her patient. These challenges to their traditional role and training may explain the lack of involvement by psychoanalysts in reacting to the HIV epidemic.

It becomes evident that regardless of the researcher’s orientation, insight into the existential situation, for researcher and patient alike, can become as salient a consideration as phantoms and phantasies. Phenomenological studies of the HIV+ person’s experience, stressing their own point of view, produce a richer description of their situation and our response to it.

A narrative analysis of the accounts of People with AIDS (PWAs) is one attempt to present the individual experience. It supplements the psychological and psychiatric findings of high levels of anxiety, depression, and anger, ‘... by presenting them as an integrated experience in the narrative of the research participant’ (Viney and Bousfield, 1991, p.764). This is an attempt to understand the experience of PWAs rather than maintaining an ‘objective’ distance through diagnosis. Usually the narrative of the medical researcher dominates and excludes the lived experience of PWAs.

In their study of the post-bereavement depression of HIV+ and HIV- gay men whose partners had just died of AIDS, Folkman et al (1996) suggest that the depression felt by caregiving partners may represent a process referred to by Klinger (1977) as
Greg Madison, PhD unpublished MA dissertation, 1997, University of Sheffield

‘disengagement from incentives’⁴. In the final months of their partner’s life these caregivers are beginning to disengage and to feel the loss of intimacy, companionship, shared future life, and as they let go of these valued aspects of life they experience depression. Trying to control the depression by distancing, denial, or drugs, could contribute to longer lasting depressive mood later (ibid, p.346-7). The researchers cite Viktor Frankl (1963) as supporting the positive value of finding meaning, in this case through caregiving, even in the midst of horrendous circumstances (c.f. Folkman et al, 1996, p.347). One of the participants of the present study, Maurice, expresses the meaning of caregiving and receiving care in such circumstances as realisation of the ‘highest spiritual plane’ (Interview Question 5, P1).

In an interesting study comparing cognitive-behavioural group therapy (CBT) with experiential group therapy (ET) for HIV+ gay men, we see again the emerging theme of existential awareness and meaning as different from simple coping strategies and ‘normalisation’ pressures (Mulder, 1994). The experiential method was chosen because it was based on existential theory and the researchers saw this as fitting some of the pressing needs and themes of the participants. The ET programme aimed to,

... enhance the individual’s ability to act and speak from a personal awareness of their inner experiential process, and to develop an authentic relationship with their life situation including both what is happening in the present, and how they choose to live their life in the future. The main function of the therapist was to help the men to become aware of incongruencies between emotional, cognitive, and behavioural schemata and to restore congruence (Mulder, 1994, p.425).

The ET therapy programme emphasised existential issues; illness, death, dying, purpose in life; rather than coping skills and stress management (CBT). These researchers also acknowledge individual differences in adaptation styles by saying that perhaps ‘... patients

---

⁴ I will use Klinger’s terms ‘engagement’ and ‘disengagement’ throughout the paper as they are consistent with the perspective I am presenting, and seem quite descriptive of the experience of the participants.
who tend to be more introspective, and who want to explore their feelings concerning their illness, could benefit more from experiential therapy’ (ibid,p.430). Focusing is an example of the experiential method.

Nichols (1986,pp. 209-39) describes a process that gay men go through in reacting to their AIDS diagnosis\(^5\). He identifies these three stages; initial crisis stage, transitional state (anger, fear, terror, depression begin), and acceptance or supported denial (manage illness by living as before or finding new priorities). Following are some of the stages and themes that have been described in other phenomenological studies:

1. McCain and Grambling’s study (1992) identified the structure of living with HIV as having three processes; living with dying, fighting the sickness, and being worn out.

2. Working from a cognitive adaptation approach, Shelley Taylor (1983) investigated the process of readjusting to a personally threatening event\(^6\). She found three important themes; a search for meaning in the experience, an attempt to regain mastery over the event and over life more generally, and an effort to enhance one’s self esteem (ibid,p.1161). She concludes that the individual’s adjustment depends upon their ability to form and maintain illusions (p.1161-3).

3. Weitz (1989) concluded that ‘the key to coping with the uncertainty of having AIDS is achieving a sense of control’ by seeking information, adapting behaviours, maintaining positive attitudes and living in the present (p.279-80). The other coping mechanism is avoidance and is based upon the value that knowledge is counterproductive if it doesn’t aid coping.

\(^5\)This is based upon the Elisabeth Kuebler-Ross stage model of reacting to terminal illness. The stages she describes are; denial, anger, bargaining, depression, and acceptance (1969).

\(^6\)This was a study of women with breast cancer.
4. Siegal and Krauss (1991) identified three adaptive challenges; dealing with a possibly curtailed lifespan, dealing with stigma, and developing strategies for maintaining health (p.17).

Steven Schwartzberg’s existential study (1993) focused on how a HIV+ diagnosis impacted upon the individual’s meaning and purpose in life. He presents a phenomenological analysis that identifies ten cognitive representations of HIV and AIDS and four typical patterns of integrating HIV into a framework of meaning. The representations were items such as ‘HIV as catalyst for personal growth’ and ‘HIV as punishment’ (p.484).

The participants were assigned to a framework according to their ability to ascribe meaning to HIV; a High Meaning Group (HM), Irrelevant Meaning (IM), Defensive Meaning (DM), and Shattered Meaning Group (SM) (Schwartzberg, 1993, p.483). Although he acknowledges ‘Each subject was recorded at a particular moment in a process that should be considered ongoing and developmental...’ (p.488), Schwartzberg still assigns four groups rather than four phases of adaptation. This emphasis on content rather than process leaves the impression of four different states. Schwartzberg couldn’t find a stage model signifying process because there was no correlation between the length of time living with HIV and the ability to find meaning (p.488). He assumes that time is the salient variable in a process of adaptation.

Michelle Davies’ research of HIV+ gay men has carried forward Schwartzberg's material, refining it, and adding important new themes (1995a,b,c). In one paper, Davies concentrates on how a HIV+ diagnosis can shatter assumptions about time (1995a). When we suffer a shock, like HIV, our routine future-orientation to time becomes explicit. We lose the implicit assumption of a future and the ontological security and sense of meaning.

---

7The representations that were evident in the protocols of the current study are listed as part of the data summary in Table 1.
this provides (Davies, 1995a, p.2). Being HIV+ can impose a veil of ‘angst’ wherein the person must ‘... learn how to live in the face of their impending demise without allowing the anxiety and uncertainty to overwhelm them to such an extent that all meaning and happiness is robbed from their current existence’ (Davies, 1995a, p.11). In response to this situation, Davies has identified HIV+ gay men as having three orientations to time; a philosophy of the present, living in the future, and an empty present.

In her second paper, Davies uses R.D. Laing’s theories to elucidate the experience of the one third of gay men whose HIV diagnosis shatters their sense of meaning (1995b). These individuals experience a sense of ‘unembodiment’ in which ‘The body is felt more as one object among other objects in the world rather than as the core of the individual’s own being’ (Laing, R.D., 1965, cf. Davies, 1995b, p.4). They are described by Schwartzberg’s SM group and seem to avoid non-being by avoiding being (Tillich, 1959, cf. Davies, 1995b, p.24). They are not concerned with death because they are not convinced of life (Lester, 1992, p.1178).

Davies’ third paper analyses more specifically the ontological assumptions that are revealed by a HIV+ diagnosis. The destruction of assumptions regarding the meaning of life and the individual’s relationship to the world and time is what constitutes the traumatic nature of HIV. The existential themes of the meaning and purpose of life, perceptions of time, and feelings of control, have been identified in the literature on traumatic events as critical to their impact on experience (cf. Davies, 1995c, p.3).
Chapter 3

Aims of the Present Study

The preceding chapter presents some of the recent psychiatric, psychological, and psychoanalytic HIV research. This research seems to circumvent description as the first step in understanding experience. Some of the main phenomenological studies are presented as an attempt to describe aspects of the experience of living with HIV. In addition, stage models of dealing with a terminal illness, specifically HIV, are outlined. The explicitly existential research was then presented. The present study remains within this broad existential perspective but aims to address the HIV experience without emphasising the implicit value of adaptation.

Although he wants to downplay implicit values, Schwartzberg says that the HM group is more ‘adaptable’ (p.489), and implies that this is more desirable. He also glosses over the importance of process and what might facilitate or hinder it.

... presenting these four categories as distinct and separate is of heuristic value but distorts the actual complexity and subtlety of human experience ... Nonetheless, these categories may provide a helpful template for understanding various styles and levels of success of individuals’ attempts to forge meaning out of the AIDS crisis (Schwartzberg,1993,p.489, italics added).

I do not want to detract from what is an important existential study, but I would like to offer two comments.

We do not really know what is occurring within the four Meaning groups. We are looking at the verbal content of participant’s responses and guessing at the underlying process of meaning ascription. Are the High Meaning individuals merely turning away from their predicament and embracing positive new illusions (the importance of which Taylor describes)? Is the Shattered Meaning group lacking some ability to adapt or are they...
sacrificing adaptation for existential honesty? Are they, in a way, existentially ‘successful’ at the expense of ‘failing’ to adapt?

By looking at the implicit *process* of living with HIV, the relevance of the Meaning Groups may become clearer. Touching upon this underlying process may also introduce more of the subtlety and richness of individual experience. The process of adaptation may itself be dependent upon individual differences rather than time. Focusing will be used as a method to bring more of the deeper dimension of process and implicit meanings into the participant’s responses. Focusing itself may turn out to be a valuable method for the participants who wish to gain insight into their own experience.

*Focusing*

Our experience is never fully captured by what we say. Words refer to the experiences they attempt to describe, ‘... words carry, not only their face value, but a larger load of implicit meaning’ (McGuire, 1984, p.iv). Focusing is a natural way of attending to these underlying meanings as they occur in bodily felt sensation. For over thirty years Eugene Gendlin and others have been researching the way the body forms such a ‘felt sense’ and the therapeutic usefulness of attending to such a feeling (see Gendlin, 1996, for lists of academic and clinical research articles on Focusing).

Focusing is a way to stay with physically felt meaning and thereby to access more than we can readily put into words. Usually we operate in a way that divides experience into discrete entities; thoughts, feelings, memories, desires, combined with expectations, cultural codes etc. But the body can form a ‘felt sense’ of its situations which is ‘... wider than ordinary experience ... It has many more implicit strands and edges’ (Gendlin, 1996, p.20). Focusing prioritises the *process* of experiencing rather than obsessing over the resulting *contents*. 
The Experiencing Scale (EXP) is the main instrument for indicating changes in the experiencing process. It describes seven stages\(^8\) of experiential events (cf., McGuire, 1984, p.117): In **stage one** the person is remote or distant from their feelings. **Stage two** shows a superficial personal perspective emerging. In **stage three** feelings are reluctantly expressed as though they are rooted in external circumstances. **Stage four** is where Focusing explicitly begins and the person can attend to an ‘inner referent’ rather than exclusively be concerned with externals. At **stage five** the person begins to explore the implicit meaning of a bodily sense, and feels more than can be captured in symbols. **Stage six** is characterised by a resolution of previously unclear feelings, and a shift in understanding may occur. **Stage seven** is an elaboration of stage six, self-experiencing is comprehensive, integrated and cohesive, yet flexible and open to change (Klein et al, 1969, cf. McGuire, 1983, p.117).

Focusing is incorporated in the current study for two reasons; first, to encourage the participants to reflect on their situation in a way which is deeper than the ordinary discourse of an interview. I hope that this will add some detail regarding what is really going on for the individuals in terms of the frameworks of meaning described by Schwartzberg. Secondly, if individuals in the SM Group are ‘unembodied’ it may be that a body centred style of reflection may be difficult but therapeutically useful for them. The EXP Scale will be an indication of the level of the individual’s experiencing during the Focusing and it may indicate a correlation between depth of engagement with experience and adaptation to living with HIV.

---

\(^8\)These stages have passed scientific criteria for reliability and validity (McGuire, 1983, p.116)
Chapter 4

Research Methodology

Preparation for the Research

The research for this study began in August 1996, when a form was sent out to twenty-five HIV agencies across Britain. A covering letter asked the agency workers to make the form available to HIV+ gay men when appropriate. The first part of the form was an ‘Open Letter to Gay Men With An HIV+ Diagnosis’. It introduced the researcher and explained that the research would be written up as an MA dissertation. It stated that the aim of the research was to explore the subjective experience of HIV+ gay men from their own point of view. The second page of the form asked for topic and design suggestions for a study they would like to see concerning their lives as HIV+ gay men.

I received only two letters back from HIV agencies. About a month later, I received the only completed form from a HIV+ gay man, not associated to either of the above agencies. This individual eventually participated in the study.

I designed the study and sent another twenty letters to HIV agencies in January 1997, describing the finalised version and requesting volunteer participants. Of the few responses received, Body Positive was the only agency to respond favourably. They agreed to put up a notice in their offices and to advertise for participants in their newsletter. Eventually seven men expressed interest in the study, of which six were interviewed9.

The initial letter was intended to elicit feedback from HIV+ gay men to inform the focus and style of the subsequent research. Unfortunately, the only form returned offered no specific suggestions so the final research was not directly influenced by the participant

9 One person responded after the deadline and unfortunately could not be interviewed due to time constraints.
group. The second letter and form described the specifics of the research for potential participants and was intended to reach as many HIV+ gay men as possible; those who attended day centres, read ‘positive papers’, or were attending HIV counselling. However, as only one agency would advertise the research, it is doubtful that the final group could be assumed to be representative. In fact, it may be that the most despondent or distressed men are less likely to use services, read HIV newsletters, and especially unlikely to respond to a request for research volunteers.

The final six participants were all from London and were interviewed in their homes between 26 March and 19 April 1997. In preparation for these sessions, I became familiar with recent literature on HIV treatments and issues.

Research Design

Each session was tape recorded and consisted of an informal interview, a session of Focusing, six brief post-Focusing questions, and a short de-brief in which the participant was given a follow-up form to fill in and post to the researcher (Appendix,p.169-72). Each participant was reminded that they were entitled to pass over any question or discontinue the session at any time simply by saying they wished to do so. They were assured that nothing they said or wrote would be associated with their name at any point but that it may appear as excerpts in the final dissertation. If an excerpt of their session were used, any identifying information would be disguised10. This has been done. One participant asked to have a copy of his session tape and this was sent to him.

Interview Questions. Rather than pursue an unstructured interview format it was decided to ask open questions and follow-up clarifications when necessary. This enabled the

10 The transcripts included in the Appendix have also had identifying information removed.
responses to be comparable to the previous research conducted by Davies (1995a,b,c) and by Schwartzberg (1993) by ensuring that specific themes would be addressed. However, it also meant that this could not be considered an unbiased phenomenological study of the structure of the experience of being a gay man living with HIV.

The interview questions combined variations of the questions from the Davies interview protocol as well as questions from some of the themes in the Schwartzberg interview. Questions chosen from the Davies study were those she found to be especially loaded with respect to existential themes. The questions exclusively from the Schwartzberg design were about being gay and coming out. Although the questions were simplified, or slightly re-worded to encourage reflection upon feelings, it is assumed that they remain comparable to the previous protocols and the responses thus form a valid supplement to those studies.

The interview aimed to address the basic existential dimensions of the experience of living with HIV. For example; there were questions about whether the person experienced a process of adaptation and what facilitated it, what areas of life were disrupted the most by HIV (for example, relationships with others, with oneself, and with one's own body), what are their worst fears of living with HIV and how are these dealt with, how time and the future is experienced, feelings about death and spiritual/religious beliefs, and feelings about being gay.

**Focusing.** Following the interview there was a short break and then the Focusing session. It was explained that Focusing is a method of intensive self-reflection that is often emotionally engaging and which can bring new insights or add some richness to understandings we already have. All but one participant agreed to do the Focusing session. Everyone who agreed to the Focusing experienced some degree of emotional involvement and everyone experienced a ‘felt sense’ which they were able to stay with. This suggests
that Focusing may even be useful for individuals in the SM group though they may be experiencing a degree of 'unembodiment'.

**Post-Focusing Discussion.** This consisted of six brief questions regarding the participant’s experience during their self-reflection. It was designed to assess the extent to which Focusing occurred, the participant’s ability to access ‘bodily-felt meaning’, whether reflecting on physical feelings is unusual for the participant, and whether any new understanding came as a result of the Focusing.

**Follow-up Questions.** These questions were left with each participant to fill out a couple of days after the session. The main purpose was ethical; to assess to what extent emotions stirred up as a result of the interview and Focusing session may be lingering for the participant, to offer a chance to evaluate how the research was carried out, and to provide a way to contact the researcher’s supervisor if necessary. Only two of the forms were returned and there was no indication that anyone experienced distress from taking part in the study.

**Participants**

Six gay men volunteered to participate by ringing a number advertised in the *Body Positive* Newsletter. The study was described in more depth over the telephone and all six men indicated continued interest. The only requirements were that the men identified as gay and were HIV positive. There were no further requirements regarding age, length of HIV infection, or symptomatic status. The men were aged 25 to 53 years. They were HIV+ for 7 months to 13 years. Two of the men were diagnosed with AIDS. It was decided not to control for age, length of infection, or symptoms, due to the small number of interested

---

11 Two of the participants were subsequently thought to fit into the SM group.
participants. In addition, since the study was meant to elicit a description of six individual’s experiences rather than a general structure of the experience of HIV+ gay men, a diverse sample was as important as a representative one.

**Data Analysis**

The tape-recorded interview and Focusing session were transcribed verbatim. The interviews were examined using a style of phenomenological analysis. The aims of the analysis were

1. to develop, through a sensitive reading of the protocols, some understanding of what it is like for these six individuals to be gay men living with HIV. This understanding will be influenced by the context of pre-set questions.

2. to offer some comment upon previous research methods, assumptions, and conclusions.

3. to explore the relevance of seeing these men’s experiences as examples of general modes of human being.

The analysis was separated into two distinct phases; descriptive and interpretative. It is worth noting that although the study is of only six individuals, the amount of data, possible themes of interest, and styles of analysis, are too extensive to cover in one paper. What is presented is not, therefore, exhaustive or comprehensive. It is merely one version of many possible interpretations of life as it is being lived. It does not claim to be the truth. It aspires to be one valid comment upon how we can understand both uniqueness and general aspects of experience.

*The descriptive phase* entailed: 1. Verbatim transcriptions of the interviews, which lasted from two hours to three and a half hours. 2. Returning to the transcriptions and picking out
major themes, leaving out repetitions and material which seemed peripheral. 3. Grouping these themes into a summary that described essential aspects of each individual’s experience.  

This phase is descriptive in that it brackets researcher inferences about the material. It is not a pure description of the protocol since picking out the themes and arranging them into a summary is guided by the researcher’s interests, which also guided the original interview questions. However, analysis of the themes and intuitions of the researcher are excluded at this stage. The wording of the themes is kept as close as possible to the participant’s own wording and the wording of the summary, although still close to the participant’s account, is written third-person to reflect the distance from the original protocol. Only the verbal information from the interview is given attention at this stage. Tone of voice, pauses, style of speech and repetition are not considered. The Focusing session, impressions of non-verbal cues, and researcher intuitions are incorporated in the interpretative stage.  

In a phenomenological study, the experience being studied is asked to speak for itself, without the imposition of the researcher’s preconceptions or theories. Thereby the researcher opens himself to the world of the individual, as it unfolds in the shared space of the interview. The interview incorporates for the researcher the tension of connection and remaining distant, in the role of researcher. This presents the drawback of not entering fully into the other’s experience and therefore the potential for misunderstanding and inaccurate inference. But it also enables the account to be raised to a more general level, the formation of an ‘intimate distance’ which allows for a public level discussion.  

---  

12 The material from the descriptive phase is included in the appendix.
The initial transcribing of the sessions allowed the opportunity to slowly relive the interview. It was also a chance to reflect upon the participant’s voice quality, the pace of talking and meaningful pauses, as well as recollections of the researcher’s experience during the session. These transcriptions were then re-read carefully until ‘meaningful themes’ could be delineated. According to Giorgi (1975), the researcher reads the protocol and marks whenever there is a shift in meaning. This results in the protocol being divided into ‘meaning units’. Since I was not seeking to arrive at a general structural description for all HIV+ gay men, I combined the delineation of meaning units with their grouping into themes. The final stage of the descriptive phase was to write a short summary of these themes for each individual.

The interpretative phase entails the articulation of psychological meaning by dialoguing with the material. It is the task of explicating what lays implicit in the text. This also involves leaving out idiosyncratic or redundant information. This is the attempt to uncover what is essential to the experience as well as the meaning of the experience for the participant. It involves taking into account the affective qualities of the interview, the impressions of the researcher, the Focusing experience as well as the participant’s report of their Focusing as evident in the Post-Focusing Discussion.

This phase of the analysis also involves the danger of imposing on the material the researcher’s own prejudices, theories, and interests. It is a delicate balance to bring meanings out of the text rather than transplant preconceptions onto the text. The intention is to remain as true to the original sense of the participant’s experience as possible, and to pull out some of what lies implicit within. Ideally, these interpretations would have been validated by each participant.
While interpreting the protocols, I was guided by the procedure of Heuristic Research described by Moustakas (1990). Heuristic research emphasises that the self of the researcher is present throughout the process;

I begin the heuristic investigation with my own self-awareness and explicate that awareness with reference to a question or problem until an essential insight is achieved, one that will throw a beginning light onto a critical human experience (p. 11).

The heuristic researcher seeks to understand the wholeness and unique patterns of experiences in a way that is scientifically organised and disciplined (Moustakas, 1990,9-16). Unlike the detachment of purely phenomenological studies, the heuristic researcher undergoes a vital identification with the experience. He values the tacit domain that underlies intuition. There is a link between ‘... the implicit knowledge inherent in the tacit and the explicit knowledge which is observable and describable’ (ibid,p.23). Moustakas describes the phases of heuristic research (pp.24-32), including the importance of Focusing in facilitating a receptive state for achieving clarifications. He then contrasts heuristic and phenomenological inquiry, ending with

... Whereas phenomenology loses the persons in the process of descriptive analysis, in heuristics the research participants remain visible in the examination of the data and continue to be portrayed as whole persons. Phenomenology ends with the essence of experience; heuristics retains the essence of the person in the experience (p.43).

In the section that follows, each participant’s summary is given a heuristic analysis and then compared to Schwartzberg’s phenomenological categories of ‘frameworks of meaning’ and Davies’ ‘existential themes’. The question of process is presented in the context of Focusing and EXP Scale ratings. The theme of universalising the HIV experience is included in the later discussion of Heidegger’s ontology.
Chapter 5

Interpretations

The summary description for each participant is presented in the Appendix\textsuperscript{13} and serves as the template for the following interpretations. The interpretations remain closely based upon the material from the descriptions. Each individual is also discussed in terms of the meaning categories and existential themes of previous research and any issues this raises.

“Arthur”

Arthur’s positive diagnosis brought devastation to a life that was already difficult. The strongest themes to come out of his session were an overwhelming sense of loss and the lack of support for coping with these losses. It is therefore not surprising that Arthur may have difficulty in seeing his diagnosis as meaningful or positive in any respect.

Arthur’s casual lover of 5 years left him when he insisted that they begin using condoms. This rejection was repeated by his brother and then his family. Arthur also found that for the most part he could not count on his friends for support. This left him isolated from intimate relationships, compounding his sense of loss. At this point turning to an HIV support group saved him.

The years have softened Arthur’s original devastation a little. However, he still has trouble coping with any reminders of his life pre-HIV. Although he has remained quite healthy, seeing other men disabled by HIV has made Arthur afraid of what debilitating effects the virus may have on him. He says alcohol and his faith in God help him cope with these fears and during the break between the interview and the Focusing Arthur decided to have a drink. This reinforces the impression that coping can sometimes be an alternative to adapting.
Arthur has not worked since his diagnosis and because of his age, he has been told he will not work again. This has drastically altered what he can expect from his life. He is left without plans, living in a present that seems void of positive agency, moving towards a pre-determined future.

Arthur says he is happy being gay (Interview Question 7, P2) yet he seems to yearn for a heterosexual family life which he will never have. He remained in the closet for years and still waits for others to figure out that he is gay. This suggests that he does not view his sexuality and lifestyle as positively as a heterosexual lifestyle.

The theme of loss was reinforced by his Focusing session. His two main physical sensations were of heaviness, in his legs and in his stomach, and a sense of control from his head. Arthur begins by keeping distant from his feelings, by saying what he already knows about his situation. Then he finds a meaningful heaviness in his stomach, with which he does not feel safe. Being with his feelings is equated with not being in control. The heaviness in his stomach is connected to not knowing his ex-lover was dying and not being there to say goodbye. Arthur begins by telling himself he has to accept why he was not told about his ex-lover’s death, but a shift occurs when he just acknowledges the need to know the truth (Focusing P32-3). This brings a change in Arthur’s understanding of the situation but more importantly it momentarily brings a shift in the way he approaches his feelings. He moves from a controlling, ‘telling’ attitude to one of listening and acknowledging.

According to Schwartberg’s ‘Patterns for Ascribing Meaning to HIV’, Arthur would fall most readily into the Shattered Meaning group. He would also most easily fit into Davies’ existential themes of ‘the empty present’, ‘no control’ and ‘overwhelmed’. This supports

---

13 The ‘meaningful themes’ for each participant are also included in the appendix.
Davies’ association of these themes with the SM group. However, these categorisations may obscure the individual aspect of Arthur’s account of living with HIV. Namely, his sense of loss, lack of support, and distance from feelings that threaten to overwhelm him. It leaves one with the impression that in a sense the process of adaptation for Arthur froze at a beginning stage. Given a little support he may have developed a relationship with his feelings of loss that could have facilitated a different process of adaptation to life with HIV.

“Michael”

Michael says he is not bothered by being HIV. He seems to take it in his stride and to cope with life quite easily. Although he initially thought he only had a year to live, he wasn’t too bothered. However, he may achieve this ease by keeping distant from deeper, more difficult feelings. He was worried the first time he thought he was positive and he was shocked when the doctor said his conversion sickness indicated he might not do well. There seems to be a contradiction between his reported feelings about HIV and his reactions to situations where he is confronted by what it may really mean.

Michael has bad days when the reality of his diagnosis sinks in. He does nothing to engage with this difficulty; instead, he just waits for it to pass, which it does. The intervals between these days increase the longer he lives with HIV. So Michael’s coping mechanism seems to be to keep some psychic distance from distressing feelings. He says this himself, ‘I’m told I’m into denial (laughs). I mean my argument is that if I wake up in the morning smiling and can function, who cares about a bit of denial (laughs)’ (Interview Question 1, P5).

However, denial doesn’t seem to be the correct term. Michael has incorporated HIV into his life enough that it forms the background against which all other concerns lessen in importance. He has adapted enough that the possibility of a cure leaves him feeling ambivalent. He watches his weight because he thinks of it as a symptom of his illness.
And although Michael is more consciously aware of time, he has not altered his relationship to time significantly. This relationship to time may be a good indicator of Michael’s overall strategy: to be aware of the situation at some level without allowing it to have a negative impact on his life. The fact that he sees having HIV as ‘joining the club’ may indicate that he chooses to emphasise the positive or perhaps mundane aspect of living with the virus.

Michael’s interview was striking in his use of ‘non-immediate language’. He often reverted to ‘you’ rather then ‘me’ when talking about HIV. For example, ‘If other people are ill, I suppose if you see them unwell and that sort of probably sort of, you reflect on that’s probably going to happen to you’ (Interview Question 3, P3). Non-Immediate language has been correlated with psychic distancing of the subject from the communication (cf. Kuiken et al, 1986-7). He rationalises about death rather than connecting with his own feelings on the matter. At the same time, Michael’s strategy allows him to cope well, to accept responsibility for his life, and feel in control of what happens to him.

Michael’s Focusing session was characterised by minimal affective involvement. He accessed a felt sense quite easily and was able to connect it to an issue regarding a relationship he finds stifling. It seems that a part of Michael is trying to break out of the safety of his present routine, to fulfil more of his potential, and find adventure. It may be that something in Michael’s distance from the darker side of HIV has also kept him trapped in a way of life that is not completely satisfying.

According to Schwartzberg’s Frameworks of Meaning, Michael would likely fit best into the Irrelevant Meaning group where HIV has not had a major impact on his understanding of the world. He reflects quite obviously Davies’ existential themes ‘Positive action and attitude’ and ‘Minimisation of meaning’ of the threat of death. Both of these themes are highly correlated with the IM group. However, on the theme of time, Michael does not
clearly fall into a philosophy of the present, nor is he future oriented and he specifically points out the self-destructive nature of living in the ‘empty present’. The first two themes are associated with the IM group.

The categories according to Schwartzberg and their associated themes from Davies’ research seem to miss an essential aspect of the individual’s experience; the process of Michael’s meaning ascription and some of the strategy behind this choice. If we see Irrelevant Meaning as an adaptive coping style, which maintains a distance from the traumatising effects of living with HIV, then we are placing a high value on ‘health’, as Michael does. Taylor (1983) has emphasised that recovering normal functioning after the trauma of cancer can rely upon illusion. Michael seems rather to employ a kind of self-deception, facilitated by psychic distancing. This allows him to remain disengaged from a deeper reality, which is still felt occasionally without impinging upon life generally.

“Glen”

During the interview Glen re-told, in detail, his story of being HIV. He didn’t want to know his status and was right that the knowledge would shatter his lifestyle. It resulted in the loss of his health, home, relationship and career. Without any support for his own losses, he embarked upon supporting others. It is not surprising that he is angry and resentful about what he has endured alone. Now that he is the last survivor, he wonders who he can count on to stick with him to the end.

There is a major theme of protecting others no matter what he himself is living through. There is resentment about feeling he has to do this. Glen seems to feel that he will be deserted when he needs support the most, and indeed, there is reason for him to assume this. His experience has left him suspicious of people, and he guards against intimacy to protect himself from being hurt. He seems disappointed by his family, friends, and life
generally. At the same time, Glen says that AIDS is one of the best things that ever happened to him.

AIDS/HIV has matured Glen. He was wrenched from a fantasy life to the real world, the reality of death, and of caring. It has altered the way he relates to himself and his values in life. He was initially devastated about having to give up his successful career, now careers seem unimportant and it’s the simple pleasures in life that he relishes. He never wants to return to the rat race. Outside the trap of working life, weekdays and weekends are equally valued. Time is an artificial marker. He regrets he had to get HIV to learn these things.

There is a complex mix of positive realisation about life and unresolved feelings about having to arrive at this stage, through devastating losses, completely alone. He is angry about being alone while unable to open to anyone, to be vulnerable in his pain and illness for fear of desertion. He copes by maintaining his dignity, which in its style may further perpetuate his experience of isolation.

Glen believes there is an afterlife and is comforted by the feeling that his mother and others who have died are there waiting for him. During the Focusing Glen cried for himself. It was rare for him to allow time to be with his own feelings. He fears that his feelings could send him over the edge yet he was able to engage deeply and safely during the Focusing. He felt his aloneness and emptiness and found a vivid image to represent this;

'It was the first time I sort of ever felt that feeling, that it was that that empty space was like a large empty room ... Strangely enough that feeling was like I was in that room and the only sound in the room was me stirring a spoon in a cup, echoing in this huge room' (Post-Focusing Discussion, Question 3, P2).

Glen is so afraid his real feelings will drive people away that he usually just jokes and keeps his feelings at bay. It was strange for him to engage at this depth with anyone and he felt
like something was finally becoming real for him. It’s as though Glen’s life has been usurped by AIDS. The loss and emptiness of this is overwhelming. After the Focusing Glen spoke more slowly and his tone had softened considerably. He spoke more of his inner life and less about what had happened around him. He feels the cruelty of anyone having to die on their own and the impression was of anger being transmuted to sadness as he imagined he might die alone.

According to Schwartzberg’s ‘General Frameworks of Meaning’, Glen would fall most clearly into the ‘Shattered Meaning Group’. However, Glen presents a very different quality of experience than Arthur. This is revealed most clearly by comparing the two Focusing sessions. From the interviews alone we might feel confident that Glen and Arthur share a SM response to their diagnosis. However, during the Focusing, Glen was deeply engaged in his experience whereas Arthur was not. This Focusing detail suggests that Glen’s adaptation requires a somewhat different interpretation than Arthur’s.

Glen has valued some of the insights he has gained as a result of the changes he’s had to make in his lifestyle. But his responses would not be characterised as High Meaning. He feels ready to die and there is a grief which seems to ask ‘What was this all for?’ It leaves the impression that perhaps Glen is unable to ascribe meaning to the amount of trauma he’s witnessed in life. The impression is not of denial, quite the opposite. Glen seems to have faced the realities of his situation realistically and keeps what feels to him to be a necessary distance from some of its deeper meanings. Glen’s session suggests that some SM responses indicate features of ‘existential honesty’ rather than failed adaptation. Yet, the situation is obviously more complex than this; for example, Glen’s unresolved anger might have as much effect upon adaptation style as his honesty.

Glen’s session expresses themes of ‘HIV as irreparable loss’ and ‘HIV as isolation’ (he clearly does not indicate HIV as relief, catalyst for spiritual growth, or HIV as strategy).
According to Davies’ ‘Existential Themes’, Glen again presents a complex picture. He describes a philosophy of the present, which is a re-orientation away from the everyday to something more meaningful for him. But this present is not characterised by deep engagement or meaning. On the theme of meaning, he described himself as “overwhelmed” after the Focusing and as living in fear of being affectively overwhelmed generally. His style of control fits most closely with ‘positive action and attitude’ but the word responsibility might be more appropriate. In sum, it is tempting to say that Glen’s ‘shattered meaning’ is both an honest response to the impact of HIV in his life and an indication of the difficulties he continues to have with this situation.

“Noah”

Noah was the youngest participant and had only been diagnosed HIV+ for seven months. His attitude was in striking contrast to the responses of the other participants. He attributes this to his knowledge of HIV and thus his lack of fear, and his general positive attitude. He does not see HIV as life threatening and was relieved by his diagnosis. It seems likely that recent developments in treatment (he is on combination therapy) have a marked effect on the meaning attached to receiving a positive diagnosis. Research has suggested that a HIV+ diagnosis at an early age can be most devastating (Davies,1995c) but Noah does not exemplify this. It raises an interesting question regarding whether the recent availability of combination therapy suddenly makes previous research regarding adaptation somewhat obsolete.

Another consequence of Noah’s age is that he grew up in a society that had a markedly different attitude to gay sexuality. He’s never experienced being in the closet, and says he doesn’t have unresolved issues regarding sexuality. This differs from the older men who,
although they are positive about their sexuality, have lived through a process of coming out to various degrees of hostility and rejection\textsuperscript{14}.

Noah gets annoyed when others, who were diagnosed in a completely different treatment climate, do not share his optimism. He experiences their negativity and ignorance toward their diagnosis as a bad influence on him. This seems to indicate that his positive outlook may be vulnerable in the presence of disconfirming attitudes. Noah sees HIV as a challenge. He takes a very active role in his treatment and accepts a high degree of control over his life. Since being diagnosed, he has begun longer-term planning, and he feels more settled in his life.

HIV has made Noah a bit more self-accepting but otherwise it has had so little impact that he talks as if he is not infected. His attitude toward death and religion is secular and quite matter-of-fact. During the Focusing Noah remained quite intellectual. He accessed a familiar issue of reluctantly finding himself in the role of educator and supporter and consequently not receiving support for his own needs. This generates some anger and is draining for him. It presented itself as a trapped irritated feeling in his throat; a feeling that is not allowed expression.

Noah pretends not to need others, which frustrates his desire to receive support. He can easily switch off his own feelings and does not like to be emotionally overwhelmed. During the interview he laughed easily and during the Focusing he maintained an attitude of affective distance. He describes himself as a private person and has a strategy of withdrawing from people when he needs to attend to himself emotionally.

\textsuperscript{14} It would be interesting to investigate the relationship between reaction to a HIV+ diagnosis, homophobic experiences in coming out, and attitudes to being gay.
Noah’s attitude seems confident and positive and he may maintain this helpful coping by keeping distant from his inner emotional life. He says that being emotionally weak is a goal of his. Presumably, this is partly to evoke the strength in others that would allow him to receive the support he desires but cannot admit to needing. The mood of the interview and the Focusing were reminiscent of Michael, and the IM group seems appropriate for Noah. Likewise, he is ‘future oriented’, and has an orientation of ‘positive action and attitude’ and a ‘minimal meaning’ response to his infection. The unique experience for Noah is to be diagnosed in a time when HIV does not automatically bring the assumption of hastened death. He has not had to re-adjust from this assumption to the realities of the new therapies.

"Maurice"

Maurice, like Glen, recounted many incidents during his interview. This conversational style may be related to his expressed fear of getting close to his feelings. Like drugs, this type of story telling may be a distraction from a deeper emotional process. The most striking theme in his interview is Maurice’s relationship to his feelings. When he first found out his diagnosis, he coped with the news by repeatedly getting stoned. He later realised that he was living as though he was about to die. There was a big shift in his lifestyle when Maurice realised this.

Maurice describes his ability to deal with other people who are in emotional crises. He does this by switching off his own feelings. While he values his ability to support others in crisis, he acknowledges that he does not get support in return when he needs it. He states that the highest spiritual plane for humans is reached through unconditional giving and receiving of love in a caring situation, like when someone is dying (Interview Question 5,P1).
Although Maurice believes he is now making positive lifestyle changes (which he is grateful to HIV for catalysing) and improving his relationship with himself, he still has trouble staying with ‘darker feelings’. Sex and drugs are two ways that Maurice still distracts himself when he’s distressed, for example when he’s reminded of his illness by someone else being ill. Health is an important factor in how HIV impacts upon Maurice’s consciousness.

Pre-diagnosis concerns don’t seem important to Maurice now. Now he worries about dying in a horrible way, and not fulfilling his potential or finding his purpose in life. Thinking about the future is difficult for Maurice because it involves planning for something that his condition may circumvent. This seems to have a negative impact on his ability to find and commit to a life project. It’s as if anything based upon the future highlights the possibility that his future may be foreshortened. He says, ‘... I need to find something to do. And my fear is that when I do find that, I do invest myself, that I’ll get sick and I’ll die’ (Interview Question 1-2, P5). The possibility of death intervening in his project provides the rationale for not seeking one. This seems to leave Maurice in an unsatisfying ‘empty present’.

Maurice indicates that this self-sabotage may be traced back to his father leaving the family, and Maurice ‘going on strike’ at that point. This may be an example of HIV being a ‘magnifying glass’ on issues that are already set in the individual’s biography (Interview Question 1-2, P7). Whatever the full underlying reasons, it does seem clear that Maurice does not find his short-term, immediate gratification strategy able to satisfy his larger need for creative fulfilment. He accepts a remarkably large degree of responsibility for his life situations, which may explain some of the guilt he feels regarding his lack of vocational success.

Maurice was the only participant to decide not to do the Focusing. He explained that getting close to his feelings was too scary. He needs to feel very safe and secure with the
person he’s with before he can trust them with his feelings. Not knowing me, he wasn’t sure I would be there for him. This seems linked to Maurice repeatedly being let down by his mother who did not allow him to cry and who could not support her son’s feelings.

Rather than Focusing, we just discussed what this style of self-reflection would feel like for him. It would be foreign for Maurice to stay with his physically felt feelings. His attitude to his body seemed to signify that it is a pleasurable sexual object, but not subjectively experienced, from the inside. He describes himself as cerebral and tends to think through feelings. He identifies emotions by observing his behaviour. This indicates a classical ‘external locus of control’ style.

Maurice doesn’t fit easily into any of Schwartzberg’s ‘Frameworks of Meaning’. Perhaps ‘Defensive Meaning’ is the closest fit as Maurice used personal growth language and spoke of positive changes, yet most striking was his sense of stuckness and fear regarding feelings, illness, and commitment to a project. The HM and IM groups do not fit and there is not enough indication of his underlying feelings to say Maurice has experienced Shattered Meaning. This raises the interesting point that assignment to meaning groups reflects partly the degree to which a participant is self-disclosing and ‘affectively lucid’, rather than just their ability to adapt. The Focusing session would have added interesting information about how Maurice felt at a deeper level, and may have indicated more clearly what the deeper impact of HIV has been on him.

Maurice superficially describes themes which indicate ‘HIV as a catalyst for personal growth’ and implicitly ‘HIV as irreparable loss’ and ‘HIV as strategy’ (disclosing his status can draw people closer and provide a rationale for not finding a life project). Davies’ existential theme of ‘empty present’ is the only theme that clearly is indicated in Maurice’s session.
On the theme of ‘control’, he seems to describe a belief in responsibility based upon awareness or ‘power of the mind’ at least superficially. When he is healthy, the impact of HIV is minimal but when he or his ex-boyfriend is ill, Maurice is overwhelmed. This may imply that Maurice is implicitly overwhelmed by his diagnosis and he cannot under certain situations successfully distract or distance himself from this. This interview highlights the guesswork that always occurs when researchers infer the meaning of protocols and especially when there is no deeper touchstone, like Focusing, to assess interpretations.

"Sebastian"

Sebastian has responded to his HIV status in a way that clearly reflects a High Meaning adaptation. Along with Glen, Sebastian is the only other man to also have an AIDS diagnosis. This may partly explain the deeper quality present in their interview responses and Focusing sessions compared with the other four participants. Perhaps AIDS ‘concentrates the mind’ in a way that a HIV+ diagnosis in itself may not. This may be because the presumed terminal nature of HIV is increasingly uncertain.

Sebastian has an ‘inner resource’, which quickly switches him from bad news to practical response. This seemed to minimise the initial traumatising effects of his realisation that HIV was life threatening. However, this turn to the practical is not a distraction from the reality of his situation but a response to it. He made early decisions about being open about his status although he feared rejection from others. This openness, while being courageous in the social climate of thirteen years ago, may also have been the healthiest response. Sebastian’s attitude to his HIV and being gay is the most consistently ‘out’ of the six men interviewed (although Noah has never been in the closet, he is not as clearly a ‘queer with attitude’ as Sebastian describes himself). How this attitude might relate to the response to a positive diagnosis is again an interesting question.
A strong recurring theme in Sebastian’s comments is the universalising of his situation from HIV+ people to all humans. He clearly feels that HIV presents all the basic human existential issues we all face in a focused and immediate way. It does not present anything unique to itself. He concludes, ‘... AIDS isn’t about AIDS ... AIDS is about everything. It’s not just AIDS, it’s about living ... that’s the whole thing about making it meaningful’ (Interview Question 3, P 3,4,5). AIDS, in this sense, is no more a disaster than life itself. Some researchers have contended that this universalising indicates a denial by the individual of their specific situation (for example Schwartzberg, 1993). However, there is little evidence for this interpretation in Sebastian’s case. In fact, such a suggestion by researchers could also be interpreted as the researcher’s defence against identifying with the participant’s situation as being common to their own.

An important theme in Sebastian’s experience of personal growth is that we can choose our response to any life event, and to life itself. Choosing an open response which values truth can lead not so much to a search for meaning but to questioning whether there is in fact meaning, i.e. a search for truth. Sebastian exemplifies this approach and describes facing his terror of death, losing all his beliefs, being prepared for death and then not dying. He has now come to trust a process of life as it unfolds naturally. His experience has brought him to an understanding which echoes both existentialism and Eastern philosophy (both of which he refers to).

The two areas of Sebastian’s life which he feels are most affected by HIV are work and relationships. Having accepted death, his worst fear now is rejection. He has ‘handed over’ concerns about an after-life and death. This leaves life as his legitimate jurisdiction and life is about relationship. Having given up work his life has acquired a new sense of

---

15 Recent research suggests that Heidegger’s ontology is actually based upon his reading of Taoist texts (May, 1996).
freedom from the demands of others. It is tempting to ask to what degree this free time to reflect upon life and the absence of work-related obligations has affected the depth of his insights. There are other important themes in Sebastian’s interview, his view of sexuality, spirituality, and coming out, for example.

The Focusing session confirmed Sebastian’s commitment to engagement with his unique psychological process. He was already acquainted with Focusing and was able to contact a felt sense, which he followed until a deep shift seemed to resolve the issue in some way. The shift occurred when he allowed himself to turn to the blocked feeling in his throat and acknowledge it’s positive aspect (Focusing, P31). Michelle Davies (1995c) speculates that the individuals who exhibit a HM adaptation seem to be more focused upon their own life process and less concerned with others. Sebastian’s Focusing session was the only one of the five that seemed related to an inner blockage to expression rather than a concern regarding interpersonal relationships. Of course, expression is also about relationship, but in a different way.

According to Schwartzberg’s ‘Frameworks of Meaning’ Sebastian is in the HM group. He exhibits the representation of ‘HIV as catalyst for personal growth’ and for spiritual change. Other themes seemed implicitly evident almost as traces of phases he’s already passed through in his process of adaptation. Davies’ existential themes are less easily assigned. Sebastian readily describes a ‘philosophy of the present’ coupled with a sense of on-going projects and the plasticity of time. While he exhibits a sense of being responsible for his choices, there is a deeper spiritual sense of honouring a connection with the world,

16 It is interesting to compare Noah’s approach to the block to expression in his throat with Sebastian’s approach. It reinforces the impression of a relationship between meaning group and Focusing styles.
which makes the question of ‘control’ complex. Sebastian values giving up attempts to control and trusts a natural loving force instead.
<table>
<thead>
<tr>
<th>Dimension</th>
<th>Study</th>
<th>Arthur</th>
<th>Michael</th>
<th>Glen</th>
<th>Noah</th>
<th>Maurice</th>
<th>Sebastian</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaning Group</td>
<td>(Schwartzberg)</td>
<td>Shattered Meaning</td>
<td>Irrelevant Meaning</td>
<td>Shattered Meaning</td>
<td>Irrelevant Meaning</td>
<td>Defensive Meaning</td>
<td>High Meaning</td>
</tr>
<tr>
<td>Evidence of HIV as ...</td>
<td>(Schwartzberg)</td>
<td>Irreparable loss, Isolation</td>
<td>Belonging</td>
<td>Irreparable loss, Isolation</td>
<td>Relief</td>
<td>Unclear/ambivalent</td>
<td>Personal growth, Spiritual growth</td>
</tr>
<tr>
<td>Time</td>
<td>(Davies)</td>
<td>Empty Present</td>
<td>(Unclear)</td>
<td>Philosophy of Present</td>
<td>Future</td>
<td>Empty Present</td>
<td>Philosophy of Present</td>
</tr>
<tr>
<td>Control</td>
<td>(Davies)</td>
<td>No Control</td>
<td>Positive Attitude and Action</td>
<td>Positive Attitude and Action</td>
<td>Positive Attitude and Action</td>
<td>Power of the Mind</td>
<td>(Unclear)</td>
</tr>
<tr>
<td>Meaning</td>
<td>(Davies)</td>
<td>Overwhelmed</td>
<td>Minimized</td>
<td>Overwhelmed</td>
<td>Minimized</td>
<td>(Unclear)</td>
<td>Spiritual</td>
</tr>
<tr>
<td>Attitudes to:</td>
<td>(Present Study)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Body</td>
<td>Temporary Alienation</td>
<td>More Conscious</td>
<td>Very Conscious</td>
<td>No Change</td>
<td>As Sexual Object</td>
<td>Inner Attraction</td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>Avoided Sex</td>
<td>No Change</td>
<td>Loss of Trust</td>
<td>No Change</td>
<td>Disclosure of Status</td>
<td>Fear of Rejection</td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>No Difference</td>
<td>More Conscious</td>
<td>More Present</td>
<td>Concrete Future Plans</td>
<td>Urgent and Drags</td>
<td>Plasticity, and Urgency</td>
<td></td>
</tr>
<tr>
<td>Death</td>
<td>Little Effect</td>
<td>No Change</td>
<td>Less Fear</td>
<td>Matter-of-fact</td>
<td>Life is Precious, Fear</td>
<td>Confronting, Fear</td>
<td></td>
</tr>
<tr>
<td>Spirituality</td>
<td>Christian</td>
<td>None</td>
<td>Non-Doctrinal Catholic</td>
<td>Nothing Concrete</td>
<td>Psychic Experience</td>
<td>Experience of a Life-force</td>
<td></td>
</tr>
<tr>
<td>Care About Others</td>
<td>Family and Ex-Lover</td>
<td>Obligated to Friends</td>
<td>Feels lack of care in return</td>
<td>Educating Others</td>
<td>Yes, and feels lack in return</td>
<td>Deep Connectedness</td>
<td></td>
</tr>
<tr>
<td>Gayness</td>
<td>Ambivalent</td>
<td>Matter-of-fact</td>
<td>Glad but difficult</td>
<td>Never in Closet</td>
<td>Celebrates it</td>
<td>About Malesness</td>
<td></td>
</tr>
<tr>
<td>Work</td>
<td>Not Employed Pre-HIV</td>
<td>Quit but re-considering</td>
<td>Career Not significant now</td>
<td>No Mention</td>
<td>Issue of Committing to projects</td>
<td>Freedom from Work</td>
<td></td>
</tr>
<tr>
<td>Control</td>
<td>Pre-determined</td>
<td>Yes</td>
<td>Short-term</td>
<td>Yes</td>
<td>Yes, Responsibility</td>
<td>Partial, and Letting-go</td>
<td></td>
</tr>
<tr>
<td>Adaptation Process?</td>
<td>(Present Study)</td>
<td>Yes</td>
<td>No. But fewer bad days</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Focusing</td>
<td>(Present Study)</td>
<td>EXP 2/3 Loss</td>
<td>EXP 3/4 Trapped</td>
<td>EXP 5/6 Loss, Alone</td>
<td>EXP 2/3 Emptied out by others</td>
<td>Declined to Focus</td>
<td>EXP 5/6 Shift in Blockage</td>
</tr>
</tbody>
</table>

**TABLE 1.** A summary of possible categorisations of the six participants on themes from Schwartzberg (1993), Davies (1995), and from the current study.
Chapter 5

Discussion of Existential Themes

Numerous variables and themes are suggested in these men’s accounts. Some may be fruitful avenues for further research. For example, the impact of the initial trauma on subsequent meaning ascription (and how this impact is related to treatment options available at the time of diagnosis). Other variables include the effect of the men’s attitude to their gayness, the age of the participant, the amount of support available to him, and his health history. The individual’s personality; his ‘locus of control’, how he relates to his own feelings, and his position on introvert/extravert scales may indicate how he grapples with the task of finding meaning in the foreign territory of a HIV+ life. These motifs are briefly picked up and then dropped in order to return to the main point of the paper.

Consistent with phenomenological studies it is important to remember that each participant’s experience remains essentially individual. Emphasizing certain variables, existential themes, and frameworks of meaning can obscure the essential unity of the lived experience. Individuals who fall within the same framework, for example Arthur and Glen, may reflect that framework in significantly different ways. However, the existential themes from Davies’ research, by being more specific than general frameworks, seem to elucidate the present protocols more fully. Following is an application of the themes of time, ontological insecurity, and the meaning of life and death, to these participants.

Time. Having a ‘future-orientation’ to time provides security in the belief that things are related meaningfully and therefore people act ‘more reasonably’ (Davies, 1995a, p.2). This implicit assumption of a future becomes explicit through a shock, like being diagnosed HIV+. Noah is the only participant whose diagnosis reinforced an urge to plan for his future. This seems related to the fact that HIV did
Greg Madison, PhD unpublished MA dissertation, 1997, University of Sheffield

not shatter his assumptions at all. For him it was not a shock but a relief and an
opportunity to realise his desire for a more settled lifestyle.

I think its made [my plans] more concrete … I think I’ve settled down … like with
the flat I’m in, I’ve been there nearly eight months now which is the longest I’ve
spent in a flat on my own, oh my god, I’ll be raising children next (Noah, Interview,
Question 4,P1).

As advances in treatment change the nature of a positive diagnosis, it may be that
this ‘future-orientation’ response will become more common.

A positive diagnosis shatters some individual’s assumptions about their future. For
them, ‘ … the experience of the present is likely to become an end in itself, rather
than simply a means to an end (one’s future life), the reality of which has become
increasingly uncertain’ (Davies,1995a,p.3). Maurice is aware that his ‘normal life’ has
ended but he has been unable to mobilise an alternative life. Instead, he distracts
himself with drugs and sex. Arthur also seems to inhabit this in-between, where the
assumptions of the past are no longer convincing; yet this has not resulted in new
engagement in the present. Both seem to dwell in an ‘empty- present’, nothing is
really committed to lest it fall through, yet the attempt to maintain the status quo or
to revive what ‘could have been’ is fruitless (Davies,1995a,p.15).

I think HIV gives you the opportunity to deal with issues which you need to deal
with … I need to find something to do. And my fear is that when I do find that, I do
invest myself, that I’ll get sick and I’ll die … Having said that it’s also a convenient
cycle by which I don’t have to change (Maurice,Interview Question 2,P5).

Alternatively, HIV can ‘lend an opportunity for some individuals to achieve spiritual
growth and an appreciation of new values and meanings’ (Davies,1995a,p.12).

Those who exhibit this ‘high meaning’ response to their infection experience a
‘liberation from the shackles of everyday existence in which one is always fighting
towards a future’ (ibid.p.12). This experience of the present is reinvigorated rather
than empty. It is described by Glen to some extent (Interview Question 4,P1) but
most clearly by Sebastian,
... I like to get up about four in the morning often because I’m so excited, I’m like a kid. I’m so excited, like what’s happening today? … the days seem very complete in themselves … I just live for today and I’m not going to worry too much about the future … you know I’ve all these plans and they’ll happen if and when they happen. (Interview Question 4, P3).

**Ontological Insecurity.** In an attempt to understand the experience of the Shattered Meaning group, Davies cites RD Laing’s *The Divided Self* in which the phenomenon of ontological insecurity is characterised as ‘The body is felt more as one object among other objects in the world rather than as the core of the individual’s own being’ (Laing, 1965, c.f. Davies, 1995b, p.4). The individual identifies the controlling intellect as the ‘true self’ and the observed body as the ‘false self’. Both Arthur and Maurice could be identified as exhibiting this sense of ‘unembodiment’. In Arthur’s Focusing session, he describes his head as wanting to control the feelings in his stomach (Focusing, P15-20). Maurice uses his body as a sexual object and is too frightened of his feelings to reflect upon them. However, the social context of being gay may also be relevant. In ‘Towards a Model of Gay Affirmative Therapy’, Dominic Davis (1995) writes, ‘… many lesbians and gay men have grown up afraid of their bodies. Society has given them powerful messages about their bodily impulses being perverted, sick, dangerous, and specifically a message that their feelings will be out of control’ (p.32).

**Life and Death.** This is the third theme Davies has explored (1995c, p.3-11). She found that many HIV+ gay men minimised the threat of HIV either by ‘universalising’, ‘relativising’ or ‘making a joke’ out of it (1995c, p.11). In the present study, Maurice, Michael, and Noah all relativised their diagnosis. Noah and Michael viewed their diagnosis as quite irrelevant to their lives. Maurice relativised his HIV by emphasising other aspects of his life and changes in his lifestyle rather than the impact of the virus. Glen used humour to cope with the realities of his situation. Sebastian ‘universalised’ his situation. ‘Universalising the threat of death involved highlighting the essential comparability of the HIV infected person’s existential
condition with that of the human condition more generally’ (p.11). However, Glen first went through a process of confronting openly his situation and then seeing it as indicative of all human existence. This does not seem like a minimising strategy. It is less clear how Arthur minimised his HIV infection if at all.

Davies reports that the IM group have considerably lower depression ratings than the other two groups. She suggests that this group’s refusal to accept the threat of death ‘… may be instrumental in facilitating adaptation to living with a HIV+ diagnosis. The absence of this form of denial in the High Meaning group may, in turn, account for their ‘closer’ association with the Shattered Meaning group’ (1995c,p.20).

If we value survival or adaptation, the IM group is most ‘successful’. This concurs with Taylor’s (1983) conclusions that the ability to look at the facts in a way that stresses the positive and obscures the negative is correlated with adjustment. Denial protects against crisis (Taylor,1983,p.1168). She says, ‘… normal cognitive processing and behaviour may depend on a substantial degree of illusion, whereas the ability to see things clearly can be associated with depression and inactivity. Thus, far from impeding adjustment, illusion may be essential for adequate coping’ (p.1171).

Results from the present study seem for the most part to replicate the preceding existential analysis. However, there are two original themes that may add to what has gone before. One theme concerns the process of adaptation. It is assumed that these men undergo a process of adaptation to the traumatic event of being diagnosed positive. It is possible that individuals go through their process at different rates, depending on variables such as their depth of experiencing (EXP scores), familiarity with psychological process, amount of support, health, age, etc. Although Schwartzberg downplays the process of adaptation in his analysis, he does suggest that time is the salient variable in processing trauma rather than experiencing style (1993,p.489). The present study indicates that the individual’s level
of experience (EXP stage\textsuperscript{17}) is correlated with their process of adaptation (and therefore their meaning ascription).

The second theme concerns the issue of universalising the HIV experience. Davies accepts that the HIV+ individual is in the same situation as every human except that ‘…subjectively … there is a world of difference because a HIV+ diagnosis has the capacity to impose … Angst’ (1995a,p.9). Martin Heidegger (1927) says that awareness of death can bring a feeling of Angst about everyday life for any human. Davies suggest that HIV+ people usually experience Angst during the first 2-4 years after diagnosis; after denial and before adaptation (1995a,p.10). The HIV+ person experiences the world in two ways; moving towards life and towards death. Heidegger’s descriptions of the modes of ‘human being’ suggest that this is not unique to the HIV+ person. By applying Heidegger’s phenomenology, we return the HIV+ individual to the realm of general human possibilities while reminding the ‘healthy’ population of its most authentic potential. The question of process will lead back to this theme.

\textsuperscript{17} The EXP Scale is not measuring only a momentary state. It signifies more of a personal style. Though not a trait, it indicates the individual’s general current relationship to their experience.
Chapter 6

Process, Experiencing, and Meaning

The discussion of the process of adaptation is really a discussion of the relationship between experiencing and meaning. We are, in Gendlin’s words, ‘...rejecting the infatuation with content, and refocusing upon the connection of content to its source’ (Gendlin, 1990, p. 94). In the present study, we get a glimpse of the implicit source of meaning in the Focusing sessions. It signifies the relationship between two levels of inner activity going on simultaneously,

One level is ‘symbols’ [which] ... includes perceptions of the physical body, of behaviour, of the environment, as well as cognitions, emotions [etc.] ... The other level is ‘experiencing’ ... Experiencing is the pre-verbal, pre-symbolic sentience which flows along underneath and gives meaning to symbols (McGuire, 1984, p. 1).

Gendlin refers to experiencing as the ‘implicit, pre-ontological being-in-the–world’ (1965, p. 240-3). Explicit formulations arise form this pre-thematic experiencing. But our describing pre-supposes that the language is appropriate and that the experience has some fully shaped pattern to describe: ‘one assumes that the given awaits attention as one, this given, rather than the reverse – that units of givenness are first unitised by our attention ...’ (ibid).

Understanding this implicit level of experiencing sheds light on the amount of information that is accessible to us. In his most recent book, Focusing-Oriented Psychotherapy (1996), Gendlin writes,

Each moment is a new constellation in which the past functions implicitly – and hopes for the future, along with hopes for the future from the past, are recontextualised ... The past is newly remade in every ordinary present experience ... An imagined future is also an essential constituent of any present experience ... The implied future we imagine now is always part of the meaning of the present (p. 67).

Focusing in the present simultaneously implies giving attention to our past and future concerns. From the point of view of experience, there is not a present, past, and
future in linear sequence. Each moment is rather a new constellation into which salient strands of the past and hopes and fears for the future are woven. The Focusing transcripts record individuals ‘dipping’ into this deeper level, to greater and lesser degrees, and then expressing themselves from there. These sessions suggest that individuals in different meaning groups relate to their experience at different levels. Glen (SM group) and Sebastian (HM group) rated higher on the EXP scale and were more deeply engaged with their feelings during the Focusing. For both of them, this resulted in a physically felt shift.

(R31) Sometimes it helps to let it know you know it’s trying to help.

(P31) Ya. (pause) It softened.

(R32) It softened a bit when you let it know you know it’s trying to help.

(P32) It's a sense of relief from it.

(R33) So it relaxes a bit when you hear that it's trying to help you.

(P33) It's changed into one big eel that's literally spinning with pleasure. One big one (long pause).

(Sebastian, Focusing Session)
In this case, a blocked feeling changed when it was acknowledged as trying to help. Such a ‘felt shift’ usually follows a pregnant silence during which something sentient, deeper than cognitive or verbal activity is going on (McGuire,1984,p.5). This implicit bodily process works much slower than usual discourse.

Noah and Michael (IM group) were in control of their feelings, and therefore less affectively involved in the Focusing. Research suggests that intellectual self-control is a form of self-deception (Kuiken,1986-7). Arthur (SM Group) and Maurice (DM group) remained disengaged from feelings that they sensed as threatening in some way.

18 This ties in with the previous interpretation of Michael’s Focusing session.
Focusing facilitates moments of affective insight, experienced as a shift from initial vagueness to felt certainty regarding a new conception of personal concerns (Kuiken et al, 1986-7). These insights seem as if they had always been there without being realised before (ibid, p.342).

... strange I haven’t talked about it to this extent for some time, well actually not in this way at all. It’s not been this deep to anybody before. It just seems like, um, a strange feeling. It’s like I’ve finally admitted something, it’s like sort of being an alcoholic and saying I’m an alcoholic (Glen, Post-Focusing Question 6, P1).

Novel imagery, such as reported in Glen and Sebastian’s Focusing, seems important in facilitating affective insight. Another study found that reflection on personal mortality which was affectively engaging rather than intellectual, initiates psychological change (Kuiken and Madison, 1987-8). This can result in a re-prioritising in which some concerns may be seen as no longer deserving of one’s commitment and a psychological withdrawal from these concerns occurs. The experience of withdrawal is similar to loss and can be associated with melancholy (Klinger, 1977; Kuiken and Madison, 1987-8, p.110).

Perhaps individuals who reflect affectively upon their situation may undergo a cycle of disengagement from their concerns with the HM group re-committing themselves eventually to new values. The SM group may be comprised of those individuals who stall after disengagement and do not re-engage to new concerns. The IM group remains distant from their affective process and hold on to their previous concerns by denying that their situation has changed in any significant way. Other research seems consistent with this interpretation (for example, McCain and Grambling, 1992). We might therefore expect that an individual’s affective engagement in their experience is correlated somehow with the sense of meaning they have in their diagnosis.
For some people, their initial experience of a HIV+ diagnosis signals the need to change certain aspects of their life and the opportunity to make deeper sense of the way they had been living. On the subjective level, HIV can call the person to his inner world, to create a framework to re-interpret this new view of life. The research of HIV+ gay men indicates that individuals in the HM group undergo this kind of transformation after their diagnosis. These men seem to find themselves at a point where they are more often guided by an inner reference as opposed to social forms. The individual who maintains an inner continuity at this deeper level is unknown to the external culture. The dominant view has been that nothing arises from inside that is not the result of society, social class, history and language ‘… But although each one of us is socialised, what arises bodily from behind and beneath and beyond the socialisation is more intricate, and can make more sense and be more ethical than our cultural training’ (Gendlin,1996,p.20). Society defines simplistic patterns as reality and then defines as pathological anyone who is more complicated than these forms. We are trained in the deep-felt belief that we ought to fit these forms and may spend our life trying to do so. That is unless something, like the trauma of HIV, wakes us up to this oppression by the external and reconnects us to our internal intricacy. The inner realm is already social. The body knows the language and the society as well as much more. However, for some reason we don’t typically live like this, from the inside out.

What is there in us which makes us so hesitant to confront our felt meanings and use them? What scares us so that we cling to our constructs only, that we find comfort in limiting ourselves to grinding out implications from given constructs only? I believe that it is our failures at living and the poor quality of the human being which we so often feel we really are, underneath (Gendlin,1966,p.55).

19 This may explain the higher depression scores for HM and SM groups. Individuals in these groups have both experienced the loss of disengagement from their pre-HIV lives.
‘Authenticity becomes an issue when the individual fails to creatively respond to the demands of his world, thus immobilising himself and denying the dialectical relationship he has with the world’ (Carter, 1984, p.207). As one deepens the connection with bodily felt meaning one moves through the cycle of disengaging from an old being-in-the-world to a new one. According to David Levin, ‘Embodiment is not a curse, not an affliction, but the only opportunity we shall be given to learn the poetry of mortal dwelling’ (Levin, 1985, p.68).

Many of us are caught up in a web of daily life, surrounded by a bustle which does not encourage us to pause and think very deeply about ‘Being’ as such. Our ontological self-development and our existential self-awareness are intimately tied to the depth of our self-questioning and our connection to experience. According to Martin Heidegger, this reflection inevitably reveals us as ‘thrown’ into a world that existed before we did. We did not make this world in which we live, but we can create a response to it which is our own, and thereby contribute to it and change it.

Heidegger offers a two-way process of self-understanding: a critique of the inauthenticity of the Self which is lost in everydayness ... and a meditation on the character of the true self which emerges from concealment in the light of an appropriate existential self-understanding (Levin, 1985, pp.4-9). Along Heideggerian lines we could say that each person has their own journey to make,

... the nature of this journey will be partly determined by our facticity and our fallenness. Our orientation to our lives has a rootedness in a kind of embodied constitution which is uniquely ours, as well as in the ways we have been formed by our social nexus of family and culture. However, who we become as unique individuals rests on how we take up our facticity and our fallenness (Davis, 1984, p.39).
Chapter 7

HIV and the Being of Human beings

The experience of living with HIV can be understood phenomenologically as a traumatic existential crisis. It can result in the individual confronting their life in an urgent manner. As some of the participants in the current study have pointed out, living with HIV puts universal human issues under a microscope.

And that’s what I feel HIV does. It’s like a magnifying glass on problems, uncertainties and doubts, and death and everything becomes a bit more sharper (Maurice, Interview Question 2, P7).

So identifying with the HIV+ person’s situation also teaches us about our selves. If we get close to his experience, his response to HIV informs us about our relationship to our own situation.

In Being and Time (1927) Heidegger proposes that from our everyday understanding of our own being we can reveal a more profound understanding of the meaning of what it is ‘to Be’. He wants to try to comprehend the Being of beings. Heidegger does not want this inquiry into Being to be guided by our most obvious or conventional ways of understanding. To see most fully we need to leave our already existing accounts and theories and study life in non-specialised contexts (Mulhall, 1996, p.18). We need to study the everyday but not in an everyday way (our sciences, philosophy, and research like the present paper are imbued with this everydayness as much as any other activity is).

According to Heidegger, human being is distinctive as the being that can enquire into its Being. He calls human being Dasein, stressing its distinctiveness. He does not think that Dasein’s ordinary or usual state is the one that most fully expresses its essential possibilities. A distinguishing feature of our usual state is that we fail to grasp our own human character
since it seems too close, unnoticed. If our everyday state is not authentic then our self-understanding in this state is equally not fully authentic.

Dasein is the being that is concerned with its continued living and its way of living. It has some implicit understanding of its relationship to its life. In our everyday way of being, we can choose to conform or to accentuate our differences. Either of these is to distinguish us with the Other as standard. It is not to distinguish ourselves in an independently valuable way.

Our relation to our own personal existence can be repressed or ignored but it cannot be transcended. Refusing to consider the existential questions is just another response, a decision to go on living as if they were irrelevant (the ‘adaptive’ IM group’s response). ‘In identifying with certain activities, character traits, lifestyles and visions of the good and in rejecting others, we reveal our conception of what it is to flourish as a human being, and so of what it is to be a human being, and make it concrete in our own existence’ (Mulhall, 1996, p.15).

An HIV+ diagnosis presents the opportunity for awareness of certain possibilities of Dasein. People choose their response to this opportunity. This response indicates the person’s values through their concrete choices. A High Meaning response indicates a valuing of the possibilities of Dasein. An Irrelevant Meaning response indicates a valuing of the every day realities. A Shattered Meaning response may indicate an in-between position; no longer convinced of the pre-HIV life yet unable to let go and develop new values. The Defensive Meaning response may indicate a tension between an inner SM response and a need to appear more positive to the
Greg Madison, PhD unpublished MA dissertation, 1997, University of Sheffield

Other (superficial HM response). Once a positive diagnosis is known, the possibility of confronting human being has wandered onto the field of the everyday and to decline it may cause guilt. This raises the question of authenticity.

Authentic choices are those by which the person is most truly him or herself rather than ones in which the person neglects an aspect of their being. However, this is not meant as a value judgement but more a description of different modes of Dasein,

Inauthenticity is not a diminution of Being; it is no less real than authentic existence. Nor is Heidegger’s talk of (in)authenticity intended to embody any sort of value-judgement: it simply connotes one more distinguishing characteristic of any entity who’s Being is an issue for it (Mulhall, 1996, p.37).

Thereby we see an opportunity to discuss the various responses to an HIV diagnosis as different modes of Dasein’s being; authentic or inauthentic but nonetheless all valid choices.

Authenticity is for Dasein to realise its wholeness. A basic component of authenticity is autonomy. It can be understood as ‘... the tension between socialisation and individuation, rather than a severance from society and tradition’ (Hatab, 1997, p.15).

Authentic resolute decision can be an individuated taking up of traditional patterns. Each authentic existence must still be lived in the world and so is a modification, not transcendence of the nature of social life.

Authenticity is about the way in which one relates to one’s roles in life, not a rejection of all roles. It is about how more than what. It refers to process. As human beings, we are all capable of living authentically or inauthentically. We can become lost in the distractions and lure of what Heidegger calls the ‘they-self’, but we still retain the capacity for wrenching ourselves back into our individual possibilities. If we realise the possibilities that express our real individuality, we are still vulnerable to falling

\[\text{\textsuperscript{20}}\text{ Speculation regarding the implicit values of a SM and DM response requires more study.}

Davies chose not to use the DM category because of its speculative and judgmental implications.
Greg Madison, PhD unpublished MA dissertation, 1997, University of Sheffield

back and losing our self (Mulhall,1996,p.131). To lose oneself is not to vanish as Dasein but simply to adopt one other of the different kinds of Being open to humans. 

Death. Sebastian most clearly represents a reorientation to his unique possibilities and the reinvigoration of meaning that it has entailed for him. His authenticity was awakened by his confrontation with his own death,

I have a funny feeling that meningitis was about stripping everything away. And I just didn’t believe in anything anymore. And I thought the only reason these people believe in reincarnation ... is cause they’re so terrified of dying. They’re so terrified of death, they’re so terrified this might be the end. There might be nothing. And of course that’s why I want an afterlife. But then I stopped believing in an afterlife, there was nothing ... it’s the total annihilation of the personality and we’re terrified of it ... During that meningitis thing I lost everything. Literally every belief or straw I clung on to. And I came to this conclusion, that my death is actually none of my business (Sebastian, Interview Question 5,P1).

Heidegger points out that Dasein’s authentic possibility is spurred by the awareness of mortality. Death presents Dasein with the potential for being more than a fragment of itself. It is the possibility for development. Coming to terms with finitude means acknowledging some aspects of our life will remain only possible, as plans never realised. Without accepting our non-Being as real, we cannot realise our Being as real,

And only when Being is interpenetrated with non-Being does Being consist of anything at all. Everything of significance in life – our relationships, our abilities, our work, our skills, and so on – is made significant by the ever-present fact of death (Billington, 1990, p.113).

We have our own death to die as our own life to live. Death is what most intensifies the ‘mineness’ of existence. Nothing else is so unremittingly close to each person, and so ultimately related to each part of life. Death highlights that existence is an issue for Dasein. The fact that death is threatening shows that existence matters for human beings. It reveals life as something for which we are each responsible; that my life, like my death, is mine.

Although others can ‘die for us’, they cannot die our deaths for us. Our deaths are something we cannot delegate to others (Tennessen, 1982, p.31).
Death does not need to be expected at every moment so that one is overwhelmed by it. This is not about cultivating a sickly fear of dying but about openness in the face of one’s own potentialities. Authenticity means accepting the responsibility of projecting oneself into the world, not passively being thrown to a pre-determined fate. There is a sense of challenge rather than determinism. Dasein is fundamentally phenomenologically a Being-towards-Death. ‘Attention to our finitude can open up the world in new ways; there is a fundamental connection between limit conditions and the disclosure of meaning’ (Hatab, 1997, p.13).

Death is the possibility of Dasein’s impossibility. Death encroaches at every moment and no amount of caution or timidity can make it fade from our lives. From the outset, we are thrown into the possibility that each passing moment may be our last.

… an anxious awareness of its mortality will inflect Dasein’s attitude to the choices it must make in four central ways. For a mortal being is one whose existence is contingent (its present modes of life no more than the result of past choices), whose non-existence is an omnipresent possibility (so that each of its choices might be its last), a being with a life to lead (its individual existential choices contributing to, and so contextualised by, the life of which they are a part), and one whose life is its own to lead (so that its choices should be its own rather than that of determinate or indeterminate others) (Mulhall, 1996, p.120).

In fleeing from the authentic, in ‘falling’, a veil is drawn over death. Individual personal death is dissolved in the ‘They’s’ death – the death of no one in particular.

Death generalised and made impotent. We turn from death and are told not to be troubled by it. ‘The They does not permit us the courage of anxiety in the face of death’ (Tennesson, 1982, p.33). Through a lofty indifference to the fact of personal death, we are alienated from the potential for Being which is most ours,

We all know we will die; but precisely the fact that this is general knowledge reveals that death is grasped as the death of others, as an occurrence, and that the knowledge in question in no way involves the laying bare of phenomena, in no way involves the truth. It is ‘das man’, ‘the they’ who says that we know we shall die. It is idle talk (Tennesson, 1982, p.33).
Greg Madison, PhD unpublished MA dissertation, 1997, University of Sheffield

We therefore usually live in inauthentic modes of ‘Being-towards-death. We repress, deny, or avoid our own death by emphasising the proposition that everyone dies.

This is the adaptive response of the IM group;

Death is, I mean it's inevitable anyway. I mean this is how I view it, that it's inevitable anyway, in a week’s time, a year’s time or twenty year's time. It’s inevitable to all of us. Um, [HIV] hasn’t really concentrated my mind. It doesn’t actually have any fear for me death, because everyone dies … (Michael, Interview Question 5,P1).

Death has never been a problem for me anyway. Um, I, basically once you go you go and that’s it. It’s never really bothered me so it’s not changed much (Noah, Interview Question 5,P1).

Death discloses our servitude to ‘The They’. This revelation allows the relationship to be changed. Each of us becomes responsible for losing ourselves in the circumstances that surround us.

The They. This refers to a ‘free-floating, impersonal construct, a sort of consensual hallucination to which each of us gives up the capacity for genuine self-reflection and the leading of an authentically individual life’ (Mulhall,1996,p.69). This is the inauthentic everyday mode that Dasein usually inhabits. If a person misplaces the responsibility for life onto this ‘everyone who is no one’, s/he then also becomes no one, leaving human life neutered.

The they is concerned to preserve its averageness. It glosses over anything out of the ordinary as being something long familiar (Heidegger,1927,p.126-7). It encourages a listlessness and insensitivity to differences. It makes the everyday comfortable and easy.

If Dasein loses itself in ‘the they’ it will begin to interpret its nature in terms of popular everyday culture and daily realities. These embody the inauthentic impulse to grind down into the conventional, avoid the unusual, and abdicate everything unique to the prevailing opinion. An ontological understanding will conversely ‘subvert obvious and self-evident truths, overturn common-sense and violate ordinary language’
Greg Madison, PhD unpublished MA dissertation, 1997, University of Sheffield (Mulhall,1996,p.70).  A re-orientation form ‘the they’ to authenticity is suggested by certain themes in the interviews;

... that’s another thing that HIV has done, it’s about coming out. By that I mean get real, you know. Get honest. This is what it is actually, I’m gay, I’m me. And so I’m out to everybody... There is nobody that doesn’t know both that I’m gay and that I’m HIV ... in the end the person I had to come out to was me. In a sense by telling all these other people I had to reach a point in a sense of telling me and then defining that for myself. And that was me coming to me. Not that I’m gay but that I’m me (Sebastian,Interview Question 7,P2).

And so over time I’ve started to let go of this idea that I should have a fantastic career. I didn’t choose that, my grandparents, my culture, where I come from says this is what I should do. And I found things I’m good at. And it’s not being a senior partner at ...its helping people out when they feel like shit ... HIV has helped a lot to make these questions happen, be asked sooner, and answered sooner (Maurice,Interview Question 2,P11-2).

Dasein discovers its individual way to the world, to its authentic wholeness, by the clearing away of concealments and obscurities. It breaks up the disguises and camouflage with which Dasein hides itself from itself (see Heidegger,1927,p.129).

‘The they’ is an aspect of Dasein’s constitution as a primordial phenomenon. Absorption in the ‘they-self’ is Dasein’s default position. From this original lostness it may find and recover itself. Authenticity involves overcoming inauthenticity.

By its confrontation with finitude, an HIV+ diagnosis offers a call to authenticity, from the inauthentic default position to realisation of the individual’s wholeness. A genuine self-understanding may be gained of which possibilities in life are their own rather than one’s generally. Being-toward-death clarifies the average, vague, and ambiguous forms so Dasein can find a path to take as its own. ‘Fallenness’ is the refuge from confronting finitude.

Fallenness. Dasein’s restless absorption in the inauthentic world is referred to as fallenness. It is accomplished through idle talk, curiosity, and ambiguity. Idle Talk is speech in which speaker and listener do not stand in any genuine relation to what they are talking about. Curiosity is the seeking for novelty without any genuine desire to understand it. Ambiguity comes form an absent-mindedness that obscures what is
genuine or false and the desire to know one from the other. To be capable of falling is an existential feature of Dasein – only Dasein can fall. And we all fall.

Idle Talk refers to average intelligibility as it’s manifest in everyday communication. In it, we lose touch with the object of communication and our talk becomes ‘groundless’. Right when we fail to understand we think we understand all. In its conclusiveness, idle talk is the closing off of phenomena rather than disclosing. It is the closing of future investigations and contemplation.

In its dissatisfaction, Dasein seeks stimulation. Maurice describes this mode of being in his response to his diagnosis and his general lifestyle,

... since I split up with my boyfriend my life’s been so out of control. I was going to the gym, working, taking vitamins. When we split up I completely rebelled against that good way of living and I started smoking cigarettes, taking drugs, smoking dope, fucking everything that moves which comes my way and says yes ... (Post-Focusing Discussion,R1).

Fallenness is as evident in what Maurice describes as the ‘good way of living’ as in the latter. Dasein becomes curious, easily distracted, it flies everywhere and dwells nowhere. It can no longer differentiate genuine comprehension from superficial explanation. The surface is proclaimed as deep while the genuine looks increasingly bizarre and eccentric. This public world dominated by idle talk and curiosity permeates the understanding Dasein has inherited from its fellows and culture.

The term ‘fallenness’ is not meant to convey any negative evaluation. It is an aspect of each individual’s legitimate inheritance as a human being. Heidegger’s concern is to describe our Being, not to prescribe our ways of being.

[Fallenness] is used to signify that Dasein is proximally and for the most part alongside the ‘world’ of its concern. This ‘absorption in’ has mostly the character of Being-lost in the publicness of the they. Dasein has, in the first instance, fallen away from itself as an authentic potentiality for Being its Self, and has fallen into the world (Heidegger, 1927,p.220).

Anxiety. Anxiety (angst, dread) can rescue Dasein from its fallen state in the ‘they-world’. It shows Dasein that it has been “thrown” into a world of choice. The single
Greg Madison, PhD unpublished MA dissertation, 1997, University of Sheffield

unifying force for Dasein as it confronts the inauthentic everyday, is anxiety. It
‘emphasises that Dasein is always in the midst of the objects and events of daily life,
but that typically it buries itself in them – in flight from acknowledging that its
existence… is always more or other than its present actualisation…’
(Mulhall,1996,p.110).

When anxious the world completely lacks significance. That which threatens me is
so close that ‘it is oppressive and stifles one’s breath, and yet it is nowhere’
(Heidegger,1927,p.186). As all entities shrink into nothing, anxiety allows the
individual to be lead to self-understanding. The world has nothing more to give one.

In anxiety, falling into the world and superficial understanding of oneself from the
standpoint of the average are not possible. The natural Being-at-home in average
everydayness is gone. [Anxiety] … brings Dasein back from its absorption in the
‘world’ … It brings a being-not-at-home, an uncanniness, it lets us hover in
ourselves (Tennesen,1982,p.27).

Mindless distraction can only temporarily eclipse anxiety. Awareness of the
fundamental lack of substance and security that is a core of human life breaks
through, one is again exposed to the bare reality that provokes anxiety,

… those people who choose to live in awareness of their fundamental ability to
decide … are acutely aware that life is based in death … When life is not taken for
granted existential anxiety is experienced (van Deurzen-Smith,1988,p.39).

It is not thinking about death and its accompanying fear (SM), courage (HM), or
indifference (IM), which belongs to authentic being. It is the positive possibilities
revealed by the anxiety of death, the revelation of activities and abilities and choice
(see Heidegger,1927,p.310). It is the urgency of our concerns in the world, the fact
that we ‘care’, which bears us in our awareness of finitude. Human norms are
understandable as modes of ‘shelter’ for beings that are continually subjected to
death, loss, pain and feelings of failure (Hatab,1997,p.4).

Care. This refers to the fact that as a Being-in-the–world, Dasein must deal with that
world and finds itself caring about its dealings. Dasein is concerned about entities
Greg Madison, PhD unpublished MA dissertation, 1997, University of Sheffield

(objects) and solicitous about other Daseins. It is engaged. Authentic Being does not
demand detachment from others; rather it involves a distinctive form of Being-with.

Dasein is not always caring, concerned, and sympathetic. Claiming that our authentic
being with others is solicitude does not deny that Dasein can often be indifferent and
hostile to others. However, care is the ontological basis of all these ontic variations.
Deficient forms of it can be seen simply as renunciations of this basis. Our solicitude
for others signifies an involvement not with things of use but with others like
ourselves who are needy.

A good deal of greed, anger, and violence can be traced to the ‘fallenness’ of self-
absorption as a refuge from the losses or the threat of losses (which losses can be
material, psychological, social, ideological, etc.). Even moderation and self-
control can connect with courage, in that the person who indulges appetites at the
expense of himself or others is cowardly in the sense of not being able to

Our own suffering can open us to noticing and feeling the suffering of others. Our
experience of limits and loss can not only illuminate the urgency of our own concerns
and vulnerability, it may also bring us to care for others (Hatab,1997,p.13). If there
is a common human sense of finitude, there may be a shared sense of compassion in
the face of death, pain, and loss. Compassion requires the courage to endure the
pain of giving real attention to fellow humans in their suffering. The AIDS epidemic
has seen a whole community mobilised to act on the compassion of caring for others
even while the carer himself may be the next to suffer.

The six participants in this study all reveal complex aspects of ‘solicitude’. The
Focusing sessions of Arthur, Michael, and Noah all concentrated on their relationships
with others. Arthur continues to mourn an ex-lover, while Michael and Glen find it
difficult to assert their own needs in the presence of the needs of others. In his
interview, Maurice idealises caring for someone who is very ill as ‘unconditional love’
and ‘the highest spiritual plane’ (Question 5,P1). However, the ambiguity that
Greg Madison, PhD unpublished MA dissertation, 1997, University of Sheffield

characterises his interview is shown when Michael says he couldn’t deal with his ex-boyfriend becoming really sick.

Glen represents the clearest example of solicitude and compassion based upon awareness of finitude,

... a lot of people shy away when someone falls ill ... I never have ... I didn't see it was right that anyone should die alone. It just seemed like cruel, to me. In society, people who claim to be friends will abandon you as you were dying and when you need them the most, I think that's wrong. And that’s why I got involved and was involved with so many of them I mean all together Greg I've organised eleven funerals, including my own (Post-Focusing Discussion,P3). Although Glen is aware of the needs of others, he has not lost sight of his own needs, which have remained unfulfilled,

... from the day I've been diagnosed, I've gone through this completely alone. Completely. Not once have I been examined or have I attended my clinic or have I been, have I had needles inserted into me that anyone has held my hand, and said I'm there for you ... It would have been a very reassuring feeling (Interview Question 3,P2).

Heidegger distinguishes between dominating a person’s concerns, fostering dependence, and helping the other to become transparent in their care and to freely choose it (Hatab,1997,p.13). The latter liberates rather than dominates. This clearly demonstrates a way in which authenticity includes attention to the authentic possibility of others.

Our average everyday way of understanding our relations with others is based upon our differences from those with whom we share the world. Our usual sense of who we are is a function of our sense of how we differ from others. Others appear in their social roles. Their identity is given by their occupations. Who they are to us is a matter of what they do. Which individual human occupies each role is irrelevant and we are in the same position in their eyes. ‘Since the environment closest to them is the work-world, the identity closest to them is their identity as workers, as people performing socially defined and culturally inherited tasks whose nature is given prior to and independently of their own individuality …’ (Mulhall,1996,p.72). None of the
men in the current study is working. Some had to leave very successful careers but over the years, they have redefined themselves without reference to these social identities,

... now that dreadful question you get asked at parties ‘and what do you do?’. I mean I know I’m guilty of it myself, but now when I realise that, how little significance it is, why are people’s merits judged on their achievements career-wise. (Glen, Interview Question 4, P1).

It is often during the experience of crisis that a person can become aware of an emptiness and lack of meaning in their life. This can instigate a drive to understand life and find a sense of meaning amidst the confusion. The diagnosis of HIV can provide the crisis to instigate such a search. It can mean challenging social definitions in order to discover one’s self-identity.

_The Call._ It gives no assertions, no information about world events, no blueprints for living, no moral restrictions, it merely summons Dasein to face every aspect of its life, to compare it to its authentic capability (Mulhall, 1996, p.125-6). ‘The call’ does not dictate what Dasein’s possibilities or choices should be, for any prescription further dilutes Dasein’s concentration on reclaiming its life as its own.

‘The call’ is a voice that Dasein hears within itself. The aspect of Dasein which remains true to its full potentials calls to the aspect of Dasein which is lost in the they, ‘... the call comes from me and yet from beyond me’ (Heidegger, 1927, p.320). This experience is often described in Focusing sessions. Glen described finally admitting something to himself – a call to the truth that is known within. Perhaps it is no accident that Sebastian, the one participant clearly High Meaning, is the one who already knew a way to access the inner call to authenticity\(^2\). The voice of conscience calls Dasein back to its wholeness.

\(^2\) After the Focusing Sebastian says, ‘I’ve been taken back ... to a technique that I had done, that I’d not forgotten about, but perhaps need to return to’ (Post-Focusing, Question 6, P1).
The self-disclosure of conscience returns Dasein to its place in the world, to its specific concernful relations with entities and solicitous relations with other Daseins. In this way it can discover what its possibilities in this situation really are and can seize upon them in a way which is genuinely its own. One way of encountering 'the call' is to be in the presence of another who is genuine. This disrupts Dasein’s lostness by awakening 'Otherness’ in itself – it thus … induces an anxious realisation of itself as a separate, self-responsible being with a life that it must lead’ (Mulhall, 1996, p.133).

Davies’ research indicated that twenty-six percent of the HIV+ gay men she interviewed were identified as having a HM response to their diagnosis (1995c, p.6). Some of these men have been thrown into a confrontation with the limit conditions of their human life. Some have realised their previous lostness, heard the call to authenticity, and grown towards realising their potential as Dasein, their possibility of human being. As a society, our challenge is to receive these ‘others’ in a way that can awaken our own possibility of wholeness.
Chapter 8

Concluding Remarks

The task of this dissertation was in part to investigate the process of adapting to a HIV+ diagnosis, and to add some detail to the previous existential studies. Emphasising process and general modes of being diminishes judgements regarding who is ‘successful’ or who has ‘failed’ to adapt to HIV. Rather than high, shattered, irrelevant, or defensive meaning groups, the participants can be seen in terms of different modes of human being, each person remaining capable of falling back or realising other modes which comprise the wholeness of Dasein\(^22\). By stressing the universal human issues in the impact of HIV, we have the opportunity to heighten our own existential awareness. This discussion also attempts to bring the person of the researcher into closer identification with the person of the participant.

An authentic confrontation with death facilitates living a life that is genuinely individual and whole, a life of integrity. It reveals that life had previously been lost. This is an inherent quality of Dasein to see its lostness and call itself to attain its potential for selfhood. ‘The lost theme is not death’, according to Robert J. Lifton, but ‘the psychological relationship between the phenomenon of death and the flow of life’ (Lifton, 1979, p. 4). The experiences of these men can add a tone that expresses some acceptance of ‘the slow sad truths of life and nature … the sadness of change, loss, and death …’ (ibid, p. 28).

By describing our modes of Being, Heidegger reminds us that we are each rooted to a specific place and time, to specific facts, through a body, which we are born as and will die as. Heidegger’s thought is not oriented towards the here and now of specific

---

\(^{22}\) Combination therapy may invalidate interpretations of HIV adaptation based upon a model of trauma (Davies) and make Schwartzberg’s meaning groups outdated. However, these advances will not affect the application of Heidegger’s ontology.
human lives. Nor is it intended to make an HIV+ man’s life more meaningful for him. It is a general description of human being, a phenomenology of life.

Part of the impact of the HIV+ diagnosis is that it is not chosen. It is not through quiet contemplation that Sebastian has reached his insights. It is by being thrown into the storm of his own mortal awareness and his response to that awareness. This response is a choice. We are not compelled to seek authenticity. ‘If existentialist Being is freedom from phantoms [the past], it is also freedom for personal choice and growth (It is also freedom to go to the dogs, commit suicide, or be a murderer, depending on the values we choose)’ (Billington, 1990, p.109).

The group of individuals who have responded to HIV with existential awareness may embody Dasein’s memory of its potential. Authenticity is not impossible; it is a rare and fragile possibility from which we continually fall back.

And no community of beings to whom an understanding of their own Being necessarily belongs, could utterly lose a sense of themselves as capable of authenticity. Whether in disregarded texts, moribund institutions or marginalised individuals… some vestiges of that self-interpretation will survive for as long as human beings do (Mulhall, 1996, p.181).

All six of the men in this study have been unemployed since the onset of their HIV. They have lived with the potent combination of being diagnosed with a disease thought to be fatal and uninterrupted time to contemplate this. For some, this has lead to insight and a significant rejection of their previous way of live – our way of life.

Many have come to value the freedom and time they have as unemployed men.

I was able to reflect upon my existence, my life, and to adapt to living for now instead of grasping for the future which was never going to come. Which was what I was doing before I was diagnosed. You never live for the present when you’re in the rat race. But I’m only sorry it took something like this for me to realise it but I wouldn’t like that lifestyle back again for anything now… (Glen, Interview Question 1, P9).

I don’t work, so I don’t have the demands of other people on my day, so yes I do live differently. I haven’t worked for six years. I really resent it when people, you know its given me a tremendous freedom … (Sebastian, Interview Question 4, P3).
The advent of the new combination therapies has been a wonderful advance in HIV treatment. Many men who were waiting for death are now thinking of returning to work. For men like Michael, Noah, maybe Arthur and Maurice, this is very encouraging. However, for Sebastian and Glen, and perhaps for many who have had a deep experiential response to living with HIV, there is no desire to return to the everydayness their adaptation has lead them to reject. How will the ‘they world’ receive these men who will reluctantly return to the workplace, with an increased realisation of their authentic potential? And how will these men maintain their insights into being against the pressure to ‘fall’ back into Dasein’s default position? The urgency of these questions is becoming apparent.

I recently received a leaflet from an HIV agency describing a new ‘Back to work Project’. It’s for HIV+ gay men who have begun combination therapy and are now contemplating returning to their careers. The Terrence Higgins Trust has just circulated a leaflet describing a massive review of Disability Living Allowance that will investigate the level of benefits for HIV+ claimants. ‘Does anyone else feel more and more pressured into returning to society’s concept of a justifiable existence i.e. a nine to five job and all that goes with it’ writes Drew Colverd in this month’s *Axiom* (1997,p.46). He also writes about overcoming the stigma of receiving benefits, ‘...I’ve learned that there are many more ways to make a valid contribution to society than being able to say I work in an office all week’. In the same edition of *Axiom* Sean Strub writes,

> With the relative return of health, I and others have returned to a land of judgement, blame, demonisation and even greater marginalisation. It’s better than the alternative, death, but it does make me wonder why the compassion, understanding, and acceptance we grant the dying can’t be part of all our lives, every day (1997,p.19).

---

23 A magazine for HIV+ gay men.
The question is occurring now whether society, ‘the they’, will make a place to learn from these individuals, ‘Because they in fact have a lot to learn from us about truth, intimacy, passion and finding the validity of one’s own soul’ (Strub, 1997, p. 19).

We can choose to see the AIDS pandemic as a grim crisis for humanity, and given its appalling and relentless toll on precious human lives, of course we are entitled to do so. But equally we can choose to see it as an extraordinary opportunity, individually and collectively, to move forward. We can choose to be stirred out of our complacency to insist on and fight for a response focused on fundamental and far reaching change … (Spence, 1994, p. 19-20).
References

Bor, R. (1991) 'Efficacy of Psychological Therapies for People with HIV Disease', *Aids Care*, 3(4): 405-7
Cooper, Mark (1997) 'Thank You for Being a Friend', *Thud*, April 3:41
Davies, Michelle (1995a) 'Shattered Assumptions: Time and the Experience of Long-Term HIV Positivity', *In Press*
--------- (1995b) 'The Divided Self: The Destructive Potential of a HIV+ Diagnosis', *In Press*
--------- (1995c) 'Ontological Assault', *In Press*
--------- (1995) 'Crossing and Dipping: Some Terms for Approaching the Interface Between Natural Understanding and Logical Formulation', *Mind and Machines*, 5: 547-60
--------- et.al. (1986-7) 'Moments of Affective Insight: Their Phenomenology and Relations to Selected Individual Differences', *Imagination, Cognition and Personality*, 6: 341-64
Lester, David (1992) 'Ontological Insecurity and Fears of Death', *Psychol. Reports*, 71:1178


McGuire, Kathleen N. (1984) *The Experiential Dimension in Psychotherapy.* Eugene OR: working draft, permission to quote granted


Sartre, J.P. (1956) *Being and Nothingness.* New York: Philosophical Library


Spence, Christopher (1994) 'The AIDS Pandemic: Crisis or opportunity?’, *University of Kent Open Lecture Series:* London Lighthouse


Tennesen, Herman (1992) *Contemporary Continental Philosophy II.* Edmonton: University of Alberta Bookshop Publ


APPENDIX

Arthur’s Description ........................................................................................................ page 74

Meaningful Themes .......................................................................................................... page 75

Transcript ......................................................................................................................... page 79

Michael’s Description ........................................................................................................ page 87

Meaningful Themes .......................................................................................................... page 88

Transcript ......................................................................................................................... page 92

Glen’s Description ............................................................................................................ page 102

Meaningful Themes .......................................................................................................... page 104

Transcript ......................................................................................................................... page 109

Noah’s Description .......................................................................................................... page 123

Meaningful Themes .......................................................................................................... page 124

Transcript ......................................................................................................................... page 127

Maurice’s Description ....................................................................................................... page 133

Meaningful Themes .......................................................................................................... page 135

Transcript ......................................................................................................................... page 140

Sebastian’s Description .................................................................................................... page 154

Meaningful Themes .......................................................................................................... page 156

Transcript ......................................................................................................................... page 160

Session Protocol ............................................................................................................. page 170
Essential Description of Participant 1

“Aurthur”

Arthur is 53 years old and has been HIV for over 10 years. When he was tested he didn’t know a lot about HIV and he tried to reassure himself, but something deep inside knew he’d be positive. He was devastated by the news. He was also unemployed at the time and then his casual lover of 5 years left when Arthur insisted they start using condoms. The only thing that saved him was Body Positive. They provided support and Arthur became one of their counsellors although he was still devastated.

Arthur’s family reacted badly to the news. Although his brother was initially sympathetic he quickly turned hostile and told the rest of the family against Arthur’s will. The family were rejecting, they never discuss HIV and Arthur is not welcome at home. His brother apologised for his lack of support just before he died and this made a big difference to Arthur but things have become even more difficult with his parents.

The passage of years, being exposed to supportive people and information, and staying in good health have improved things a bit now. But it’s taken years to want to socialise again. Arthur gets very emotional when he hears music that reminds him of his pre-diagnosis days or when he goes out and notices all the men who are missing. It’s difficult to cope with.

Arthur was not well supported by friends during his adjustment to HIV. He also had to decide whether to tell new people that he’s HIV or to just socialise with other positive men. He temporarily lost his connection with himself and for a while could not enjoy his own body sexually. Knowledge and time helped Arthur accept his body again.

Because he has seen how the virus has killed his friends, the worst fear for Arthur is how it will kill him. He is afraid of going blind or ending up in a wheelchair. He worries about this when he remembers how his friends deteriorated or when he sees incapacitated men at the drop-in centre. His faith in God and having a drink helps him cope with these times.

Because he has not been able to continue working, Arthur’s future has altered drastically. This is due to the HIV and to being old enough that it is difficult to find work in the current employment market. Now he doesn’t plan as far ahead as a year and really takes things one day at a time. He doesn’t experience time differently but somehow he lives daily in a way that feels different. He’s quite happy to stay at home or to go out occasionally. He doesn’t believe he controls his long-term future; this is pre-determined.

HIV has made Arthur look to his faith for strength. He was urged to leave the Church of Scotland when he accepted being gay and it took a long time for him to return. He does accept other religion’s versions of God.

Arthur always knew he was gay and is quite happy with this. He accepted being gay when he was about 20 but continued to say he was heterosexual for years. He has gradually come out over the years and leaves it for people to figure out themselves. Arthur considers himself lucky to have had only a few bad experiences regarding his sexuality. He feels he could have conformed to a heterosexual life if there was also a man in the
Greg Madison, PhD unpublished MA dissertation, 1997, University of Sheffield

background. He’s envious of married men watching their children grow up but feels it would be heartbreaking when they develop independence. He’s glad not to experience that or the financial pressures of raising a family.

MEANINGFUL THEMES

Question 1

How I felt first
1. Before the test something deep inside said I might be positive, but at the same time I reassured myself. Little was known so I developed my own theories.
2. I was devastated.
3. My life circumstances at the time made it worse. I was unemployed and involved in a 5 year casual relationship which ended when I insisted on using condoms. Refused to acknowledge Christmas card from him 2 years ago. (abandoned)
4. The only thing that saved me was Body Positive. I began going to Sunday meetings and then the weekend workshop. This was fantastic and I became a counsellor but was still devastated.
5. My younger brother (who had role of older brother) promised not to inform my parents. He was sympathetic then a week later he was hostile and rejecting.
6. Brother told family who were also rejecting, offered me no support, told me not to come home for Christmas.
7. A woman friend was very supportive and intervened to get me invited home the next Christmas. I felt lucky to have this friend
8. HIV still never discussed at home.

I feel differently now
1. I’ve come much more to terms with HIV (after 10 years).
2. My brother, as he was dying, apologised for not supporting me. That made a big difference to me.
3. My parents still reject me. I am completely excluded from family news or events (brother’s funeral, mom’s birthday). I am not welcome at home.
4. Things have improved in some ways, but are worse with parents.

What changed my feelings?
1. Length of time.
2. Meeting people, doctors, media over the years.
3. Staying in good health during this time.

Question 2

How has HIV affected me the most?
1. It’s taken years to want to socialise again.
2. I couldn’t listen to music that would remind me of how things were before
Greg Madison, PhD unpublished MA dissertation, 1997, University of Sheffield

(going to bars etc.). (loss)
3. I can listen to some music again (opera, symphony, dance). But music from the 70s and 80s brings very emotional flashbacks. It brings it all back.
4. Going out now makes me aware of all the men who are gone. It’s very hard at times, I cope with it.

It’s affected relationships with others
1. At first I had no interest in sex. Couldn’t get an erection for 6 months.
2. Knowing I’m HIV makes it complicated when I meet someone. I had to decide if I told people or if I just met other positive people.
3. People either said get on with things, or they quit ringing.

It affected my relationship with myself
1. At first I lost my connection with myself then I found it again.

It affected my feelings about my own body
1. At first I couldn’t even masturbate. If you don’t love your own body you can’t love another’s. This changed back so I could enjoy my body again (and another’s).
2. Knowledge and time facilitated accepting my body again. I know a man who after 11 years still doesn’t want to be touched, to have sex.

Question 3

My worst fears
1. My worst fears are about what the virus will do to me because of seeing it kill wonderful friends all in different ways. I’m afraid of becoming blind or ending up in a wheelchair. I’m afraid of HOW it will make me deteriorate.
These fears are triggered by
1. Remembering friend’s last few years of life.
2. Seeing incapacitated men at the drop-in centre and thinking that will happen to you (here he corrects his pronoun to ‘me’, ‘to me’).

How I cope
1. By faith in god.
2. alcohol (was drinking during the interview).

Question 4

HIV has drastically affected my future plans
1. HIV, plus ageing, plus the employment market, add up to a drastic change in my future plans.
2. Now I just take one day at a time, month by month short-term, I don’t even plan for next year.

It hasn’t made me experience time differently
I live daily in a way that feels different now
1. It’s difficult to answer but my outlook is different now. Now I’m quite happy to be at home or go out once and a while, not every night or all night. I don’t like the pushing crowds.

I don’t believe I can control my own future
1. In the long-term things are pre-determined.
Question 5

HIV hasn’t affected my thoughts or feelings about death
1. Except it has affected my expectations about the way I might die.

Question 6

My religious beliefs
1. I was brought up in the Church of Scotland and my faith remains.
2. I left the church when I accepted being gay because others in the church said I should if I was going to lead a homosexual life.
3. It took me a long time to return to the church and being HIV has made me look more to my faith for strength.
4. I accept other faith’s concepts of god but was so disturbed by what I was taking in from the Koran that I stopped reading it.

Question 7

My feelings about being gay
1. I always knew, but I might have conformed to a heterosexual lifestyle if things had been a bit different as I grew up. But there would have always been a man in the background.
2. I’m envious of married men seeing their own children grow up. But when they are 3-4 and become their own individuals they can break your heart. So I’m glad not to experience that.
3. Being unemployed I can understand the financial pressures of trying to maintain a family’s standard of living.
4. In summary I’m quite happy being gay.

My coming out
1. I accepted I was gay when I was 19-20. I didn’t let anyone in the office know.
2. I worked 10 years at the same office and tried to maintain I was heterosexual. I did my job well so my sexuality was the Achilles heel.
3. I accepted myself in the early 60s and then came out gradually. I was not prepared to come out to all and sundry.
4. I’m out now but I don’t tell people I’m gay. People find out gradually, they are intelligent enough to put two and two together, and their reaction is good thank god.
5. I’ve been lucky I think, only a few bad experiences and usually in business not private life. (nothing about family here).

Focusing Session

Themes
1. I know I’m living with HIV more easily now.
2. The feeling comes from my legs. They felt like lead and I wanted to scream. This is a recurring feeling and then it eases. I think it’s about losing
the use of my legs in the future. It’s about living daily with HIV, it never goes away.
3. Heaviness around my tummy but my head says it’s NOT OK to be with it. My head is staying in control, to feel safe. It’s easy to feel both these parts.
4. These feelings are connected to memories of the love of my life. The heaviness needs to know the truth about his death - why I wasn’t contacted so I could say goodbye. I need to just accept that his friend will never let me know why.
5. It was H. who actually decided and told his friend not to tell me. I should have been more assertive, I was too easy then. It’s too late now.
6. It would be wonderful to see H’s brother and clear up a few questions.

Post-Focusing Questions

1. Focusing brought back the memory of living in the flat with the love of my life.
2. I was able to find and stay with a feeling in my stomach.
3. This wasn’t new, I’ve done it many times.
4. Something new came, it was H who was in control, not his friend, H decided I shouldn’t know. This became clear to me.
5. This was helpful.
6. I now know I have to try to contact H’s friend and his brother. Feels good to come out with this realisation. This time of year is poignant for this memory and a piece of music goes along with this memory.

Impressions

The participant spoke slowly, measured. His voice was quite monotone, his mood seemed a bit flat. He smoked and drank during the session. He used non-immediate language a bit and corrected himself at one point. He stayed quite in his head during the Focusing but was able to feel his body and that it was not safe to stay with these feelings. Something unresolved about a very important relationship. A new insight and an action step came from the session. On the experiencing scale (EXP) I would say he remained quite low, level 1-2 during the interview and 2-3 during the Focusing. He did seem close to tears and chewing lip when he acknowledged his need to know, whether he would or not, about his ex-lover’s death. This seemed the point at which he was most deeply engaged with his present experience.
Question 1

P1 Before I went for the test, something deep inside was telling me because of my lifestyle there was a very good chance it would be positive. But at the same time I was saying to myself but we haven't engaged in this and we haven't engaged in that, because all those years ago so little was known I had my own theories about how you could catch it. So when I was told I was positive, I was devastated.

R1 Right.

P2 And it didn't help at that time I was also unemployed, and I had been in a relationship for 5 coming on 6 years, a casual relationship but it was a relationship because I saw him at least once a week, and when he came here that night to get the results his attitude was ‘well I told you not to have it, we’ve both been around, we’ll just get on with what’s been happening and we still won’t use condoms’ and I said ‘sorry, from now on condoms’. And his attitude was ‘no, I wish you well’ and he walked out. And I haven’t seen him since, I had a Christmas card 2 years ago which I refused to acknowledge.

R2 Right. So when you first found out for you the news was quite devastating ...

P3 Absolutely devastating.

R3 And there was also that you were unemployed, and the response of your partner. The whole thing all together was a lot.

P4 Yup ... the only thing that saved me was that Body Positive was up and running, and at that time there was no helpline number, it was a private number I was given for that night and the following night. And when my friend left I phoned that number and spoke to a fellow Scot. And he was very sympathetic because he let me know he was in the same boat, and he said if you want to phone tomorrow night, don’t use the second , I’m at home, you can call me, which I did. And on the second night he advised me to go along to their Sunday meetings and by going to the Sunday meetings within a month I had done the BP weekend which was quite fantastic, bloody hard, because it dealt with issues from to be tested or not to be tested, and then positive results and going through the stages and it finished up on a Sunday afternoon with coping with death from an HIV illness. At the same time I knew that I had got a great deal from it and because of that I also became a telephone counsellor because I felt I could also perhaps help somebody else in the same position. But at the same time I was still devastated.

R4 Yeah.

P5 And also my brother and I were never close; he was always taken as big brother although he was younger. He was always taller, bigger, and we’d made an agreement that whatever the result he would not inform my parents. When I told him that night I was positive, he was very sympathetic, he was very easy but within a week on a Saturday night he’d phoned me and he was shouting down the telephone that I was, what was the expression, a leper, never to return to Scotland, he didn’t want to know me. I immediately put the telephone down and phoned my mother and it had already been agreed I’d be going home for Christmas as usual, and the first thing she said was, ‘Your father and I have been talking, wouldn’t it be better if you stayed in London with your friends this year?’ And I said, ‘Mother, the arrangements are made I’m coming home,’ and she persisted and I said has brother been out to the village and she said yes, and I have enough to do coping with your father, but there is nothing we can do for you and she put the telephone down. So brother did the dirty. It was a difficult time.

R5 Yeah it sounds like it. Not only your reaction, but other people’s reaction.

P6 Especially family. And yet the other side of the coin is, a woman who I worked
with since I was 20, and she was much older than myself, when I told her, it was no problem. And when I told her about the telephone conversation with my mother, because she had met my mother on one occasion many years before, she immediately said, give me your mother's address, I shall write to her. And the next Christmas I was invited home, although it was still difficult. They didn’t want to discuss HIV or what it meant. And that woman is still standing by me. But over the years of course I’ve found that she herself has lost men friends to HIV and she’s an intelligent woman, she’s an aware woman, so I was very lucky then.

R6 So if you think back to how you felt when you first found out do you feel differently than that now?
P7 Oh yes. yes.
P8 I’ve come much more to terms with HIV, at the same time, my brother had a heart attack 2 years ago. It was a second heart attack. He knew that he wasn’t improving because he was looking older and going through the same therapies himself and I think he knew he was dying, or going to die, and he apologised for not standing by me. So that made a big difference, but my parents on the other hand still have not changed. If anything, it’s an even worse situation because brother did die a year ago, I wasn’t welcome at his funeral, my parents let me know that. I went home to Scotland last October after 6 years for my mother’s 80th birthday. She didn’t want me to go to Scotland. I turned up on the doorstep on her birthday and within an hour my father was lying to me about winding up my brother’s estate and throwing me out of the house. And then, 3 weeks after that, I found out my mother had fallen down the stairs and broken her hip, when I phoned my father he put down the telephone. Within a week I packed my cases and went back to Scotland and then was told by the sister in the hospital, your father has great influence, your mother doesn’t want to see you, and within a week, I was told to return to London. And I still don’t know what’s going on at home.

In some ways, things have really improved. On the other hand, when it comes to parents, it’s even worse. It’s a worse situation today.

R8 So, in terms of your feelings, that’s improved. The relationship with your brother’s improved.
P9 Well he’s dead now. But with my parents it’s even worse. That hasn’t improved.

R9 I think you’ve answered at least some of this, but the next question is, what do you think has brought about the change in how you feel?
P10 Um, I think the length of time I’ve lived with HIV, the number of people I’ve met, doctors, programmes on television, newspapers, I think just living with HIV for just over 10 years.

R9 So just the length of time.
P11 The length of time. And I think also being fortunate in the fact that I’ve never developed anything, any serious illness, and I’m still here.

R10 So it’s the length of time and that you’ve had good health.
P12 Uh huh.

Question 2

P1 Well when I first found out, I didn’t want to go out, I didn’t want to socialise. And it’s taken many years to break out of that. At the same time all those years ago I found I could not listen to an opera, a piece of symphony music, a piece of dance, I couldn’t listen to the disco music that I used to dance to or hear in bars, it was just too much. Over the years thank god that’s changed I can now listen to music but I still find, it’s because I’m going out now socially in bars that when they play the music from the 70s and 80s, which seems to be more and more I get flashbacks to where was I then, what was I doing, who was I running around town with, and I think
music has this effect. It's very emotional.
R1 Ya, it can bring it all back.
P2 It brings it all back. And when you're standing in your favourite bar and you're conscious and you're always aware of the number of men who have gone, it's very hard at times... I cope with it.
R2 You've touched on this a bit, I'm wondering if it's affected your relationships with other people.
P3 Oh yes. Um, to begin with um, I had no interest in sex. I think for the first six months of being told I was HIV, I couldn't even get aroused. It took a long time to want sex again. And then of course you had the complication of knowing you're HIV, do you tell the other person, do you keep your mouth shut, do you only mix at Body Positive and try to meet somebody within Body Positive who is positive, it was difficult.
R3 OK. So it's certainly affected your sexual relationships, and social ...
P4 And social, oh yeah the number of people who was either, you know put it behind you and get out there and forget about it or there was no reaction and no more telephone calls.
R4 Yeah. Has it affected your relationship with yourself?
P5 To begin with yes. But then when I came to terms I found me again.
R5 OK. So at first it was like you kind of lost the connection with yourself and then you found it again.
P6 Uh huh. Yes, very much so. Yes.
R6 And the last part of this question is, has it affected your feelings about or relationship to your own body?
P7 To begin with yes, of course. I didn't want to, as I say I couldn't, I couldn't get aroused. So I couldn't even masturbate, because my attitude to sex has always been if you don't know your own body, if you can't love your own body or enjoy your own body how can you enjoy somebody else's? And once I got rid of the old feelings, I was back to what I used to feel. And I still feel that unless I can enjoy my own body I can't appreciate another man's body.
R7 So at first it somehow interfered with enjoying your own body and then that changed backed again.
P8 It changed back.
R8 Do you have any idea, was there anything that helped facilitate that change back?
P9 I think it was knowledge. And time. But then again that's how I feel, but I was talking to a man last night who's the same age and known longer than myself he's HIV and he's never had sex in 11 years. He's slept with other men. But that's all he's done. He just couldn't touch, he didn't want them to touch him. And I think that's very sad.
R9 So for you time has, through time you've kind of worked through something and gotten back to ...
P10 ...where I was at the beginning.
R10 Where you were before. It doesn't happen with everyone, but for you it has.
P11 Uh huh, ya.

Question 3

P1 My worst fears, oh dear ... I've watched so many wonderful friends die of HIV related illnesses and they've all died differently. So my worst fears are what is the virus eventually going to do to me? I'm frightened that I might become blind, or finish up in a wheelchair.
R1 So your worst fears are about how your health might deteriorate.
P2 Uh huh, and not knowing how.
R2 The next part of the question is what triggers these fears, or when do you find
yourself thinking about the worst?
P3 When I remember friends over the last 2 - 3 years of life. And at the same
time because I still go, um, to a drop-in centre here in Camden, and meet other men
who I know are ill, who are incapacitated, you never get away from thinking that
eventually something’s going to happen to you - or to me, to me.
R3 So remembering friends or seeing other people who are ill makes you think
about what will happen to you.
P4 Uh huh.
R4 OK. And just the last part of this is what do you do to cope during these
times?
P5 My own faith in god. And um the alcohol helps. (laughter)
R5 Your faith in god and a drink or two.
P6 Ya (laughter).

Question 4

P1 Drastically. Not just HIV, um, getting older, and the employment market, that
even 5 years ago I was told by a top accounting agency ‘sorry we’re not going to
send your details out again because nobody is asking for you to come for interviews,
the fact is you’re too old’. So before HIV came along I had a sort of plan for the
future but that’s gone and I take each day as it comes. I don’t plan for next year or
the next year. I take it day by day, month by month.
R1 OK, so it’s really drastically affected your plans for the future in that now you
don’t plan long term, you plan much much more in the short term.
P2 Ya, in the short term.
P3 I don’t think it has. No, no difference.
P4 And do you live daily in a way that somehow just feels different now?
P5 Yes. Yes. It’s a difficult one to answer.
P6 Ya, OK, you just know you live in a way now that just feels different, though
you might not be able to say what that is, it just feels different.
P7 It feels different ... and it is different because I have a totally different outlook
to the outlook I used to have. Like socially, um, I might go to the bar and in the old
days it wouldn’t be enough just going to the bar on a Friday or Saturday night, I
would then have to go on to a night-club. Now if I do go to the bar on a Friday or
Saturday night I want to come home. And also at the same time once upon a time I
would go out every Saturday night whereas now the majority of Saturday nights I’m
at home. I’m quite happy to be at home. I can't put up with the pushing the shoving
the crowds.
P8 And do you believe you can control your own future?
P9 No.
P6 It’s out of your control.
P7 To an extent yes. I think long term, perhaps it’s my outlook on life but um it’s
written in the stars or written in the cards or whatever. I think when Prince Charles
once said when he was asked about the assassin, he said well if your name’s on the
bullet there’s nothing you can do.
P8 So there’s almost an element of it being pre-determined or ...
P9 Yes.

Question 5

P1 It hasn't, the only way it’s affected them is, the way I might die. That’s the
only change. My feelings are just the same.
R1 You’ve answered the next part of this question, which is about your own
death, so we'll move on ...
Question 6

P1 Hmm, yes, I was brought up in the Church of Scotland from an early age, I dropped out of the church when I first accepted my sexuality, not so much because of what I thought, it was the pressure of peers, men I respected who I mixed with who were so called evangelical who told me in no uncertain terms if I was going to lead a homosexual lifestyle I should have nothing to do with the church. My faith remained, I didn’t go to church, it took me a long time to return. And I think being told I was HIV made me look more to my faith and it does give me strength ... today.
R1 OK, So you would describe your beliefs as Christian - the same Christian beliefs you were brought up with.

P2 Ya, Christian, to an extent, um, at the same time um, I’m one of those men who I don’t believe that my god is a god just for the Presbyterians or the Church of England. I believe god is called many names, so I’m quite happy, I mean I did try to read the Koran once and I was so disturbed at what I was taking in I had to put it down it was just too close for comfort. So I’m very easy with other faiths.

Question 7

P1 Well to begin with I think I always knew I was attracted to my own sex. At the same time I think that if things had been a bit different as I grew up there is probably every chance I would have conformed to society and would have married and probably had one or two children but at the same time I have to be honest to myself that in spite of that there would always have been a man in the background. I’m envious of married men, having children, I think watching children grow up knowing that they’re yours, on the other hand I also watched them over the years that you can watch them till the age of 3 or 4, they then become their own individuals and then they can break your heart. So in some ways I’m quite glad I don’t have them. And at the same time being unemployed I can well understand the the hell that some parents must go through when they realise they don’t have a salary, they don’t have, they’re not going to maintain a standard of living and how it’s going to affect the family, I can well understand that.
R1 So if you were to just sum up your feelings about being gay ...

P2 I’m quite happy being gay.
R2 And could you say a little about your coming out, if you have ...

P3 When I first accepted that I was gay and that was when I was 19, 20, although I had one sexual experience before that with another man, I kept it I kept it very very quiet. I did not let anybody in the office know. Although because I worked for the same company for 10 years between 20 and 30, the staff of course suspected because of company dinners, dances, parties, I never brought a girl along. And because I held down my job well I noticed that the Achilles heal as far as they were concerned when they had a few drinks they moved in on the gay side of my character, or the possibility I was gay and at the same time I still tried to give the impression that no, I’m heterosexual but I haven’t met the right girl, yet. Then it was a gradual process, of coming out. But then of course I came out in the early 60s, or I accepted myself in the early 60s. Although certain people were prepared to come out to all and sundry I was not.
R3 So for you it was like around the age of 19 or 20 you accepted it yourself and then for a while you didn’t come out to other people, and then you just started gradually to come out. And would you say that you’re ‘out’ now?

P4 Yes. I don’t tell people I’m gay, but I know even within this estate since I moved in here December ’78, that a number of the neighbours who have lived here since then they have gradually realised over the years that I am gay. Nobody ever says anything but there is a reaction, a nice reaction thank god.
R4  So you don’t have to tell people but they gradually find out and that’s OK.
P5  I think people are intelligent enough. The fact you live on your own, the fact that you’re quite happy to buy flowers in the local market stall, that you keep a cat, um I think they put all these things together, and that’s it.
R5  Is there anything else you’d like to say about what their gradual process of coming out was like for you?
P6  Well of course you always have the bad experiences, um, and I found them more in business than in private life. Otherwise I’ve been lucky I think.
R6  So it’s been a positive experience?
P7  Uh huh. Yup.

Focusing Session

R1  ... so with your attention down there, I’d like you to just kind of say gently inside yourself, where your attention is, ‘what does it really feel like for me to be living with HIV right now’ and just see if some place inside there might be a feeling that begins to come, it might be slight or vague ... (pause) ... does something come inside when you ask yourself that?
P1  Ya, because um, I know, I know I’m living with it much more easily.
R2  OK, and does a kind of a physical feeling come some place in your body when you ask yourself ‘what’s this all just feel like for me?’. It might be a feeling like a little tightness in your chest or a little heaviness in your stomach, or a lightness, it could be anything like a physical feeling that comes down inside the middle part of your body when you ask ‘just what’s it all feel like for me’.
P2  It doesn’t really come from the middle part of my body. It comes from my legs.
R3  OK, so the first thing you notice in your body is your legs. And does it feel OK to have your attention there in your legs where you feel that?
P3  Uhhuh, yup.
R4  And could you say anything just about how it feels there in your legs?
P4  Well now they feel easy but when I came up, when I went out to do some shopping before you arrived, um, coming up the two flights of stairs they felt as usual like lead and I wanted to scream.
R5  OK, yeah. So they felt like lead and you wanted to scream and now they feel a bit easier than that.
P5  They feel much easier, that always happens.
R6  It always happens that it goes from the lead feeling to this easier feeling.
P6  Yup.
R7  I’m wondering if you stay with that easier feeling in your legs if there might be a sense of what that might mean for you. There might be some meaning to that. It might be that if you ask yourself down inside, not in your head but down inside, ‘what’s this about for me this whole feeling in my legs?’ Some feeling might come inside if you ask yourself that.
P7  (pause) I think it’s losing the fear of ... having problems with my legs at some time in the future.
P8  Losing that fear.
P9  Ya.
R9  Almost like there’s a part of you that’s afraid you might have problems in the future with your legs.
P9  Yes, ya. Everytime.
R10  Everytime you have this problem with your legs, it’s about that ...
P10  You know I think it’s just um, it’s just living daily with HIV, it never goes away.
R11  OK, yeah, it’s always there.
P11  It’s always there.
R12  And is there a sense of how that feels inside for you? Just to say that it’s really always there?
Greg Madison, PhD unpublished MA dissertation, 1997, University of Sheffield

It’s always there and at the same time I know I am so so lucky, so far.

So there’s a sense that living with it is always there and another sense that so far you’ve been really lucky.

Yes.

I’m just wondering if you pay attention to the middle part of your body is there any physical sensation there that might somehow be related even though we wouldn’t know how to what we’re talking about? Any tightness or heaviness or anything ...

Only a bit of heaviness.

Uh huh, can you get a sense of where that slight kind of heaviness comes in your body?

Around the tummy.

Maybe just take a minute to check if it would be OK to let your attention go right down inside to where that kind of slight heaviness in your tummy is. Just to check and see if it would feel alright to be down there with it.

No it’s not, OK. And I’m then wondering if it would be OK to be with the part of you wherever that might be that says it’s not ok to be down here.

Ya, that’s in my head.

So there’s something in your head that says it’s not OK to be down with the slight heaviness in your tummy. OK. Would it be OK to be with the part of you in your head?

Yes.

Maybe just to acknowledge it, to say ‘I know there’s that place in my tummy but I have to be with my head here first’ or something.

Yes.

Maybe by being with the place in your head that says don’t go right to your tummy, um you can begin to get some sense of what that place is feeling from it’s point of view, almost like it might have an attitude or something to say from its side.

I guess I could say it’s feeling like it’s staying in control.

Like the place in your head is staying in control. Did I get that right?

Yes, ya. It’s wanting to stay in control.

Ya. And I wonder if just by staying with the part that wants to stay in control if you might get some sense of kind of how it’s feeling or what’s important about this control, or what it’s about for you.

Well I think it comes down to feeling safer, feeling safe.

I wonder if there’s a way to check with that place inside that wants to keep control, to check with it ‘is it like this is more safe somehow?’

Uh huh, it’s about feeling safe, keeping safe.

So it’s the head part keeping you safe and the place that was or is in your tummy. Is it OK to kind of have both parts, like acknowledging that they’re both there?

Uh huh, that’s easy.

I’m wondering if you could spend some time not figuring out or anything but just staying with the place in your head that’s keeping you safe and the slight heaviness in your tummy whatever that’s about and just kind of settling down and having your attention in both places, just seeing if anything comes from that, it might be a memory, a word that describes what it all feels like for you right now, or maybe what it’s connected to in your life having those two places.

 Uh huh, that’s easy.

I’m wondering if you could spend some time not figuring out or anything but just staying with the place in your head that’s keeping you safe and the slight heaviness in your tummy whatever that’s about and just kind of settling down and having your attention in both places, just seeing if anything comes from that, it might be a memory, a word that describes what it all feels like for you right now, or maybe what it’s connected to in your life having those two places.

Well I think it’s just memories. (pause)

Something about memories has you feeling like this right now.

Ya.

And is that OK.

Ya, it’s fine.

And just by staying with it for another minute or so I wondering if you can get
some sense of what it is about those memories, whatever they are, that has you feeling like this right now, kind of slight heaviness and this place that wants to be safe, like there might be something about all those memories that just brings this kind of feeling right now.

P28 OH! ... that’s an easy one ... it’s the love of my life who came here for 2 years. Sexually it was a disaster, mentally there was nothing like it. Ya.

R29 And is there a sense inside that ya, that’s what it is.

P29 Ya, there is.

R30 I wonder if there’s anything that the heaviness might need to feel just a little less heavy now?

P30 (pause) ... I think to know the truth about his death. To know the truth why his friend at that time did not contact me, made no effort to contact me, so I wasn’t there to say goodbye.

R31 So there’s a sense there in your tummy that the feeling is really about needing to know the truth and something about not getting to say goodbye.

P31 Oh ya. And I doubt if I ever will know the truth as to why his friend at that time did not contact me. I don’t think he’ll ever let me know. But then I think he was jealous of the fact that although he was Henry’s lover for many years, Henry and I still had a very very deep special bond. And I basically have to just accept it.

R32 So there’s a realisation that you may never know the truth. Would it be OK to kind of send a message down to the part of you that needs to know almost saying ‘I know you need to know’. Accepting that part that needs to know this, even if it never will. Letting it know you hear what it needs.

P32 Ya, ... ya.

R33 And just to see if you can make an accepting space to welcome any feelings that come inside then.

P33 Ya, ... (participant seems emotional, chewing mouth, verge of tears maybe).

R34 With your attention still down inside I wonder if there’s any sense that something more may need to happen, to be said, or heard, anything that might still need to come right now. Or if it feels like this is kind of OK.

P34 Ya, it’s OK because I have to acknowledge that Henry decided and told his friend what he wanted. And I think mistakenly he thought it was a bad time when in actual fact it would have been fine.

R35 Like he was trying to help but it didn’t turn out that way... (pause) ... and you might want to just acknowledge that all those feelings are there, so the part of you holding it all knows you’re with it.

P35 Yes, it always will ... (pause) ... all those years ago, 5 years ago, I should have been more assertive and gone to Wales, and seen both of them. I was too easy then.

R36 Knowing what you know now, the way it worked out, if you could do it again you would have been more assertive.

P36 Uh huh, yes. It’s too late now... (pause) ...uh huh.

R37 Is there anything else that feels a little unfinished with this now?

P37 Well it would be so wonderful to bump into Henry’s brother. He might be able to answer the questions the friend wouldn’t answer.

R38 Could you get a physical sense of how wonderful it would really feel just to run into him?

P38 I would be elated.

R39 And can you feel a bit of that now if you just imagine that happening?

P39 Yes. Yes. Uh huh.

(we gently finish off the Focusing session by slowly moving away from the feelings)

Post-Focusing Questions

Question 1
P1  Remembering him here. The fact that he was, he had to study every weekend because he was becoming a chartered accountant. So the flat was always very quiet ... (pause) ... it was a very easy relationship. Yes, remembering those times.

R1  Is there anything else you’d like to say about what happened for you during that self-reflection?

P2  Oh yes, and the first time I met his big brother who was the same age as myself. Big brother didn’t know but could only wonder if his younger brother had told me the truth that he used to interfere with him as a smaller boy, I wasn’t very happy with his big brother at that time.

Question 2
P1  Yup ...(pause) ... 
R1  Was that the feeling in your stomach, or ...
P2  Ya.

Question 3
P1  Not really, no.
R1  This is something you’ve done before or
P2  Many times.
R2  OK

Question 4
P1  Yup. Ya, I suppose Henry was being Henry and he didn’t want me to worry or be down, and his friend had to do what he asked.
R1  OK, almost like something new in realising that Henry was -
P2  In control. yes, the friend was only doing what he was told.
R2  And that became a bit clearer here?
P3  Yes.

Question 5
P1  It was helpful, hmm.
R1  OK, in some way helpful.

Question 6
P1  I think it makes it clear to me that I’ve got to try and get in touch with Henry’s friend. It will be hard to get in touch, I mean he’s probably sold up packed up and gone elsewhere.
R1  It might be difficult to actually locate him. But from this time it seems there’s an action that seems right.
P2  Uh huh. Ya, and the same is true of Henry’s brother although it might be easier to locate him.
R2  And out of this experience now it seems it would be the right thing for you to try to make those two contacts.
P3  Yes.
R3  Does it feel OK to come out of it with those two action steps?
P4  Oh definitely.
(further discussion)

P5  It was a good reflection, good time of the year to do it. Because um, the two years that Henry came and went here he always went home for the holidays and when the relationship, although the so-called affair came to an end after two years and we were still the best of friends, and we used to laugh, he found it amusing that I had a tradition Easter morning of playing (an opera) and the second Easter before he went home I made him sit and listen and understand why I listened to it. And from then on I think that he also listened to it. But then he liked music too.
R5  So this time of year is especially relevant.
P6  For this particular piece of music.
R6  Ya. And for this memory.
P7  And for this whole memory, ya.