

Chapter 9

Understanding How Individuals Construct Their Discourse of HIV/AIDS

Introduction

As discussed in the previous chapter diagnosis of seroconversion, together with the implications of diagnosis, are social objects that have been described and defined by elements of the common sense discourse of HIV/AIDS. Individuals interact with these socially defined objects and frequently are overpowered, initially, by the objects' socially defined meaning. As a consequence individuals are faced with the dilemma of reconceptualising their self-image. Since the common sense discourse categorises individuals infected with the virus as having a rapidly fatal, infectious disease, informants immediately perceived themselves to have begun the dying trajectory and to have a strictly limited life-span. That is, they thought that their health would deteriorate rapidly and they would die an undignified death within a relatively short period. These individuals continued to experience varying degrees of emotional turmoil until they were able to distance themselves from the influence of these powerful elements of the common sense discourse. Creating distance from the intensity of their situation enables individuals to recognise that their subjective experience differs from that categorised by the common sense discourse. It also enables them to acknowledge the validity of their subjective reality. In beginning to accept this difference individuals then interact with different social objects - the personal implications of diagnosis and the daily living with HIV/AIDS. It is important to understand how individuals define these objects and respond to this interaction for it is through this cluster of objects that individuals develop a structure within which they make meaning of their new situation, in particular, facing their impending death.

Although successfully challenging some elements of the common sense discourse informants are not able to completely escape the influence of all elements of the discourses of HIV/AIDS and homosexuality. Despite rejecting, for themselves, the social identity of the other, individuals believe that other members of the society are still influenced by the common sense discourse and still react negatively toward infected individuals. This

perception is fuelled by the Australian mainstream media's continued coverage of the disease.

The development of a self-image and subjective reality that differs from the common sense discourse and, at the same time, have the self influenced by other elements of the common sense discourse, creates a duality of existence which presents individuals with a major dilemma: how to interact with the daily experience of living with HIV/AIDS when the self is liberated, in some respects, from the influence of the common sense discourse but, at the same time, the self is also influenced by social interaction with other members of the community and internalisation of the generalised other.

The purpose of this chapter is to analyse the responses of individuals to the ongoing subjective experience of living with HIV/AIDS and, in particular, how they interact with their imagined future. The chapter begins with a brief examination of how individuals' responses concerning disclosure of their HIV and illness status are influenced by their interpretation of interaction with others and the perceived possibility of rejection. An analysis of the disruption to social relations follows, with particular emphasis on the impact of individuals' interaction in specific situations which initially appear to be familiar and have a known configuration of meanings. This analysis raises the issues of whether non-infected members of society are responding to issues of morality or mortality and why individuals' concerns about their experiences of living with HIV/AIDS are not heard. The influence of personal perspectives on living with HIV/AIDS and the influence of HIV/AIDS on personal perspectives is explored. In examining how individuals interact with imagined future scenarios, particularly dreaded issues, the questions concerning what triggers thoughts of the future, what type of future individuals construct and what emotional responses they have to these dreaded issues is addressed.

Interaction with others

The common sense discourse focus on the other and the related social issues, rather than the medical issues of the virus and its effects, has serious implications for informants and their social interaction with others. Results from the current study support the findings of Minichiello (1992) that suggest disclosure and concealment of HIV status appears to be contingent on a complex interaction of individuals learned perceptions of the stigma

associated with homosexuality and the disease, actual experiences of informing others, the nature of the relationship and the individual's interpretation of it. All informants in the current study were wary of social interaction that they perceive might result in their rejection and took action to distance themselves from the prospect of such rejection. In many cases they indicate that it is the belief that others would reject them if they disclosed their HIV status.

Rejection can take a number of forms including rejection from family of origin, significant others, friends, health care professionals (HCPs), social contacts and casual sexual partners. For example, although Kyle states that he tries to believe that there is nothing personal in people's reaction to his KS lesions (extract **8.36** page 259) he indicates that he has become secretive and furtive and avoids going to places unless he feels "totally secure" (extract **8.35** page 259). He also indicates that he experiences considerable emotional anguish when he is rejected in this way. He describes an incident and his response:

9.1 Kyle: Like everybody — I want to be accepted. I mean, when — you've got a situation where you've been at the pub and you roll up your sleeves, and somebody — and you're talking to somebody for three quarters of an hour, and you're having a wonderful time, no sex, nothing involved, no pick ups, and they see your arms and then get up and walk away.

Interviewer: So what's that like for you? What does that do for you?

Kyle: Well, it destroys you! It destroys you because you are being judged — by a condition — you're not being judged as an individual — you're not saying "Hey I don't like this person because — you know, he sells heroin to five year olds" or "I don't like this person because he goes out and kidnaps three year olds and forces them to have sex". *You are judged by your appearance — and a possible medical condition.* [Emphasis added] (Kyle, 1 1432-1467)

For Kyle the most hurtful aspect of this rejection is that it is based on people's response to the signification of the effects of the virus rather than any aspect of his personality. Kyle also reports that the most insidious aspect of living with KS is the visibility of the lesions robs him of his "right to disclose" his HIV and health status. Kyle states that, particularly within the gay community, someone with Kaposi's is:

9.2 ... walking around with an invisible sign that says "I have full blown AIDS".... I mean, there's nothing wrong with having full blown AIDS — *the point is it takes away your right to disclose. And the right to choose who you tell. So you have no choice of privacy.... Kaposi's takes away your right of privacy!* Now everybody has that right — in their medical conditions — I mean, even the boys who have mace and become skeletal — I mean, they can turn around and say to somebody — "Hey, I've got, you know, cancer". — Mine just says

succinctly “AIDS!” — because the only people who get Kaposi’s are elderly Mediterranean people — ahhh — people who have gone through transplants get Kaposi’s, but it clears up straight away with Interferon — uhm — or elderly Jewish people. — *So you have no choice of privacy.* It’s not as though you’re going to mislead anyone — but if I walked into the PLWA Drop-In Centre with my arms like that — right, and sleeves rolled up, people would look at me and say “That person has full blown AIDS” — I don’t even have the right to disclose. [Emphasis added] (Key, 1642-656; 1468-1498)

Fear of being rejected as a person makes informants reluctant to disclose their HIV status to others, particularly to their family of origin. Informants initially suggest that they choose not to disclose to their family because the news might upset them. However, as the interviews progress informants begin to speak about their fear of rejection. For example, in discussing the circumstances surrounding disclosure of his sexuality to his parents (during his hospitalisation after his suicide attempt) Geoff provides reasons why he had refrained from earlier disclosure. However, his interpretation of his parents’ expected attitudes and their reaction to his homosexuality proved to be false:

9.3 Geoff: My expectations was that my Dad who’s a real hard um well he’s quite a hard labour man, he would be the hardest person to face and my mother would be very understanding. It was in fact the opposite. My mother was, and to this day doesn’t really understand although she thinks that the sun shines out of ... [partner’s name] bum, she really loves him, um Dad was very, very understanding and — very supportive and to this day Mum and Dad are wonderful. *The only deal I’ve made with them is that, that I wouldn’t discuss my relationships, etcetera, or my sexuality with close family in ... [family’s home town] because they’d feel uncomfortable.* I’ve discussed my sexuality with them but I haven’t told my parents that I’m HIV positive, although that time is, is approaching I think.

Interviewer: What stopped you from telling them?

Geoff: I didn’t think it was appropriate um they’ve had a lot of things to deal with in the family anyway and *I’ve always been seen as the strong one in the family. I’m the only one that went to uni. and got out of ... [family’s home town] sort of thing. Um Dad’s always saying how proud he is and everything else.* I think I, my, my judgement on the whole issue was that I don’t think it’s appropriate to tell them because I’m well and I have been for nine, up till this year, and just lately I’ve started becoming ill and T-cells are only 20 at the moment. Um now that I’m becoming ill I think I’d better start thinking about preparing the family in case I get worse or whatever. So because I was well for nine, eight, eight to nine years I didn’t think it was necessary to tell them. (Geoff, 1621-636; 648-664)

It is clear from this extract that in deciding whether to disclose his sexuality to his parents Geoff is interacting with the previously developed image he has of his father (as “a hard

labour man”) and, consequently, he would be the “hardest person to face”. However, his perceptions were proved wrong. Despite his father’s unexpected behaviour it appears that Geoff continues to interact with his previously perceived image of his father when deciding not to disclose his HIV status. Geoff alludes to the possibility of his father rejecting him if he discloses that his health status. It is also clear that in this scenario Geoff is also interacting with the self-image he developed through interaction with his family of origin (“the strong one in the family” and the one of whom dad is proud). The possibility of being forced to give up this self-image is a contributing factor to Geoff’s decision not to disclose his HIV status. It is also evident that another contributing factor is Geoff’s perception of his parents response to disclosure of his sexuality. After informing his parents of his sexuality Geoff agrees not to discuss the issue, or his relationships, with other close family members in his home town because his parents would feel uncomfortable about other people knowing. There is little doubt that his parents’ request, regarding non discussion of the situation with other family members or friends, adds to Geoff’s perception of the stigma associated with homosexuality. Furthermore, Geoff’s comments about his situation in the family and his father’s pride indicates that Geoff’s interpretation is that disclosure of his HIV status might prove too much for his parents who may, in turn, reject him because of the stigma associated with HIV/AIDS.

The fear of rejection and being blamed for transmitting the virus is so strong that one informant (Mitch) refused to disclose his own HIV status even when a previous casual sexual partner contacted Mitch to advise him that since their sexual activity he had discovered that he was HIV-positive. Although this man informed Mitch that he’d engaged in unsafe sexual activity with someone else Mitch was still too afraid to disclose his own HIV status.

9.4 Even when someone who I had sex with told me he was HIV, he found out afterwards that he was, we’d had safe sex, um — I clamed up, I couldn't tell him, I mean *I was too scared to tell him, I thought he'll blame me for getting it*, whereas he'd already told me he'd had unsafe sex with another guy. [Emphasis added] (Mitch, I 1476-1488)

Responding to issues of morality or mortality?

A number of informants experienced situations which initially appear to be familiar and have a known configuration of meaning, for example, seeking medical attention (see extract **8.28**, **8.29**, and **8.30** on pages 254-256). However, in these situations routine social

interaction was disrupted in that some health care professionals did not respond in ways expected by informants. Initially an explanation for this practice may be sought in the social issues emphasized by mainstream media reporting of the disease (e.g., homosexuality, immorality, deviance). It is possible that a link may exist between health care professionals' (HCPs') personal opinions concerning these social issues and their responses to those individuals living with HIV/AIDS. That is, those HCPs who perceive homosexual behaviour and lifestyle as either deviant, abhorrent or immoral may be the ones who avoid individuals infected with the virus. However, since informants in the current study also experienced similar 'discrimination' and the creation of social distance between some members of the gay community and themselves (see extracts **8.31**, **8.32**, **8.34**, **8.35** and **8.36** pages 257-259), it is unlikely that social issues such as morality, homosexuality, and participation in socially defined deviant subcultures alone account for the behaviour of these particular non-infected individuals. Therefore, it is important to look to some other aspect of the disease rather than its social construction to provide a reason for this avoidance.

Evidence from the current study suggests that it is the association between the virus and death that results in the creation of social distance between people living with HIV/AIDS and non-infected individuals, both gay and non-gay. This specific link is made by one informant, particularly in respect to the gay community (see extract **8.36** page 259). This informant suggests that people avoid social interaction with him not only because the KS lesions are so visible and are a reminder that he has an opportunistic infection resulting from HIV but also because the lesions represent inevitable death. He believes that he is "judged" and rejected because of a "medical condition" rather than his behaviour (see extract **9.1** page 277).

The commonly held community attitudes toward death and the common practice, even among HCPs, of avoiding discussion of the emotional difficulties associated with dying are identified by another informant as a form of social isolation and a situation which creates difficult emotional dilemmas for him. This informant openly discusses the difficulty he has even raising these issues with a range of people. He believes that when he raises these issues with people they "hear what they want to hear" but do not hear his emotional pain.

Consequently, Stan believes that the only people who “hear” him are others who are going through the same experience:

9.5 Stan: See it’s hard, how do I, how do I say it. Yes, I can talk to people about it and I can talk to ...[current partner] about it and I can talk to my psychologist at ...[named hospital] about it ... but they’re not in that situation, maybe they are and they don’t realise it, I don’t know, but they’re not in that situation and um it just doesn’t have a sense of honesty about it. They tend to say “Oh, well, what would you do?” And you talk yourself through it anyways um or they say “Oh, look, you’ll get better” or you know “There are things you can do to, you know, keep yourself occupied and why” — or even worse — “Look, you’re OK, don’t be so bloody, you know, whingeing” and so on, and, and *you get a range of views but none of them are really heart-felt* because they just are not in that situation, and I guess my friend is very much going through the same thing, and is, and there’s just that bonding because of that, so we talk about it. And therefore *if he went [died] it would suddenly take away an outlet for my emotions, it would go, yes.*

Interviewer: Are you actually saying that, that there are some people, even though you’re able to talk to them, that don’t really hear what you’re saying?

Stan: Yeah. Yeah. *They hear what they want to hear. And or they, it’s discounted or they interpret it or whatever they do with it.*

Interviewer: But they don’t hear what it’s like for you?

Stan: They don’t hear. That’s right. They say, “Well — you’re going to be OK. You look fine today. Don’t worry about it. Er or um let’s do this and this and this and I’m saying “Well that’s three years down the road”.

Interviewer: And it sounds to me like there are some times, not all the time, but there are sometimes you, you want to and need for yourself to, to actually face what’s happening to you.

Stan: Yes.

Interviewer: And talk through your emotions?

Stan: That’s right. Dump them all out without being, without being um having someone be critical of it, or having, or in a sense being analytical of it, just having someone say “Yeah, I’ve been there, and it’s pretty hard too, isn’t it?” or that’s a shit sort of thing. Um just being able to do that.

Interviewer: And you don’t think anybody that’s not in that situation can, actually hear the pain? The emotional pain?

Stan: That’s what I’m saying. In my experience, that’s the case.

Interviewer: That nobody can hear the emotional pain?

Stan: No, that’s right, ... um the only difference between this [HIV/AIDS] and any other natural occurring thing [death] is this, that this speeds up the death, the life cycle, it says ‘You’ve got to be, you’ve got to go through high speed emotional development and maturity to cope with this thing, it’s going to happen sooner than it is later’, um — but everybody else is too, and *most people aren’t prepared for it, and that’s the thing, is that you confront people with it and they don’t want to talk about it, they really don’t want to talk about it.*

Interviewer: Don’t want to talk about what?

Stan: *Death.* [Emphasis added] (Stan, 1904-2063)

A number of important issues are raised in this extract. Firstly, in interacting with his imagined future (deteriorating health and inevitable death) Stan is beginning to develop a self-image of a person who is dying. In interacting with this self-image Stan has a need to discuss issues relating to his current life and future. This need is currently being met by a close friend who has developed opportunistic infections and appears closer to death than Stan. Secondly, Stan is fearful of what will happen when his friend dies. He believes that although he can 'talk' about his experiences with other people (e.g., current partner, psychologist he is consulting) their responses are not "heart-felt" because they are not going through the same experience. Stan believes these people "hear what they want to hear" or, more importantly, make interpretations of his responses which he then interprets as discounting his experiences.

It is apparent that, in consulting a psychologist, Stan was entering a situation with a known configuration of meaning and expectations of how participants would engage in interaction. It is also apparent that Stan's expectations about how the psychologist would act were not met. That is, Stan expected to be able to talk through his experiences, have them heard and acknowledged by the psychologist. In turn, this action would enable Stan to validate his experiences. However, Stan perceives the responses from the psychologist as platitudinous and unhelpful. This adds to Stan's fear of his friend's impending death as he believes that then he will not have anyone else with whom he can discuss these important issues.

The issue of people not hearing the subjective experience of individuals living with a life-threatening disease and not being able to adequately respond to the emotions aroused by this experience is crucial to the provision of support for individuals living with a life-threatening illness. In routine social interaction this may occur because the topic of death is embarrassing or upsetting and people avoid both the subject and the emotions aroused by it in order to maintain smooth social relations and conduct rather than denying death (Kellehear 1984). The issue of HCPs avoiding emotional issues has been raised elsewhere (e.g., Bor & Miller 1988; Peräkylä & Bor 1990; Siegel & Weinstein 1983). The critical issue appears to be that HCPs do not effectively hear the subjective claims of individuals confronting their impending death or adequately respond to the strength of emotions this experience engenders. An explanation for this phenomenon is that the discourse patients use to discuss their experiences differs from the professional discourses of dying and death

used by HCPs. That is, in using a different conceptual framework HCPs may not be trained to hear and, therefore, understand an individual's alternative perspective and subsequent interpretation of their experiences. This is also an important issue for individuals living with a life-threatening form of cancer and will be discussed in detail in Chapter Ten.

Personal perspectives and living with HIV/AIDS

Prior to diagnosis of seroconversion individuals have an established perspective or way of interpreting objects with which they interact within the context of their daily lives. Although diagnosis may be classed as an extraordinary event it is still a social object that occurs within the context of individuals' organised daily routine and structure. That is, diagnosis occurs while individuals are engaged in routine daily activities such as interacting with work, colleagues, friends, shopping and cleaning the house. After their initial response to diagnosis, which is frequently overpowered by the common sense discourse, individuals use this established perspective to interact with and interpret the implications of their seroconversion. Furthermore, this frame of reference is used to assess and select appropriate responses to the ongoing daily living with HIV/AIDS. Individuals' responses to the acknowledgement of their now limited life span and the implications of their HIV status vary. For some individuals their frame of reference is such that it can readily incorporate the experience of diagnosis and its implications without requiring major change. However, for others it appears as though confronting the prospect of their own death destabilises their frame of reference and prompts critical re-evaluation of their perspective about life and a reappraisal of objects considered to be personally significant.

No changes in frame of reference

Three informants in the current study indicated that their frame of reference did not change appreciably after diagnosis. The significant issue is that, after their initial reaction to diagnosis, these individuals did not perceive their HIV status as inhibiting them from engaging in routine daily activity. That is, each of these individuals did not perceive that their HIV status encroached significantly upon their normal interaction with other social objects. Consequently, each of these informants did not make critical changes to their lifestyle. However, each appeared to have slightly different perspective on life and how they made meaning of their interaction with social objects. One informant has a perspective that approaches life with a positive attitude and perceives it as a series of challenges; the

second informant has a laissez-faire perspective; the third informant operates from a controlling perspective.

Life challenges perspective

One informant operates from a perspective that sees life as busy and full of a series of challenges. Within this perspective he acknowledges his HIV status as one of the challenges that life has presented and proceeds to live his life to the best of his capacity. He describes this perspective as:

- 9.6** I think that life force — that energy that you get — from not being negative — is something that keeps you going, I think — And I don't see it as being denial. I think in a sense it's a challenge.... I think if you've got lots of things going on in your life anyway, and you're motivated and you see everything as being a bit of a challenge, something you've got to do, I think that's where that thing comes from — finding so many things that are a challenge to prove that you can do them for yourself too, I think is one thing.... I think you've got to continually challenge yourself with new experiences all the time.... I guess it's setting yourself challenges — which keep you motivated. (Keith, l 537-542; 843-851; 941; 1945-1946)

Keith does not distinguish between routine daily activities and HIV-related experiences, and provides the following explanation:

- 9.7** Well, only because I think they're interrelated. I don't think you can separate the fact that you're HIV with uhm — well I don't think you can say “Oh well I'm HIV therefore I won't do this or I won't do that.” I just think “Well, you're HIV but at the moment it hasn't affected — it's not affecting you in any way at all that's going to change your life, so you don't change your life, until you've physically forced to change it.” Ahhh — and I really do think that a negative approach will bring on the disease a lot faster, I really do believe that. And I think — [SIGHS] you know, that whole cliché quality of life. Well you don't kind of all of a sudden go into a black hole for the next six or seven or eight years 'cause who knows, it could hit me tomorrow, I don't know. But you don't — eight years, nine years ago, if I decided “Oh, it's all dreadful, it's all dreadful”, I mean, I'm HIV — well you wouldn't have gone — I wouldn't have gone to Italy, I wouldn't have gone to India, I wouldn't ever have done anything, because I would think “What's the point I'm going to be dead”. *Well everybody's going to be dead.* [Emphasis added] (Keith, l 2006-2044)

It appears from this extract that another aspect of Keith's perspective on life is an acceptance that death is a normal part of life and the event is not something to be feared. (However, as will be discussed below, Keith is afraid of the process of dying.) Perhaps it is this acceptance of death as part of the natural process of life that frees Keith to face the challenges of life rather focussing on the “negative” aspects of illness.

Keith applies his prediagnosis perspective, or “philosophy”, to his experience of living with HIV:

9.8 ... it’s a matter of getting yourself — I don’t know, just getting yourself motivated all the time. I mean, there’s no time to be sitting around getting bored. I get very frustrated with people who say they are bored. And I keep thinking, oh well in terms of my disease as well, “Who’s got time to be bored?” But then, *I’ve always had that philosophy anyway*. [Emphasis added] (Keith, 1967-976)

Keith makes the comment that he is too busy meeting the range of challenges in life, including those related to his HIV status to think or worry about negatives or his probable future:

9.9 I really don’t think that you’ve got time to be thinking about it. You can’t dwell on the negatives of what will happen — because what this does is just put a cloud over everything, and you can’t enjoy what you’re doing, so I think you just go on doing whatever you do — I went to ... [named] University yesterday and enrolled for my PhD.... and they said to me “Oh you realise that it will probably take you at least seven years?” and I thought “Yeah, well I probably haven’t got seven years”, but I ok, that’s what I want to do. Now I’ll start doing it, and if I get ill and I can’t go on with it, which I expect I will get ill and I won’t be able to go on with it but that doesn’t mean that I sit back and think “Oh well I really wished I had a go at my PhD”. You just do it! ... I just think — this is just the way it is. Some of us — some of us have got the disease and some of us haven’t. And those who haven’t are very fortunate and those who have just have to deal with it and just cope the best you can. There’s no way of saying ‘Oh I wish it hadn’t happened to me’, or ‘If I hadn’t done this, or I hadn’t been there —’, I mean, it’s all pointless. It’s absolutely pointless, I mean, you’ve got to look to the strengths of — of you existence as it is now — like your friends and your boyfriend and — and — ahhh — not go around weeping and wailing. It’s not going to do anybody any good. (Keith, 1100-131; 387-405)

From this extract and extract **8.17** (page 247) it is apparent that Keith has been able to apply his personal philosophy of life to redefining the social meaning of diagnosis to one of a more individually relevant nature. That is, Keith has redefined the social objects of diagnosis and its implications within the boundaries of his personal perspective about life and the challenges it presents. Having done so he believes there is no reason to allow his HIV status to interfere with his life. An integral aspect of his perspective is his belief that focusing on the “inevitability” of his probable future is a negative experience. Throughout

his narrative he makes a number of comments about not making changes to his lifestyle because of his HIV status:

9.10 I haven't changed my lifestyle any great deal. At any time I physically haven't felt that I'm ill — and even now I'm still 800 T-cell, I mean, I've only dropped 200 in over about eighteen months — So, and the doctor said to me last week that I'm as healthy as a cow — still — and she said “Whatever you're doing, just keep on doing what ever you're doing. It's obviously working.” *Well, I mean, I think that whole thing of focussing on the future and the inevitability and what will happen — is a recipe for depression....* I don't not do anything that I want to do. I still go travelling. I went away to India last Christmas — for a month [Emphasis added] (Keith, l 197-212; 1378-1381)

Through interaction with his partner Keith obtains significant support that enables him to maintain his personal philosophy. Speaking about his partner Keith says::

9.11 ... he's actually extremely supportive.... He just thinks “Look until something dreadful happens and you have to be hospitalised, or you have to have a nurse in, nothing is changed, still have sex with a condom, and you just get on with it”, and I think he's a great support in those terms too. He doesn't look at me as some kind of leper and want to throw me out the door and — ahhh — like I mean, I know other people whose boyfriends kind of — haven't taken too kindly to find out they're HIV. Well he's never done that. (Keith, l 1388-1404)

Social interaction with friends, who have a similar approach to life and living with HIV/AIDS, provides additional support for Keith's perspective on life. His friends also set themselves challenges:

9.12 I think ... in their own career paths that they've chosen, or their own kind of area of creativity that they've chosen, yeah I think they continually kind of set themselves up challenges, and it's a challenge to succeed too I think and to prove that they can do what they're setting out to do, especially the artist ones who are kind of holding exhibitions and painting away madly and doing all that and becoming successful in what they're doing. It's a challenge they set up and — ahhh — they're not afraid to fail either. It's a matter of “Alright, we'll give this a go and — hopefully it'll work”, and I think it's setting themselves a challenge and trying to prove that they can do it for themselves. It's not like saying — “Oh well I might not — you know, I might fail in that or I might not succeed in that so I wont have a go” (Keith, l 984-994; 1010-1028)

This perspective enables the individual to engage in effective social interaction on a daily basis. It's focus is on the living of life, acknowledging that situations confronting individuals are not always going to be easy and may challenge the individual to learn new ways of coping. At the same time it is not congruent with the professional discourse of anticipatory grief. Adherents to this latter discourse could claim that this informant is in

denial about the impact of his of his HIV status in that he does not acknowledge the emotional impact of future losses. However, this would be a serious misunderstanding of Keith's frame of reference and the importance challenges have for him in living his daily life.

Laissez-faire perspective

Another informant has a more passive approach to life. Mark outlines his support for the belief that individuals' perspective on life influences their interaction with diagnosis and the implications of seroconversion and their subsequent ability to "cope" with their HIV-related experiences. Marks states:

9.13 ... as far as people's coping with it [being HIV-positive], it just depends on their own emotional, their own makeup, their own strength. Um with friends of mine who have discovered they were positive I mean a lot of them were emotional wrecks, I mean, but they were emotional wrecks before that anyway, um so I think it's just the way you handle yourself, the type of person you are. Um — no, I'm sort of in control of it, in control of my feelings toward it at this stage. As I said, as it goes further down the track it all could change. (Mark, l 689-706)

In interacting with the knowledge of his HIV status Mark finds it difficult to believe his seroconversion because of the absence of observable symptoms (see extract **8.12** page 241). This reflects his passive approach to situations: at the time of interview he does not have symptoms that interfere with his life, consequently, there is really nothing for him to worry about. In the above extract Mark acknowledges that his responses may change when he begins to experience physical changes and begins to interact with these new social objects. However, until that situation occurs Mark considers there is no reason to change his lifestyle. In support of this decision Mark comments:

9.14 I'm not the one to sort of sit here and depress myself over it because um unless there's a cure — there's just nothing I can do, I mean I can sit here and worry, you know, eight hours a night it won't change it, so I don't worry about it. (Mark, l 486-493)

In discussing why he does not engage in contemplating his future and how it might be affected by his HIV status Mark provides clarification of his personal perspective of life: he does not believe in thinking "too far ahead". Mark says that even prior to his diagnosis he thought of the future:

9.15 ... more in months, um I usually just plod along with life um I've never really made too many long distance plans or commitments so um with life and, you

know, we can make plans and then — I've got friends who live by the calendar and, you know, and on, you know, 31st July 1994 we're going to do this, but um nine, nine out of ten times it never works, um so I think in a way it's good to have goals, I think, I have had little goals my life and sort of gone through them, but um in a way if you make long term plans I think um you disappoint yourself a lot. People change, our ideas change, um you might plan something for next year and um we're all subject to change, you know, our feelings might change, our emotions um you might have the long term plans and you know you can change them four or five times within a space of time. (Mark, 1 762-787)

The importance of this perspective is that it also allows the individual to function effectively in social interaction. It is also not congruent with the professional discourse of anticipatory grief. Like the previous perspective, adherents to the professional discourse of anticipatory grief could make a case for Mark being in denial about the impact of his future losses. However, since Mitch only thinks in terms of a few months when normally considering his future and currently he is not experiencing any specific symptoms or deteriorating health his 'routine' future is not affected. Therefore there is no need for him to be concerned.

Control through rebellion perspective

The third informant who indicates that he made no changes to his post-diagnosis lifestyle provides an insight into a different approach to life - one of taking control of his situation through rebellion. The importance of control for Kyle is demonstrated throughout his narrative by constant references to the most significant aspect of KS: it takes away his "right to privacy" and his "right to disclose" his health status when he chooses rather than others immediately knowing his has AIDS because of the visibility of the lesions (see extract 9.2 page 277). However, in an attempt to regain some control for himself Kyle uses a pre-tanning lotion to cover the lesions so that he can engage in routine social activities (see extract 8.35 page 259). He also took control of his treatment regime and "demanded" time off once a month:

9.16 And I crack the shits, excuse me, literally crack the shits. I demanded a day off a month, and I had to fight like cat and dog to get that.

Interviewer: A day off what?

Kyle: From the treatment. I mean, — it's — I — quite frankly, I spend more time at ...[named hospital] than most part time workers have a job. Right? And I wanted something different. I wanted a break from the routine, so I said I wanted a day off a month. Uhm ... which sort of didn't go down very well. (Kyle, 1 846-873)

Kyle believes he is a “born survivor” and does not see the need to change his approach to the struggles of life. In discussing his approach to his HIV status he says there is:

9.17 ... none of this positive thinking as in “Hey every night I will meditate for five minutes and you know, imagine my T-cells increasing in numbers” — uhm — I still drink the same amount of alcohol, which would be anywhere from nothing to seven glasses of wine a week, depending — I still went out in the early stages. I still smoke dope — I didn’t take chemicals, as in speed or reekies or anything like that and I think that’s one of the reasons why I’m still alive.

Interviewer: But you didn’t change your lifestyle?

Kyle: Absolutely not! No! Why should I? I mean to say if I’m not putting anyone in physical danger, if I’m not — uhm —hurting anyone, as in emotionally, by my actions -- if I am earning a living — and if I am responsible enough to have the test and have myself monitored, why in the friggin’ hell should I change my lifestyle. I mean, you — you tell me — because I get annoyed with that because people who tell you to change your lifestyle are actually controlling your life. They don’t give you the choice. Now, my definition is — of whatever I do — I choose that. (Kyle, l 2150-2199)

Although Kyle’s interaction with others is influenced by his perception of their responses, particularly their “rejection” because of his KS lesions (see extract **8.35** page 259), he does not make major changes to his general lifestyle. He still engages in prediagnosis activities such as attending gay venues and puts and ‘cruising beats’ (albeit after attempting to cover his KS lesions with pre-tanning lotion):

9.18 I didn't engage in any unsafe sex practices — but I certainly went to ...[named gay venue] — because for me to meet a partner in the regular social context of communication, etc., etc., at any of the social venues was fine. (Kyle, l 431-435)

The importance of this perspective is that it enables the individual to have some control over the way he lives his life with the virus. However, it may lead to difficulties in some social interactions. For example, HCPs may expect compliant behaviour when interacting with Kyle as a patient receiving treatment and misinterpret his ‘rebellion’ as aggression rather than assertion.

Changing priorities or lifestyles

Some individuals appear to be influenced by the inevitability of the end result of infection with the virus - death - and interact with their own imagined death as the social object. These individuals respond to the perception that their life span is now limited. In this

situation the discourse of grief defines and categorises ways individuals are expected to respond, that is, by acknowledging anticipated losses and engaging in the grieving process. However, some individuals in the current study did not respond in this way. In interacting with their imagined death, and in choosing to respond to their illness experience by making certain changes to their lifestyle or priorities, these individuals appear to be influenced by three different perspectives. These perspectives have been called the 'self-centred' perspective, the 'prophetic' perspective and the 'self-awareness' perspective. The difference between these perspectives lies in their focus.

The self-centred perspective

The focus of this perspective is life-centred. That is, individuals using this perspective respond by perceiving that they had sufficient time before their death to enable them to embark on accomplishing self-defined important activities, goals or outcomes. This has important ramifications for individuals who appear dissatisfied in some way with aspects of their current life, perceive it to be unfulfilling or preoccupied with completing tasks that are primarily socially defined as meaningful. In developing a new self-image that incorporates the understanding that their life-span is now limited, and interacting with this new self-image individuals assess new response options, for example, continuation of their current, personally unfulfilling lifestyle and undertaking a more self-fulfilling and personally meaningful lifestyle. As a consequence of assessing these options individuals begin to perceive a need to re-evaluate their goals and priorities in life or ways of living life. What were once considered as important motivating factors in their life (e.g., climbing the corporate ladder, establishing a private business) are superseded by other, less economically driven factors (e.g., spending more time with significant others and friends, embarking on travel).

An example of this perspective is demonstrated by Mitch, a professional health care worker in private practice, whose initial response to his diagnosis was quite dramatic (see extract 8.2 page 235). However, his "hysteria" decreased as his symptoms abated. He then realised that his subjective experience differed to that defined by the common sense discourse of HIV/AIDS. Since he now believed that he had some future, albeit of unknown length, he realised that he needed to reevaluate his priorities. Talking about that period in his life Mitch says:

9.19 ... that's when I started to realise 'Well, you know, it's not all happening right now. There, there is, there is still time there for me to do things' and *I started to set priorities then* and travel is one thing I've always wanted, I wanted to go overseas um — I stopped allowing other people to push me around or tell me what to do all the time, like in a relationship I got — I suppose I sort of felt I was a bit — pushed around at some stage so I started to think 'No, it's look after me and I'm going to make my decisions from now on and bugger other people'. And I did go a lot like that ... when ...[ex partner] and I split up. I sort of started thinking 'Well I'm looking after myself now and I feel much better about it and I feel good. I'm taking this new direction' and I felt really good about myself then. [Emphasis added] (Mitch 1, 1364-1388)

Experiences gained during his overseas travel facilitated Mitch's reconceptualisation of his self-image (see extract **8.42** page 264). Mitch also indicates that at this time his attitude was:

9.20 ... there's nothing wrong now, so why worry about it? Just keep — keep going and keep on — living.... Physically, there was no outward sign that there was anything wrong with me.

Interviewer: Right. So you still knew that you were HIV positive?

Mitch: Yes.

Interviewer: You weren't saying that 'I'm not positive'?

Mitch: Oh no, no, I'm not stupid. And I would never try to deny something. It's not possible. No, I'm — I'm happy to — happy? I'm trying to admit, you know I'll admit it, OK, that I've got it. I know what the possibilities may be um but again if — if I allow myself to keep thinking like that I'll only get depressed again. I don't see the point in that. It just doesn't make sense to think about that. Because, yeah, there's going to be a time, and this is *probably what I'm scared of now, there will be a time when I can't say well I can put that away for now* because it's not happening. I mean it's going to come eventually when I can't say that any more and I'd rather worry about it then.... I sort of feel that ... it's still silly for me to expect nothing's ever going to happen but at the same time I'm not waiting for it to happen now. [Emphasis added] (Mitch, 1 1586-1637; 1674-1678)

This extract indicates that although Mitch does not think about his HIV status very much he is not in denial about the infection. Rather he puts thoughts about the illness "away" and gets on with doing the things that he now considers important. He also realises that a time will come when he will have to confront the thought of his deteriorating health and death. As indicated in the above extract, one of his "fears" about this future is that he will "fall apart" again like he did when he was first diagnosed. (Mitch's fears relating to the future are discussed in more detail below.)

In developing a new perspective about life and what it means to him, Mitch realises that in order for him to achieve these important outcomes he must reorganise his life. Mitch consciously decides to focus on getting on with living rather than the probably effects of his infection. As a result he reviews his current life and work and concludes:

9.21 I've found another practice where I can work with a lot less stress, a lot less responsibility and triple my income so I'm sort of thinking Well, why not?... I created this [current] practice, it is there but at the same time I keep thinking 'Well, what's the point of wasting all my time on it now? I want to be overseas, I want to be doing things whenever I want to and not to be tied down to such a commitment.' ... My priorities now — are selfish. I mean I want to look after me and um going overseas is probably the most breathtaking experience I ever had, just meeting people which is one of my favourite things to do. (Mitch, 1 2163-2196)

The effect of this perspective is to reinforce the priorities in life and a commitment to live as fulfilling a life as possible. However, there is potential for conflict with beliefs within the common sense discourses of HIV/AIDS and anticipatory grief. One belief focuses on the need to discuss emotional issues and receive support from others going through similar experiences. Alternatively, there is a belief in the need to undertake psychological preparation for the inevitable decline in health and eventual death. At times during his narrative Mitch also raises these issues (demonstrating the influence of these beliefs within the discourses) but then reinforces for himself that this perspective is working effectively for him and enabling him to engage in enjoying his life. As with the previous perspectives, some observers may inappropriately interpret this response as denial.

Prophetic perspective

The focus of this perspective is illness-centred. That is, individuals using this perspective respond by focusing on the inevitability of the disease trajectory and any changes in lifestyle are driven by individuals' attempts to delay the inevitable progression of the disease. For example, Stan was initially quite "demotivated" by his diagnosis but in symbolically distancing himself from the common sense discourse was able to see that he was still well and needed to get on with life (see extract **8.40** page 264) as best he could. Soon after his diagnosis Stan also began a campaign of finding out as much as possible about the disease. His interaction with this "knowledge" considerably influences his perception and responses to the disease. As can be seen from the following extract, Stan's belief in the information he was reading informs his perception of his life-span: he thinks it

is strictly limited. His adherence to this perception is so committed that Stan frequently compares his current health status with the ‘accepted’ trajectory outlined in articles, such as the one cited in the following extract, and ‘updates’ his prediction for the progress of his disease, and the length of life remaining to him. This process was instrumental in motivating Stan’s decisions to change his lifestyle.

9.22 ... my time frame is partly, it’s almost partly predictive and, what’s the word for it, um — it’s almost fatalistic that I think this is what’s going to happen, therefore it may happen. Um but that’s the way I think. I think in shorter terms.

Interviewer: Right. So how long have you been thinking for twelve months?

Stan: Twelve months? Twelve month intervals? Probably from 19 — um I reacted that way in 1987, I thought I might have a couple more years in ‘87 there was no, there were no life-extending drugs then, now they are talking about them. Then when AZT came along in 88 — the reaction there was Well, so far it’s extending some lives ... [for] a couple more years, um then ... actually around ‘89 I figured from what I had read, I read quite a bit about the, the biochemistry aspect of it and the immune, the um the sensitisation process and so on, so I’ve got four more years. This — all these drug books give a life of four or more years and in *The Scientific American* in 1989 there was an article on, on the um it was a statistical study of AIDS victims and it goes from, goes from — seroconversion on down to death and it’s over a um, what is it, I can’t remember whether it’s seven or nine or ten years, whatever, and it showed the T-cell progress downwards over that period of time and all the, and all the um the, what’s the word for it, diseases that take advantage of the, of the situation. So I focused on that, and said ‘Oh well my T-cell count’s here, I took, I started taking the drugs and then I suddenly leveled off and stayed there so I figured Oh, I got three — it’s been thirteen years since I think I got sick, so I figure, you know, maybe another year or so, and that’s my view. So I’m always — *I’m too scientific to believe that um it’s not going to happen*, that there’s some magic that I can, — herbal cures or oxygen therapy or everything else. *I just assume that this is the progress of the disease*. Um but at the same time I do everything I can on a daily basis to forestall that. On the one hand I’m saying it’s going to happen, on the other hand I’m saying Well I’ll do my best to keep going. [Emphasis added] (Stan, l 1126-1209)

The critical issue is that Stan believes this timeframe: he perceives this trajectory has prophetic qualities, assumes that this is how his illness experience will unfold and responds accordingly. Stan also uses friends’ illness experiences to assess his progression on the illness trajectory (see extracts **8.18** and **8.48** pages 248 and 268). Stan makes the comment:

9.23 This time last year I was saying ‘Well, I mean you’ve got eighteen months.’ That was in January 1992, ‘I’ve got eighteen months, so maybe I’ll leave my job and take a big pot of gold and just relax a bit more.’ (Stan, l 1113-1120)

The strength of Stan's commitment to the predictive capacity of his accepted timeframe can be seen in his comment:

9.24 I almost put a, a date on my death if you like where I say um by this time next year I'll probably be bedridden and I think that'll be it. (Stan, 1 1082-1087)

Stan makes changes to his lifestyle that are aimed at reducing his stress levels and delaying the disease's progression. He informed his employer of his HIV status and the need to reduce his work-related stress levels. At the same time Stan was caring for a friend who was also HIV-positive and sick. It was at this time that, again in response to the disease progression, Stan saw the need to change his lifestyle still further:

9.25 My immune system dropped away quite rapidly too and it was all stress related. I wasn't taking care of myself enough, and so I then discovered I needed to balance this, *I needed to say [to myself] there's a few more things in life I want to do so I've got to pace myself* and I have to worry about myself a bit, but I don't want to be too egocentric so I, I'll, I'll sort of balance my life out a bit if I can. [Emphasis added] (Stan, 1 504-513)

Stan decided to take more control in his life. He made significant changes to his work routine and reduced his stress levels considerably:

9.26 I said 'OK, now I no longer just have to work at the job, I can be self-directive more than I have been in my career'. I can say, and I used to, and I started to be a bit more aggressive, I guess, or opinionated, and I would say 'I don't like this, those are things that I, I think are wrong, we can improve that, we can do this better, we can do these things better', because um hey, you know, *life is short*, so I would start being a bit more outspoken than I had been, which was, which was useful. [Emphasis added] (Stan, 1 561-574)

Stan eventually left work because it was again becoming too stressful. He began working with friends in a less stressful environment. At the time of interview Stan was still making changes to his lifestyle to reduce stress:

9.27 And what I, what I'm tending to do now is sub-consciously looking for um, people and situations that are, where I can relax, that it doesn't bother them and they don't care and they're good enough friends and they, and they're, and I can just go back and I go and relax and it doesn't matter who I am, whatever, and how sick I am, and, and, and I'm starting to seek out those quieter moments more and more and more. (Stan 1 1374-1387)

It is of interest to note that although Stan changed his perspective concerning what were the important goals and objectives in the life remaining to him he did not change his

perspective on, or method of interacting with, life. In discussing his approach to life Stan indicates his belief in having “visions”, or plans, for the future and working toward them:

9.28 ... we have a view of ourselves; in ten years or twenty years, we have a vision of where we'd like to be and we tend to work on, you know, getting there, I guess to some degree. Whether it's retirement in a little house or whether it's you know, being top of the totem pole or whatever, in some way you have a view of where you want to be — and that's a feeling of planned, it's a planned approach to life that and it makes you almost feel invincible that ahhh, you know, you could get run over by a truck tomorrow, whatever and that we all are going to die and that's the thing about it. And I think realising that suddenly I had got, I'd been working on ten year plans literally for myself, saying OK, I've got this far now, if I do this and this and this maybe I could, I'll develop these skills and whatever (Stan, 1 1035-1062)

On the surface it appears as though Stan is learning how to cope with his illness through observing his friends and seeing what works for them and what does not. However, it appears that the almost rigid ‘scientific’ approach Stan uses locks him into a specific trajectory rather than providing him with alternative options to living with HIV/AIDS. It is of interest to note that Stan developed AIDS-related dementia, eventually lapsed into a coma, was bed ridden and died approximately thirteen months after the current study interview.

The self-awareness perspective

The focus of this perspective is emotional response-centred. That is, individuals using this perspective focus on developing an awareness of what is triggering their emotional response and then choosing to respond in more cognitive ways. The informant using this perspective made changes to his life after diagnosis but these must also be viewed in the context of events leading up to his diagnosis. Although Brian was initially “forced” by circumstances “beyond his control” to make changes to his life just prior to his diagnosis he then chose to make further changes as a result of his diagnosis.

In early 1985 Brian and his wife attended an on-going self-awareness program called *The Forum*. Due to work commitments Brian was not able to complete the course with his wife but completed the final component of the initial course some weeks later. During this intervening period Brian was arrested at a local ‘beat’. His employers were informed by the local police and Brian was asked to resign. He was then forced to be “absolutely honest”

with his wife concerning his homosexuality and his “double life”. It was at his wife’s request that Brian was tested for HIV. Brian recalls his initial response as:

9.29 I’m sure that there was a period of about twelve months, or even longer where I was — in denial saying ‘No I haven’t got it’, even though I knew I did have — uhm — and I’m talking about after it was actually diagnosed. I wasn’t actually diagnosed — I didn’t have a test done until about 1985. And it was even after that there was a period — I’m saying to myself ‘No I don’t believe that it’s true; I don’t believe that it’s happened to me.’ And there’s a certain amount of anger that it’s happened. Uhm — so for about a year or eighteen months — that kind of time frame, I went through this — wanting to refuse to believe that it — it had actually happened to me and being angry about it and saying ‘Oh, this is the end, this is terrible.’ (Brian, l 30-55)

Brian continued to attend regular follow-up sessions with *The Forum* and was challenged by the experiential nature of the program to look at his way of responding to his diagnosis. Brian’s interaction with this program and the knowledge he gained during the initial course and ongoing sessions, became pivotal in the way he responds to the implications of his diagnosis (see extract **8.45** page 265). When Brian realised that his experience differed from that classified by the common sense discourse (i.e., his health had not deteriorated rapidly and he had not developed opportunistic infections) he began to believe that he may have some choices about his future life. He began to utilise the perspective gained during his attendance at *The Forum* to interpret and interact with objects within his life. Although Brian discusses the benefits of *The Forum* in terms of techniques learnt, what he is actually discussing is interpreting social objects through the perspective promulgated by *The Forum*:

9.30 What I’ve done with it since is to — uhm — train myself to use it — I mean it was a strategy — it was a technique, a method. It was actually some thing, although not physical, it was a technique that I could take from that course, and use in my own life — and that’s precisely what I’ve done. And what I have found for myself is that — my ability to derive benefit from it has deepened. (Brian, l 300-305; 352-358; 584-603)

Brian initially used this perspective in interaction with his homosexuality. He indicates that he “chose” not to live a homosexual lifestyle. He explains this process as follows:

9.31 Well I see that — as I am now — I’m a homosexual — with — occasional heterosexual feelings. Now the more I admit that to myself — first and foremost — acknowledgment of who you are — is a vital step — in being able to choose who you want to be. So, acknowledging that that is the way I am — I can accept it, I can be aware of it. I can be accepting of it. *When I’m aware of it and when I’m accepting of it I can then act — and how I choose to act is*

forever open to me — So I choose to act — heterosexually. I choose to — or — not quite — I chose not to act homosexually — I choose not to — to go and — get out on the beat and to engage in homosexual — activities.

Interviewer: So you've actually stopped all — homosexual activities?

Brian: I find I still think a lot about it. It's hard. I'm not saying it's easy — uhm — in fact at the present moment — as it so happens with ...[wife's name] cancer we haven't had a sexual relationship, so I'm virtually celibate — at the moment. And that's hard. And it's what I choose to do. It's as simple as that. It's kind of an experiential thing. Uhm — when you see that you've got the freedom to choose — and you practice that — you become better at it. The more you go choosing how you want to respond, the better you become. [Emphasis added] (Brian, l 1539-1592)

Brian also uses this new perspective in interaction with the implications of his HIV status: he chooses not to become emotional about things he can not change (i.e., his HIV status). He describes the effect this new perspective has on his perception of the impact of his HIV status:

9.32 So it's an acceptance of that's the way life is, which has helped me to — ahhh — achieve a state of — composure and — ahhh — freedom from stress which I think is helping me now in living longer. (Brian, l 160-166)

Toward the end of his narrative Brian identifies a dilemma which is presented by adherence to this new perspective. He acknowledges that the effect of “choosing” responses to situation is like obstructing his emotions:

9.33 It's kind of like I'm blocking a lot of it off — or — uhm — avoiding thinking about it because it still causes me — I still feel some pain going back over that stuff and reliving it.

Interviewer: So it's even painful today talking about that, to some extent?

Brian: Yes, but as soon as I see that I can see that I can also choose that it doesn't have to affect me. — — I mean, — that's who I've become. I've become this person who's able to choose the way I want to respond — to life. (Brian, l 1267-1287)

The influence of groups such as *The Forum* resides in the fact that members of the group adhere to the same philosophy or perspective and individuals take on the attitudes and beliefs of the organised group. That is, individuals internalise the generalised other of the group and accept the norms, values, attitudes and beliefs of the group. Individuals then use this internalised generalised other as a comparison for expectations regarding appropriate responses. In Brian's situation he appears to have internalised the belief that expression of strong emotions is not something acceptable to the group. Although he acknowledges that

he experiences these emotions, albeit momentarily, he then “chooses” not to respond emotionally. In terms of symbolic interactionism Brian’s spontaneous emotional response is as the subject “I”. As soon as Brian realises he is responding emotionally he begins to interact with the self as “Me” - the object that is responding emotionally to the situation. Stan then uses the perspective promoted by *The Forum* to assess his responses. Since Stan’s interpretation of the generalised other of *The Forum* does not support the expression of emotional responses Stan then “chooses” a more appropriate cognitive response. This process is clearly demonstrated in extract 9.31 (page 296) concerning his homosexuality.

Using this perspective enables Brian to engage in effective social interaction and function in life. However, this perspective is in conflict with conceptual frameworks that support the belief that it is important, particularly in a therapeutic setting, to identify and appropriately express emotions for it is through this process that individuals are introduced to the additional specifics of their emotional world and their basic experiences are grounded (Ivey 1988; Stein-Parbury 1993). Brian’s perspective is also in conflict with the belief that it is essential to deal with the intense emotions stimulated by illness and impending death (Rando 1986c). Some HCPs may make a case that Brian is in “denial” about his emotions, particularly those associated with his homosexuality. In fact, throughout his narrative Brian appears to lack affect and presents the tenets of *The Forum* and his experiences of living with HIV/AIDS with almost evangelical zeal. However, this would be an inappropriate assessment as there are times when Brian acknowledges that he experiences some emotions, but then chooses not to express them. Brian is not using denial as a defence mechanism. Brian’s reactions are in accordance with Simpson’s (1979) alternative explanation for what is generally perceived as denial - Brian is recognising reality (his homosexual feelings) and rejecting the threatening aspect of this reality (responding to these feelings) and replacing it with something more comfortable and more socially acceptable (i.e., behaving heterosexually). Furthermore, this “blocking” of his emotions may allow him to function effectively in a potentially overwhelming situation. Within a period of six months Brian was confronted with a number of major changes in his life. He was arrested and publicly humiliated about a homosexual incident, lost a career job that he really enjoyed, was forced to disclose his homosexuality and secret life to his wife, his marriage was “almost destroyed”, he was diagnosed as HIV-positive, he had to cope with the prospect that he might have infected his wife, and his wife’s health began to deteriorate

(later diagnosed as terminal cancer). Under these circumstances it could be argued that if Brian begins to vent his emotions he may become overwhelmed and would not be able to function effectively.

The future

Informants in the current study speak about the future, as a social object, in a variety of ways depending on how it was symbolically designated, in what situation and the importance attributed to it. For example, the future was given limited consideration by some informants (see extract **9.15** page 287) and greater emphasis for others (see extract **9.28** page 295). At times the future was symbolically designated as an 'unknown' both in terms of what it might contain and its possible duration. In other situations a specific time limit was placed on the future (e.g., Stan in extracts **9.22**, **9.23**, **9.24** pages 293 and 294) or the time frame expanded depending on the proximity, to diagnosis, of the individual's contemplation of the future. For example, one informant recalls that at diagnosis he believed that he had no future (see extract **8.2** page 235). However, at the time of interview he makes the comment:

9.34 I can peek a little further into the future than I could a few years ago. A few years ago next year was very hard to think about, Now I can fairly comfortably think about next year. The year after I'm starting to think Mm, you know, well I won't plan too much for the year after but --. (Mitch, 1 1663-1673)

However, imagining their future as consisting of a range of 'dreaded issues', particularly continued deterioration of health, the presence of specific symptoms and a HIV/AIDS-related death, creates problems for both individuals and HCPs (Bor & Miller 1988; Peräkylä & Bor 1990). These future scenarios are also the focus of the discourse of anticipatory grief and hence of importance in this thesis. Several important questions arise when focussing on individuals' reaction to these scenarios. What triggers thoughts of the future? What type of future do individuals construct? What emotional response do they have to these scenarios?

Triggering thoughts of the future

Informants thoughts about their own possible future are triggered by a variety of situations or incidents. For example, images displayed on electronic media prompt individuals to contemplate their future (see extracts **8.4** and **8.7** page 238). Other informants began

thinking of their own probable future as they observed their friends' experiences during the various parts of their illness trajectories. For example, although Keith says he does not focus on the future (see extracts 9.6, 9.7, 9.8, 9.9, and 9.10 on pages 284-286) there are times when the "inevitability" of the illness experience stimulates thoughts about his own future. During his narrative he identifies several incidents of this nature:

9.35 I've had lots of friends that have died; I've been with people as they've died and — I kind of — you think of the inevitability of it all.... the expectations of seeing how people collapse [think is the most frightening part. *You can actually see that coming along in the future yourself....* it's obviously extremely traumatic. And it's not — it's not only traumatic just because you're losing a friend, *but you're seeing your own kind of death, or — your own future in front of you,* which is extremely difficult, and it's doubly — and it makes it doubly difficult. You're not just losing a person, you're looking at — like when you go to funerals, you're saying "Well, you know this —" that's traumatic as well, *because you can see the inevitability of — of your own infection.* [Emphasis added] (Keith, 189-93; 158-160; 286-300)

Another informant talks about watching close friends who are already experiencing opportunistic infections and comparing his experience to theirs. At the same time Stan believes he sees his probable future:

9.36 I think I was watching him and seeing a bit of myself, my fears.... in watching him, this the same person that I lived with in, in 1987, and he doesn't live far from [here], but he's um I'm just watching, reflecting on how he's performing, how I'm performing and just doing this sort of constant comparison and trying to say, "Well, how is he coping with it? And he's seemingly content in coping with it now and I'm not as much." (Stan, 1275-277; 1834-1846)

Stan is not only reminded of his impending death by seeing his friends who are experiencing any one of the range of opportunistic infections but also in his dealings with older people, particularly those of his parents age (80+ years of age). Stan indicates that he observes, talks with and learns from these older people with whom he feels an affinity because of a shared future - facing impending death within a relatively short time period:

9.37 ... so I've been watching them and learning from them and actually comfortable in talking to them, so, you know, about it, because um the only difference between this [HIV/AIDS] and any other natural occurring thing is this, that this speeds up the death, the life cycle, it says 'You've got to be —, you've got to go through high speed emotional development and maturity to cope with this thing, it's going to happen sooner than it is later', um — but everybody else is too, and most people aren't prepared for it, and that's the thing, is that you confront people with it and they don't want to talk about it, they really don't want to talk about it.

Interviewer: Don't want to talk about what?

Stan: Death.

Interviewer: Death?

Stan: Yeah. And, and they, and they see a long future and — so only in talking to my parents and in talking to people who are in life-threatening situation do you start to get some, some empathy or something, some sympathy. (Stan, 1 2040-2075)

Reminders of possible futures also occur for individuals who are receiving treatment for opportunistic infections. For example, Kyle is distressed during his outpatient treatment sessions when he is confronted with another patient who appears so sick that Kyle thought the man was “going to die there” while having treatment. Kyle acknowledges that his own distress arose because this man reminded him of his probable future. As Kyle interacted with his imagined future he also thought of the many friends that had died and that now he did not have many friends left. In turn, these thoughts triggered Kyle's emotional response - fear. Kyle identifies that one of his main fears about dying is being alone (see extract **8.53** page 271).

Responses to future scenarios

Although individuals are able to achieve, for themselves, a degree of freedom from the influence of the common sense discourse by recognising that their experiences are different and then validating their subjective reality, they are forced to resort to the common sense discourse to provide meaning and understanding when confronted with new or unfamiliar situations. Consequently, when constructing and interacting with imagined future scenarios, informants rely on elements of the common sense discourse to define and categorise possible experiences. Therefore, the focus of the most common future scenarios is on some of the major health-related issues of the common sense discourse of HIV/AIDS, namely various forms of deterioration in health, becoming dependent on partners, friends or family, the process of dying and the event of death rather than anticipation of possible losses. Consequently, the dominant response to these dreaded issues is fear and anxiety and not grief as is defined by the discourse of anticipatory grief.

The process of dying

Elements of the common sense discourse associated with the process of dying are influenced by the vivid imagery of the HIV/AIDS illness trajectory and AIDS related death

portrayed in the electronic media, news reports and films. One informant speaks of the images of people dying:

9.38 When people start to die it's really a pretty ugly thing and the whole body just collapses basically and things just don't work like they should. It's sort of a it's a horrible thing to think about but it happens to everybody um it shouldn't be happening to someone my age perhaps but you know with this it does. (Mitch, 1 3052-3059)

Individuals respond to these images by projecting themselves into similar situations in their imagined future. Consequently, in interacting with this imagined future they see themselves having similar experiences, imagining what they would think about in those situations and how they would feel. These images are so powerful that one informant remains awake some nights thinking about what might happen to him. When asked what occupies his thoughts during these periods Mitch responds:

9.39 ... the fear of — I've always claimed I was never afraid of dying but I was afraid of the stigma I suppose attached to it. Um —

Interviewer: Attached to dying? Or —

Mitch: Of AIDS.... The fear was going through the illness before I died. Um — the degradation um — the thought of ah — I suppose I've seen images on TV of these people in bed looking very ill. I've seen people being carried by their other halves and I mean they just look so dreadful. Pitiful. Um — and I suppose I don't like to think about that happening to me and especially you know have ...[partner] to look after me. It's not a very pleasant thought I feel a little bit awkward at the thought that I have to rely on him or — not that that makes me feel awkward, it makes me feel guilty perhaps — embarrassed um — in some respects part of me would still like to crawl away and hide until it's all over and — and just let me worry about it (Mitch, 1 846-860; 1106-1126; 3068-3077)

As part of interaction with this imagined scenario Mitch thinks about various possible experiences. In imagining his deterioration and developing dependency on others, particularly his partner, Mitch feels awkward, guilty and embarrassed as he has never liked to be dependent on others. In constructing this possible future and interacting with what, to him, is the dreaded issue he perceives as his probable future, he responds with fear.

Another aspect of these imagined scenarios that creates problems for Mitch is his anxiety concerning how he will react when confronted with the fact that his health is deteriorating. He is scared that he will “fall to pieces” and respond in the same “hysterical” way he did when he was first diagnosed:

9.40 I hope that my coping will be a little better than last time. I was really ashamed of myself actually last time and I don't want to be like that again. (Mitch, l 1715-1718)

One informant indicates that when interacting with his imagined future he thinks that he will experience a “horrible ending” Stan responds with fear when he thinks his future includes the development of AIDS-related dementia and its subsequent implications:

9.41 Stan: Fear of the future. Um I guess um fear of a horrible ending.

Interviewer: What do you call a horrible ending?

Stan: A horrible ending is not having your facilities and your faculties to live with pride, to feel like a leper. or to feel and, and to be reliant, dependent on other people. (Stan, l 1234-1245)

In interacting with this imagined future scenario Stan also develops a future self-image with which he also interacts. He sees himself not only as a leper but also losing his faculties, his independence and being reliant on others for assistance with routine daily life. As is demonstrated in the following extract Stan's fears tumble out as he thinks and talks about his imagined future. In identifying his fear about his health rapidly deteriorating and his death Stan recalls his friend's experiences and imminent death. In turn this triggers thoughts about who might be available to care for Stan when he is ill and dying. He fears that no one will be available to care for him as his death approaches. He identifies his fear:

9.42 ... of dying and rapid deterioration, that someone could get so — if someone gets so sick, suddenly lose their will to live — and that no-one was going to care for me, because there's nobody else around and living in this sort of private hell and that the reaction of the gay community was, well you know, we, we don't want to know you Well I was just fearful of, of that ending, of that happening — to me (Stan, l 340-348; 492-493)

Stan is also fearful of his friend's death because they have been “very close” and have been able to talk about their common experiences, something he believes he can not do with other people who are not going through the same experience (see extract **9.5** page 281). In his imagined future, with his friend dead, Stan will not have the opportunity to:

9.43 Dump them [emotions] all out without ... having someone be critical of it, ... or in a sense being analytical of it, just having someone say "Yeah, I've been there, and it's pretty hard too, isn't it?" or that's a shit sort of thing. (Stan, l 1997-2004)

The extent of Stan's fear about being alone during his dying or being a burden to himself and others is reflected in his comment that he will “take my own life some day if I have to”

(l 1265-1267). However, in observing his friends who also discuss suicide, as an option available to them when their health deteriorates to such a degree that they no longer have quality of life, Stan is presented with a dilemma - deciding the appropriate time. He has observed some friends give in too quickly and die before their time (see the incident of his doctor friend in extract **8.18** page 248) and others wait too long so that they are incapable of committing the act. Stan expresses his fear that he will make the wrong decision:

9.44 Um so there's that balancing is that fear that I'll give up prematurely, and that I, *I'm committing some sort of horrible — you know social act* and the second part of that, you know, becomes just giving up and it's just a cowardly thing. Um on the other hand there is a fear that, that I don't want to be in a situation where I really am uncomfortable and, you know. [Emphasis added] (Stan, l 1296-1307)

In this extract Stan identifies the twofold fear associated with contemplation of suicide. Firstly, he is fearful that he may kill himself prematurely. That is, he may kill himself without realising that he still has some quality of life remaining. Secondly, he is fearful that his suicide may be construed as a “horrible social act” and, in death, people may be critical of his actions.

Developing dementia is a commonly imagined future scenario that is dreaded. One informant associates dementia with losing control of his life through the impairment of his cognitive abilities. His responds to these thoughts with fear:

9.45 I certainly have some fears. I mean, I would hope that there are no brain changes and losing my — cognitive impairment for me, that would be a worry and a concern — the losing control. (Geoff, l 1629-1634)

Dementia is also a significant aspect of another informant's imagined future scenario and is coupled with the presence of severe pain during Kyle's imagined dying process to create a dreaded situation. Kyle has already developed KS and is frightened of the pain associated with its later stages. The dilemma Kyle faces is his fear of pain and, possibly through dementia, not being able to communicate effectively with medical staff about his experience of pain:

9.46 ... because of the nature of my Kaposi's pain will become — intense ... my problem is — I may not be able to communicate my needs and desires — as to how much pain I am in ... possibly through dementia [and] dementia to me is the second worst thing you can have [after Kaposi's sarcoma] (Kyle, l 1301-1333)

Through observation of others with KS and dementia, and influenced by the common sense discourse of HIV/AIDS, Kyle has imagined a future for himself in which he develops dementia and loses control of his ability to communicate, to carers, his physical pain relief needs. For someone who operates from a perspective of control (see section 'Control through rebellion perspective' page 288) the thought of losing control is the most frightening scenario.

Kyle also speaks of the "horror" of watching someone die and the loneliness associated with such a death:

9.47 I don't want to die alone — I mean, quite frankly, to see anyone die is horrific enough. (Kyle, l 1065-1067)

An imagined future consisting of a long period of slowly wasting to death is significant for one informant. In interacting with this imagined future Keith responds with fear and anxiety:

9.48 I have a fear that it's going to be extremely lengthy and drawn out. Which is what I would not like. I'd much rather have a quick demise, than lie around for eighteen months, kind of slowly fading away. (Keith, l 430-442)

Consequences of deterioration in health

The social consequences of deteriorating health are the focus of one informant's imagined future. When Geoff interacts with this imagined future his spontaneous response is one of fear. Geoff explains that:

9.49 ... the fear was more to do with oh *my whole career was being threatened again* and the fear of losing it um my status and — um losing my situation, my status in society and in my profession.... Oh, yeah, I think um my goals, my goals were being threatened and — I think that's when I started to get quite depressed. [Emphasis added] (Geoff, l 920-927; 1267-1268)

The key to understanding the fear Geoff experiences when he focuses on this particular imagined future scenario is provided in the emphasized portion of the above extract. Furthermore, this understanding is embedded in experiences prior to Geoff's seroconversion. Geoff is referring to the situation when he informed his wife, and some close friends, of his homosexuality. As a consequence of this disclosure Geoff left his family home, he and his wife separated, he resigned from an established and promising career job and moved interstate "with only a box of books" to start a new life. Geoff left his two young children with his wife and experienced considerable difficulty maintaining

regular access visits. It took Geoff a number of years to reestablish himself in a new community and develop a new identity as a gay man. The process of reconceptualising this new self-image was particularly difficult for Geoff. When confronted with his diagnosis of seroconversion Geoff projects his past experiences and responses into his imagined future. His fears result from his perception that he will go through another emotionally painful, drawn out experience, similar to his previous experiences.

Death

In imagining their future some informants speak about the event of death as opposed to the process of dying. One informant says he is frightened of the event of death and what it means. Ron explains:

9.50 Oh yeah I like being alive.... I like my friends. I like my family um I don't want to let go of any of them. In that way I fear [death] (Ron, l 2346-2353)

A little later in his narrative Ron returns to his 'fear of death' and says that he is not concerned with the physical pain that he believes is associated with the dying process but talks about his fears of the emotional pain that is associated with death.

9.51 Ron: I mean all the peripheral things that go with the pain. You suffer the pain of dying — the actual physical pain of dying and while it doesn't worry me physical pain that will be associated with that might be associated with dying.

Interviewer: So it's actually letting go of the things that you —

Ron: The letting go. It's the regrets — the regrets yeah, yeah.

Interviewer: So it's emotional pain rather than physical pain?

Ron: Oh yes. And the fear is not the fear of pain. It's the fear of um — of — *if after there is anywhere to go of getting to a place where all those you've know and loved and cared for all those that I've loved and cared for won't be there you know.* I suppose it's all part of the letting go. [Emphasis added] (Ron, l 2607-2631)

In both the above extracts Ron identifies his emotional response as one of fear. He fears death because he will have to leave family and friends and he fears being dead because he might not find those whom he loved and cared for in life and who have predeceased him (e.g., parents, brother, former lovers, friends). However, it is clear that Ron's 'fear' is actually anxiety about separation. In the first extract Ron talks explicitly about not wanting to "let go" or separate from those people and things to which he is emotionally attached. In the second extract Ron expresses his anxiety implicitly. Interacting with his imagined future state of being dead triggers Ron's uncertainty about the existence of 'life' after death. He states he is 'afraid' of 'arriving' after death and not finding those he loved and

cared for in life. That is, he is anxious about not finding former family and friends and being able to reattach himself to them in an 'after-life'.

Anxiety about separation is an important response for another informant. However, this is initially expressed in terms of concern for his current partner. Initially Geoff expresses his 'fear' that he will become ill and die before his partner who is also HIV-positive:

9.52 Geoff: My fear is that I'll be coming ill before ... [partner] and who would take care of him.... My greatest concern for ...[partner] is his feeling of insecurity, even now, and maybe he could express it himself *but that's how I perceive it.*

Interviewer: I was really interested in, in your anxiety —

Geoff: Yeah, oh, well um how he would, I know he's a real coper, he'd actually, yeah, he'd be fine but how he'd actually deal with whatever happens, with loss, etcetera.

Interviewer: So you have some anxiety about how he's going to cope in the future without you? After your death!

Geoff: Partly, yes, yeah, which I think, yeah, that's true, yeah.... He's been a bit, *lately the way that we've dealt with fear and anxiety* and worry in ways has not been good.

Interviewer: So there is a lot of fear about the future?

Geoff: Um not so much now because we've, we've really dealt with it well but in the last say few months um for some reason there's a lot of fights um *one way of reacting to being angry I've become very yelling and screaming and that sort of thing.* [Emphasis added](Geoff, 1907-908; 1661-1684; 1715-1731)

This compilation extract demonstrates the subtle shift in focus from Geoff's partner to himself during this part of the narrative. Geoff initially identifies his fear as associated with his belief that his partner will not be able to cope with Geoff's illness and death. A little later in the narrative he returns to expressing his concern for his partner's well being. Even when asked specifically about his own anxiety Geoff continues to talk about his partner and acknowledges that he would be able to cope. When the interviewer picks up on Geoff's focus on his partner Geoff begins to shift the focus and begins to include himself when talking about his concern for the ways that "we've dealt with fear and anxiety". Again when the interviewer responds to Geoff's comments and attempts to clarify the issue Geoff responds with what he thinks is a socially acceptable response but then focuses on the way "I've" been responding lately. It appears that Geoff is really talking about his own fears and anxieties but initially projecting them onto his partner. In finally acknowledging his concern about how he is dealing with fear and anxiety it is apparent that Geoff is actually expressing his own anxiety about separation from his partner.

Informants not only imagined their own impending death and interacted with those thoughts but also imagined, and interacted with, the imminent death of close friends. For example, Geoff recounts his reaction to a close friend's non-HIV/AIDS related life-threatening illness:

9.53 Geoff: He had multiple pulmonary emboli and he could any time have a blood clot that would lodge in his lung or anywhere for that matter, but it's not HIV related, it's a congenital or hereditary thing. His sister in fact has had an operation basically for it, um a filter in the left ventricle and the rest of it, um he's now being treated for that and that's not a problem, but when he was in hospital he did almost die, it was intensive and, and *it really frightened me.*

Interviewer: What frightened you?

Geoff: Of losing him, of him dying, because he nearly died. And I think that was the beginning of me considering facing the fear of dying and from then on I think I've dealt with it

Interviewer: Right, so there was a period when you were fearful of um dying through

Geoff: *I was fearful that my closest person in my life was going to die.* And he was very afraid. I mean apart from seeing someone who was usually, we're both very strong people, *but a strong person actually breaks down in tears through fear ...*

Interviewer: Yes, OK. So at that time you were fearful? I mean basically you were fearful of, of what was going to happen and what could happen?

Geoff: Yeah.

Interviewer: You were actually projecting what might happen? Was that the first time that it occurred to you that, that he might die?

Geoff: Well it was a pretty real situation, I mean he actually had clots and was lying there before me very ill and doctors and nurses saying "He's not too good at the moment" like that, he was very low.

Interviewer: Right, so were you anticipating his death?

Geoff: Mm, mm. Yes. Yeah. Yeah, certainly it was a possibility that I had considered, a very real one. ... *The fear was um of losing someone very close.* [Emphasis added] (Geoff, I 1126-1203)

In this extract Geoff acknowledges that during his friend's period in hospital he imagined a future in which his friend was dead. This imagined future was supported by his own medical knowledge (as a nurse) and information from the medical staff treating his friend. Interaction with this future in which his friend was dead prompted Geoff's response of fear. Again, this fear is likely to be associated with Geoff's anxiety about separation from a close and supportive friend.

In speaking about the period leading up to his death, one informant reflects on his life and indicates that he has mixed feelings about his approaching death. On balance he perceives his life has been a positive experience. At the same time he acknowledges there are things he will not miss. In response to the interviewer's clarification that he is not grieving for anything in the future Stan comments that he has worked through the implications of his decision to live a gay lifestyle and not have a family. However, he does return to the issue of his greatest concern - dying alone (see also extract 9.42 page 303).

9.54 Yeah, actually and some with, some with mixed feelings, I guess, um — some things that aren't going to happen are probably quite good. I don't think I want to be um, I don't think I want to live in an old age home or, whatever, — I don't think I want to be around in forty years time and see well, the way it could be, um you know, the social fabric's changing, I think, you know, I think that the whole western civilisation is causing problems, is having problems, — you know, the, the drive to technology hasn't solved the problems, it's made it worse, and there are a number of things I'll be glad not to see, so that'd be fine, but I don't think there's anything that I would say that Gee, I would love to be here when this happens. Oh, 'd love to be here when a cure comes along. That's um, no, I don't think there's anything else that I really feel that I'm missing out on.

Interviewer: Right. So you're not grieving for anything in the future?

Stan: No, I mean, I, no, I made a decision I wouldn't have any family because I was gay, and I've done that and that has caused me, you know, grief in the past. That's got nothing to do with this, this part of it. That's something I crossed the bridge when I thought of it before and realised that, so in a way being gay is very [few words indecipherable]. life cycle because you end up without any caring children or any caring relatives to look after you in the end, um and unless you really are very fortunate to have a long term relationship, which very there are few are I think, then you die alone as a gay. (Stan, l 2316-2374)

In discussing his reactions to being infected with the virus one informant speaks of his experience of sadness and grief in response to the illness and death of close friends. Although he acknowledges that he has a limited lifespan (see extracts 9.7 and 9.9 pages 284 and 285) and there are things he will not be able to do Keith is not sad about what might happen in the future. He is too busy living his life. In fact, Keith indicates that he can not be sad for something that has not happened. That is, he can not grieve for something that has not yet occurred, but he can fear an anticipated future:

9.55 Interviewer: So the sadness is associated with actually losing a friend rather than what's happening for you in the future?

Keith: Oh yes. Oh definitely. Yeah. Because I can't — *I can't be sad for things that haven't happened yet.*— in those terms. But certainly for the loss of my friends.

Interviewer: So what emotion would you say you had, for yourself, when you consider your possible future? Or do you have an emotion?

Keith: I guess I have — well not so much an emotion — I have a fear that it's going to be extremely lengthy and drawn out.

Interviewer: A fear?

Keith: Yeah. Which is what I would not like. I'd much rather have a quick demise, than lie around for eighteen months, kind of slowly fading away. I think that's the anxiety, and that would be the fear of — of the end result of the disease, but no I don't have a great — emotion — about it — it's more the fear — it's — just the absolute bloody hassle of the whole drawn out affair. It's not like being hit by a car. It just seems to go on interminably — and that's a drain on everybody else around you; it's a drain on you; it's a drain on resources, finances, everything. Ahhh — but — no I guess I just step back a bit from having an emotional reaction as to — as to that — it's more of a fear — as I've said it's just inevitable and it's just a bloody nuisance. You know, in those terms. (Keith, 1410-461)

Summary

The primary focus of the common sense discourse on the social, rather than medical, issues of HIV/AIDS impacts on individuals' social interaction. Individuals living with HIV/AIDS become wary of social interaction that they perceive may result in their rejection if they disclose their HIV status. The action taken to distance themselves from the prospect of such rejection ranges from simple non-disclosure to making attempts to cover physical signs of the virus' effects. In opting for non-disclosure to family of origin individuals invariably interact with self-images developed through previous interaction with family members.

Individuals living with HIV/AIDS encounter a number of situation which initially appear to be familiar and have a known configuration of meaning. However, in these situations, routine social interaction is disrupted as other social actors do not respond in ways expected by informants. This is particularly evident in seeking medical attention. Informants interpret medical staff responses as 'discriminatory' and as a result of staff beliefs about the issues of morality associated with HIV/AIDS. However, the occurrence of this 'discrimination' from within the gay community suggests that the inevitability of death and fears associated with issues of mortality, rather than morality, are responsible for the creation of social distance from individuals living with the virus.

The practice, within the common sense discourses of dying and death, of avoiding discussion of related issues, also raises dilemmas for individuals living with either HIV or

opportunistic infections. Informants in the current study report that, in particular, other members of the community or even health care professionals hear only “what they want to hear” and do not allow them to ventilate their ‘negative’ emotions when necessary. The resultant ‘reinterpretation’ and ‘discounting’ of individuals’ experiences is a form of community denial of the existence of an alternative reality and an alternative discourse.

Individuals’ personal perspective impacts on how they interact with the experience of living with HIV/AIDS. For some individuals, their personal frame of reference is such that it can readily incorporate the experience of diagnosis and its implications without requiring major change. The three specific life perspectives that did not change appreciably after diagnosis are the ‘life challenge’, ‘laissez-faire’ and ‘control through rebellion’ perspectives. Alternatively, for other individuals it appears as though confronting the prospect of their own inevitable death destabilises their frame of reference and prompts critical evaluation of their perspective about life and reappraisal of objects considered to be personally significant. In interaction with their imagined death some individuals made changes to their lifestyle. These changes appeared to be influenced by the adoption of different life perspectives. The new perspectives identified are the ‘self-centred’, the ‘prophetic’ and the ‘self-awareness’ perspective.

Thoughts of the future are triggered by a variety of incidents or situations such as electronic media images, observing close friends who are further along the illness experience and observing others during medical treatment for opportunistic infections. Although individuals living with HIV/AIDS can achieve a degree of freedom for themselves by recognising that their experiences differ to that defined and categorised by the common sense discourse, they are forced to rely on this discourse to provide meaning and understanding when confronted by new or unfamiliar situations. The focus of the most common future scenarios is on ‘dreaded’ issues including major health-related issues such as deterioration of health, becoming dependent on partners, friends or family, the process of dying and the event of death rather than future losses. The dominant response to these dreaded issues is fear and anxiety rather than grief. Individuals experience fear for a variety of issues. They fear the stigma associated with dying of HIV/AIDS; they fear developing dementia and cognitive impairment; they fear the pain associated with dying; they fear a long drawn out deteriorating process; they fear the social consequences of deteriorating

health; and they fear the consequences of friends' death. In addition to these fears they identify feelings of anxiety about being separated from partner, family and friends by death and in death. Individuals living with HIV/AIDS also acknowledge their experience of sadness and grief at the death of partners and friends and past losses. However, in terms of the future, one informant's succinct response summed up the experiences of other informants when he states "I can't be sad for things that haven't happened yet".