

Chapter 8

Influence of the Dominant Discourses of HIV/AIDS

Introduction

The concept of the 'other' was presented in Chapter Three. There are strong motivations at both the social and individual level to represent the sick as different. For the social order, the deflection of social problems and resentments away from their structural social source and onto the pathologies of the individual constitutes a defensive position (Crawford 1994). At the level of the healthy individual, the defensive response is not only a denial of vulnerability and loss of control, but also an attempt to preserve the individual's privileged place in existing social relations. It has been argued that emphasising the other quality of the sick serves as a device to maintain boundaries and create social distance. A further claim is that serious illness disorients the individual and simultaneously disorders social relations. Conventional understandings are 'destructured' as the seriously ill individual questions the basic personal, social and moral implications of the illness. A crisis of self-definition is created by serious illness which, in turn, raises questions about the adequacy of conventional expectations and structures within which not only the self had previously functioned but also within which everyday social relations operate (Crawford 1994).

For gay men who become infected with HIV the concept of other is not restricted to their health status. The Australian media's presentation of HIV/AIDS as primarily an issue of morality, sexuality and participation in subcultures that are socially defined as deviant, has focussed attention on the other quality of the 'homosexual lifestyle' (Aroni 1992; Lupton 1994b). These socially constructed concepts of the common sense discourse raise a number of important questions. Firstly, what effect does interaction with the common sense discourse of HIV/AIDS have on the self-image of gay men who are infected with HIV? Secondly, does this self-image change and, if so, why? Finally, what effect does the self-image of these individuals have on their social interactions during the experience of living with HIV/AIDS?

The purpose of this chapter is to use the key concepts of 'self' and 'other' to analyse the initial responses of gay men living with HIV/AIDS. It begins with a brief overview of the development of knowledge about HIV/AIDS, the importance of the media in this process and the structuring of public knowledge concerning the disease and illness experience. Particular attention is given to the issue of individuals who, by virtue of their diagnosis of seroconversion and the meaning ascribed to HIV/AIDS as a disease, are assigned the social label of seriously ill but, in the absence of specific symptoms, do not appear or feel unhealthy. Elements of the common sense discourse of HIV/AIDS support the belief that these individuals are facing their impending death and, according to the professional discourse of grief are expected to engage in anticipatory grief when contemplating losses that will occur in the future. In examining the effect of the common sense discourse of HIV/AIDS on the self-image of gay men infected with the virus the following specific questions will be addressed: Who becomes infected - the individual or the other? How do individuals experience otherness? How do individuals reconceptualise their self-image? What impact does the concept of otherness have on the disordering of social relations? In the process of examining these questions elements of the common sense discourse of HIV/AIDS that, for informants in the current study, create a dilemma for them during their subjective experience of living with HIV/AIDS will be identified.

Common sense knowledge about HIV/AIDS

Unlike cancer, which has a long history of knowledge development, HIV/AIDS is a phenomenon of the early 1980s and, at the time of interviews for the current study, had only a twelve year history. When first brought to public attention, with the publication of the *Morbidity and Mortality Weekly Report* (MMWR) of 5 June 1981, the fatal nature of the disease was known but it would be another two years before its viral cause was identified. During the early investigative period emphasis was placed on epidemiological research that focused on defining the new disease as a biological process occurring within a determinate social matrix (Levine 1992; Oppenheimer 1988). Although evidence that the new disease was not confined to a single group within the community was available within six months of the first report in the *MMWR* (Shilts 1988; Treichler 1987) the initial speculation on the existence of an association between the new disease and some aspect of homosexual life-style has considerably influenced public perception of the disease. This centrality of so-called deviant sexuality as a perceived factor in the disease is reflected in

the early operational categorisation which changed from 'gay cancer', 'gay pneumonia', 'gay plague' and the 'Wrath of God Syndrome' (WOGS), to 'Gay Related Immune Deficiency' (GRID) in early 1982 (Gilman 1988).

The identification of four major high-risk "groups" in 1983 heralded a major shift in conceptualisation of the syndrome. Based on epidemiological data the groups considered at increased risk of contracting HIV/AIDS consisted of the "4H" group; homosexuals, heroin addicts, Haitians, and haemophiliacs (Treichler 1988). Development of knowledge concerning HIV/AIDS as an infectious, life-threatening disease with no known cure was not restricted to knowledge about the specific disease and illness experience. Since its inception HIV/AIDS knowledge has been related to a number of other issues (e.g., dying, death, hope, grief, homosexuality, morality, deviance, stigma, and intravenous drug use). Elements of the common sense discourse of these other issues also inform the community's attempts to make meaning of HIV/AIDS. Current informants, as members of the wider community, initially came to know and understand HIV/AIDS as a disease and an illness experience through these early beliefs and related common sense discourses. Consequently, at the time of diagnosis of their own seroconversion these discourses influenced individuals' expectations concerning all aspects of the disease, the illness experience and its ultimate outcome.

The close relationship between HIV/AIDS and homosexuality, which emerged with the initial media coverage of the new disease in the United States, and has never been completely abandoned by subsequent media reports of the event, had two consequences. Firstly, the formulation of HIV/AIDS related policies was affected by, and confronted, popular prejudices against homosexuals. Secondly, the existence in Australia of a small but comparably politically sophisticated gay movement meant that it exerted pressure for participation in decision-making from the outset (Altman 1992b). Furthermore, these consequences impacted on the development of the discourses about HIV/AIDS. The mainstream media, with its focus on morality, sexuality and participation in socially defined 'deviant' subcultures and the attendant apportioning of guilt (Aroni 1992), also has been instrumental in the development of a form of common sense discourse. However, it appears that the media has been more concerned with social issues than accurately reporting medical information (Aroni 1992). As a consequence of this type of media

involvement a variety of meanings and significations have flourished (see Brandt 1988; Gilman 1988; Levine 1992; Treichler 1987, 1992). Alternatively, it has been claimed that the gay community, through existing gay community networks such as the gay press and gay political and social organisations, began early dissemination of information focussing on medical aspects of the epidemic (in particular life extending drugs and treatment regimes) and strategies for prevention (Parnell 1992). The gay community's involvement in HIV/AIDS-related education campaigns resulted in continuance of the popular perception within the general community that HIV/AIDS remains primarily a homosexual problem. This activity of gay community groups and different focus resulted in the development of a different common sense discourse about HIV/AIDS - a discourse mainly used by the gay community.

Knowledge and the early discourse of HIV/AIDS

When HIV/AIDS first came to public attention there was only one way of understanding the new phenomenon. It was initially presented to the medical and lay community as a new, virulent, rapidly fatal, sexually transmitted disease of promiscuous gay men, for which there was no known treatment or cure (Grace 1991; Sontag 1991). The narratives of those individuals who were diagnosed during the early years of the new disease reflect not only this lack of general knowledge but also the original understanding of the disease, its progress and outcome. For example, one informant diagnosed in 1984 states:

- 8.1** Prior to 1983 or thereabouts, 1984, people didn't know anything about the HIV virus and uhm — it was a big surprise to a lot of people that they caught it. (Brian, 121-25)

Evidence for the extent of this lack of knowledge, even within general medical practice, is provided by another informant in recounting his experience of being informed of his seroconversion in 1985. In defending his medical practitioner's actions in conveying the test results via telephone at the informant's workplace he states:

- 8.2** It happened over the phone, which was probably not — the best way to tell someone news like that. But, in all fairness to the doctor this was new for him too and he — he was obviously having a hard time dealing with it because *he didn't know what to do with me ...* and I can remember sitting at his desk crying and *there was nothing he could do* and I was sort of almost hoping there was something he could do but I realised there wasn't so I kept thinking, 'Well, why am I here? There's no point in me sitting here, because *there's nothing anyone can do anyway*, all I'm going to get is you know a pat on the shoulder or whatever' ... I felt like, sort of, you know, the old literal, the plug had been

pulled out. Everything just emptied in front of me and all I could think of was, you know, *I'll be dead in two months* or, just, *this is it, it's all over* I suppose what I thought was going to be the outcome — I didn't think about that. The thought that I had AIDS was it. *I mean back then we didn't, we didn't know much about what it all meant. We didn't know how long it meant and you know I [was] just expecting everything to close in on me within a couple of weeks so I mean to me it was the end of the world* I had no such thing as the future — back then. There was no future. I couldn't think of it. People would ask me what am I doing next year and I'd say "I don't know" and all I could think of was that I'd probably be dead — even in late 85 No future — friends didn't mean anything. Family didn't mean anything. I was very self-centred. [Emphasis added] (Mitch, 1731-755; 435-444; 1201-1245)

This extract also reflects a number of other issues, for example, the belief within the common sense discourse that nothing could be done medically, redefining a familiar situation, engaging in the process of reconceptualising the self, and role-taking. Receiving the test results presents Mitch with a dilemma; he wants something done but also understands from knowledge then available that nothing could be done. In terms of Symbolic Interaction theory Mitch is initially presented with a situation which at a surface level is familiar and has a known configuration of meaning - he has been informed by his medical practitioner that he is not well. As a consequence he initially organises his own conduct and has expectations of others (the doctor) that relate to the regular definition of the situation - he responds by consulting the doctor in the hope that, as with other medical problems, the doctor will be able to do something to restore his health. Furthermore, in consulting the doctor Mitch demonstrates the concept of 'self as process'. Mitch initially responds to the situation (being informed of his infection with HIV) as the subject "I". That is, he reacts spontaneously to the doctor's phone call. Then perceiving the self as object ("Me" is sick), redefines the situation and acts toward that object and the new situation in ways expected by others - he engages in role-taking and responds as a sick person is expected to do by seeking medical attention. At this stage Mitch has not been able to redefine the situation as being fatal; he is not able to perceive his self as the specific object "Me" is sick with an incurable, fatal disease. However, once at the doctor's surgery Mitch realises that his conception of self is in conflict with his knowledge of the disease. He is influenced in defining this new situation by the common sense discourse of HIV/AIDS; he realises that not only is there nothing his doctor can do, but also, since there is no known treatment or cure, there is nothing anyone can do for him. Mitch then responds to this new definition of the situation in ways expected by others (through elements of the common

sense discourse). He again engages in role-taking, this time as that of a person infected with HIV and, again influenced by the perspective of the common sense discourse, is convinced he will die within a very short period.

Structuring public knowledge about HIV/AIDS

Aroni (1992) suggests that the media do not simply reflect the social world by providing information and, consequently, increasing public knowledge of it. Rather, the media structures public knowledge of the social world, and events in it, by “helping” the public to make sense of it (Aroni 1992). Lupton (1994b) reports that scanning headlines during the early years of the disease reveals that reports printed in Australian newspapers were characterised by at least eight metaphors. These were used to describe the character of the first people with the disease, its fatal nature, and the fact that the cause of infection was not known for several years. These dramatic metaphors included, ‘AIDS is gay’, ‘AIDS is deviance’, ‘AIDS is a plague’, ‘AIDS is a mystery’, ‘AIDS is death’, ‘AIDS is an enemy’, ‘AIDS is a violent attacker’, and ‘AIDS is a killer’. These metaphors dominated the early structuring of public knowledge of the disease and illness experience.

The language used in the construction of media reports focuses attention on the acute disease model of HIV illness (Crystal & Jackson 1992). This leads society to think in terms of a devastating, visible, acute, highly stigmatising condition that inevitably progresses to death over a relatively short period (Sontag 1991). As a result of the language used in discussing HIV/AIDS issues the focus is kept on the fatal nature of the disease and the process of people dying from the disease rather than living with the infection (Crystal & Jackson 1992). Consequently, through media coverage the dramatic and tragic elements of the HIV/AIDS story are presented as the norm which, in turn, reinforces the social distance between healthy members of society and those members defined and categorised as seriously ill.

The media influence on the wider community’s understanding of the common sense discourse of HIV/AIDS is reflected in one informant’s narrative. Stan’s parents, who were living overseas, wrote to him at the time that they became aware that he was a homosexual. They enclosed a newspaper clipping that contained a warning of the danger of this “homosexual disease”. Stan’s parents did not question the credibility of this clipping as a

source of accurate information. Moreover, they were so influenced by the tenor of the article that they became fearful for their son's personal safety.

8.3 They um, you know, wrote me this long letter and so on and — and that was interesting because it was when AIDS was first reported and they sent me a *clipping out of the paper about it and a warning of, of the homosexual disease...* You know, beware of, of homosexual diseases, and *they can kill you*. [Emphasis added] (Stan, 1 608-613; 710-714)

This extract reflects the effects of the early media reports' focus on what was then perceived to be the close association between the new disease, homosexuality, promiscuity and death. However, in the absence of a developed body of knowledge about this new disease, early media reports were unable to distinguish the differences between initial viral infection, the development of opportunistic infections and the actual cause of death. With the development of medical knowledge about HIV/AIDS it has become apparent that these early reports were focussing on the end stage of the disease process. At the time of these early deaths there was no way of identifying when these people became infected. With the identification of the virus in mid 1983, accurate testing procedures were developed that enabled the detection of infection. However, testing could not accurately identify the moment infection took place. That is, testing confirms that infection has occurred but not when it occurred. Since the development of accurate testing procedures retrospective surveys on banked sera suggest that infection was present in central Africa from the late 1960s and early 1970s (Crofts 1992).

Dramatic and tragic images of the trajectory and consequences of the new disease continue to be conveyed by electronic media coverage and exert influence over general understanding of HIV/AIDS. For example, one informant states:

8.4 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*. [Emphasis added] (Mitch, 1 1113-1117)

These images also influence beliefs within the common sense discourse of HIV/AIDS by presenting images of the 'typical' individual with 'AIDS' and how they die. This type of media coverage also raises issues associated with the common sense discourses of dying and death (This issue is discussed in greater detail in Chapter Nine).

This media influence is still apparent at the time of the current study. By providing information of new drug trials media coverage promulgates the discourse of hope in relation to possible 'cures' for HIV/AIDS. For example, one informant speaks of the impact a television program, aired the night preceding the study interview, had on reinforcing his sense of hope for a cure:

8.5 *I was watching something last night on the TV about this guy who's doing some new ... some new drug trial and he said "Well, look, you know *there is always hope and we always hope there is a cure*" ... well that's always in the back of your mind. [Emphasis added] (Keith, l 557-563)*

However, despite the media projecting the theme of hope, Keith succinctly identifies the dilemma such reports pose to individuals already infected with the virus:

8.6 *But — you've seen so many friends die that haven't — had the chance of even having a cure that you think, "Oh yeah, well, look — you know, it may be another ten years down the track. I'm not holding out for that. (Keith, l 564-568)*

The electronic media also influence beliefs of the common sense discourse by providing interviews with individuals living with opportunistic infections. For example, one informant identifies television as a source of powerful imagery and resultant influence over his understanding of the disease:

8.7 *I saw someone on TV once who was being interviewed. He had AIDS and made such a strong comment, you know, ... he said on the TV "*I used to think that I would be living right up to the day I died*" but now he sort of felt that he was dying, up to the day he died. In other words, he wasn't living anymore and I thought, '*Well, I don't know how long this is going to go on for. I don't want to be sort of drooping around*'. [Emphasis added] (Mitch, l 1642-1654)*

The comment made by the individual being interviewed on TV reflects the dilemma posed by one of the differences between the beliefs within the common sense discourse of dying and individual experience. It has been reported (Kellehear 1990; Leming & Dickinson 1985) that a commonly held belief is that people with a terminal illness should be able to 'rise to the challenge' of the effects and limitations of the disease and continue to live as fulfilling a life as possible until the moment of death. However, as demonstrated in the above extract the individual's subjective experience of HIV/AIDS can be quite different. Although from an external perspective the process of dying may be perceived as providing individuals with a challenge to live their remaining life fully, despite the presence of restrictions, individuals' subjective experience may be very different. For example, another informant recounts a discussion he had shortly before the death of a close friend:

8.8 I sat on the bed with him when he was kind of very ill, it was about two days before he died, and he just said “It’s boring isn’t it?” And that was his attitude. It was so boring, he just wanted to go, he just — and I said “Oh no, it’s — you know — it’s not boring”. It’s just sitting there with him contemplating, he could still talk but barely, — uh — we were just kind of going over things that we’d done over the past and all the rest of it, and I mean, he was saying it wasn’t just boring for him it was also boring for every body else that had to look after him. You know, and he was fed up. He just wanted — he didn’t want to have to put people through that — he never wanted to put people through that at all. (Keith, I 2252-2276)

This difference between the common sense discourses about HIV/AIDS and individuals’ subjective experience of infection with the virus has important implications for how individuals construct their life with the infection. This issue is discussed in detail in Chapter Eight.

Changes in elements of the discourse of HIV/AIDS

As early as 1989 HIV infection was being reconceptualised as a chronic illness rather than rapidly fatal (Chaisson 1990; Cotton 1989). However, at the time of interview for current informants there were conflicting beliefs about the outcome of seroconversion. Some informants indicate that they believe there has been no change in the belief that diagnosis of seroconversion meant rapid decline and death within a short period. One informant was so influenced by this early discourse belief that, although he had been living with the knowledge of his seroconversion for ten years prior to the interview, he makes the comment:

8.9 I would say that it’s also still current. If the same thing happened to me now I would be perhaps better forewarned um there would be more information available but ... I think that I’d very much be in the same um dilemma. That even you know the potential was that I might be dead within a year or so. Other people have died. (Ron, I 1146-1162)

Further support for the continuation of this particular belief, eleven years after the first individual in Australia was diagnosed with the virus, is supplied by another informant. In discussing his reason for not disclosing his HIV status to his parents Mitch states:

8.10 I don’t see any advantage in telling them [parents] that I’m HIV as well [as gay]. For a start they won’t understand and they’ll go through what I went through, “You’re gong to be dead tomorrow, don’t touch me, don’t touch the grandchildren.” (Mitch, I 2507-2514)

The changes in community knowledge, but not in some community values, are reflected in the narrative of an informant who received his diagnosis of seroconversion six months prior to interview:

8.11 I think it's [the community attitude] changed a lot in the last couple of years. Um — not that it's more acceptable, it's just understood a lot more. I mean, go back five years — if you brought up the subject of AIDS or HIV — you know, I'd sort of cringe away from people — most from fright or uhm — had a funny feeling about it — only because of the lack of education, not knowing much about it ... when it was early in the piece it was — uhm it used to be one of those things that, because I didn't have any friends with it — uhm — I didn't know anyone that had it. *It was one of those alien things that you just sort of read about* and that was it, but with the years gone by having personal experience with it with friends, close friends, people that I know that have passed away and now myself contracting HIV — uhm — I think over the years with the education [campaigns] *other people are not hysterical about it* [Emphasis added] (Mark, l 11-43)

Unlike informants who were diagnosed during the early years of the disease, Mark does not subscribe to the belief that he will rapidly decline in health and die within a relatively short period, primarily because of the absence of symptoms. He and his current partner sought testing to identify their HIV status prior to establishing a cohabiting relationship. Mark makes the comment:

8.12 It hasn't really hit me — mainly because I haven't noticed any changes. I haven't got no [sic] symptoms — there's no deterioration or anything yet. I suppose as it progresses it might be a bit more — sort of thing. It's hard to believe. I still — don't believe that — I mean, I know I have but — I find it unbelievable that I do have it. (Mark, l 128-142)

In this extract Mark is not denying the fact that he is HIV-positive. That is, he is not using denial as a defence mechanism to cope with his situation. He is simply stating that, given that his subjective experience is very different to the early discourse, particularly all the information and beliefs about seroconversion and rapid deterioration to death, it is difficult for him to believe that he is infected with an incurable virus. That is, he is experiencing difficulty conceptualising himself as a person infected with the virus because his perception of the common sense discourse is that someone who is infected should have some symptoms. His social interaction with friends who received a positive diagnosis prior to his own also differed from beliefs within the common sense discourse. Although Mark has several friends who have been HIV-positive for some time, none of them have died as a

result of the virus. The absence of symptoms has considerable impact on individuals' perception of themselves and the discourse about HIV/AIDS.

Confounding issues

Implicit in Mark's comments (extract **8.11** page 241) is the important distinction between two separate issues that are often confounded within the common sense discourse of HIV/AIDS; knowledge and understanding of the disease and community beliefs and values about morality, marginalised groups and mortality. Knowledge of the disease includes a number of specific issues such as what causes the disease (a virus), how it can be transmitted (via body fluids), how to avoid infection (avoiding exposure to infected body fluids), the distinction between the virus and opportunistic infections that occur due to damage caused to the immune system by the virus (e.g., between HIV and Kaposi's sarcoma (KS), or *Pneumocystis carinii* (PCP)), that the development of opportunistic infections may not occur for several years after actual infection and the disease is not specific to a social group. Alternatively, community beliefs and values about morality focus on issues concerning the social acceptability of behaviour that deviates from the accepted norms of the dominant groups in society (e.g., homosexuality, intravenous drug use, prostitution and promiscuity).

In discussing the effects of HIV/AIDS-related education campaigns Mark makes another distinction between the effects on the gay community and the general community. He believes that the education campaigns successful. However, its success is:

8.13 ... more in the — the gay community and not — maybe to some extent as far as the straight community, even as far as nightclubs are concerned and — uhm — places where people go for entertainment — so mostly gay places seem to be a lot more aware, there's a lot more posters — uhm — of more knowledge and more things you can read about it. (Mark, 157-65)

This distinction between the gay and straight communities has important ramifications for the development of different discourses of HIV/AIDS - one used by the general community, and whose transmission in Australia is predominantly influenced by the mainstream media, and others used by different sections of the HIV infected community. Differences within the HIV infected community have arisen because of the pre-existing stigma and discrimination associated with some of the at risk groups identified in early reports of HIV/AIDS. Although some Australian state AIDS councils claim to represent all

communities affected by the disease, separate organisations for intravenous drug users and sex workers have been established in other states (Altman 1992b). The development of separate organisations representing different groups affected by the virus is partially a response to individuals within these groups attempting to distance themselves from the stigma associated with homosexuality and socially defined 'deviant' behaviour. Due to the problems associated with access to a range of individuals with HIV (see Chapter Four) the focus of this thesis is on members of the gay community who are HIV-positive.

Diagnosis

Diagnosis of seroconversion for current informants occurred across a ten-year time span; seven received their diagnosis during the first five years of HIV/AIDS in Australia (1983-87); the remaining two informants were diagnosed within eighteen months prior to their interview (1991-92). Consequently, informants' narratives reflect elements of the discourse of HIV/AIDS that were current at two periods: the time of their diagnosis of seroconversion, and the time of interview. Thus, the narratives reflect beliefs and practices of the discourse during its early development and after twelve years of evolution.

Reasons for seeking diagnostic testing

Similar to the cancer sample, some informants in the current study HIV/AIDS sample sought medical attention for specific symptoms. Of the three HIV/AIDS informants in this category only one suspected he might be infected with the virus. The remaining two did not consider the possibility that they might be infected and were surprised when the test results came back positive. The remaining informants took the diagnostic test for reasons other than the presence of symptoms. Two informants were entering new relationships and all partners wanted to know their HIV status. One informant had the test because he had heard that a former sexual partner had died as a result of the virus. Another informant took the test because, at the time, "everyone was taking it and it just seemed the thing to do". The remaining informant was tested after he was forced to disclose his homosexuality to his wife and she insisted on him being tested.

Effects of seroconversion diagnosis

When informants receive their diagnosis of seroconversion they face a number of dilemmas. Firstly, like their cancer counterparts, diagnosis defines them physically and socially as unhealthy. Diagnosis of seroconversion not only signifies serious illness but also

that the individual is terminally ill. That is, effects of the virus will eventually cause death. However, this diagnosis may occur in the absence of overt signs and symptoms of disease. As with their cancer counterparts, once the knowledge of their HIV status is identified individuals are assigned what Goffman (1990) describes as a virtual social identity. Whereas this discredited virtual social identity for individuals with cancer is based primarily on the myth of contagion, degeneration and pain (Sontag 1991), for those diagnosed with HIV/AIDS it is based on the categories and attributes defined and classified by the common sense discourses of homosexuality, homophobia and morality. Therefore, unlike cancer, the attributes and significations of HIV/AIDS are based predominantly on social and moral, rather than medical issues. Furthermore, attributes of HIV/AIDS are not only deeply discredited by members of the wider community but also by some members of the subculture to which they belong - the gay community.

For the majority of informants in the current sample diagnosis occurred in the absence of physical symptoms. Hence, without the physical signs and symptoms that indicate ill health, these individuals face a double dilemma of reconceptualising their self-images: not only as being infected with a virus that will inevitably result in their death, but also as having the capacity to infect other individuals, particularly their partners during intimate social interaction. Unlike their cancer counterparts, informants in the current HIV/AIDS sample face an additional dilemma: the disease forces them to confront the issue of whether to disclose this information and to whom it might be disclosed. This dilemma is further complicated by the common sense discourse of homosexuality which incorporates the belief that people with the virus belong to a subculture that is discredited in society because it is perceived to deviate in practices and life-style from the socially sanctioned behaviour and values of the general population. (Only two of the HIV/AIDS informants had disclosed their sexuality to their family of origin prior to diagnosis of seroconversion.) In addition to these dilemmas HIV/AIDS informants also face the dilemma of resolving the difference between the common sense discourse of HIV/AIDS and their own experience of the disease and subsequent illness experience when the two were incongruent.

Impact of early common sense discourse on self-image

Early discourse beliefs concerning the virulent and fatal nature of the new disease also had an impact on the thoughts and emotions of individuals who were informed of their

seroconversion. For example, in the absence of symptoms, one informant describes this impact on his perception of himself and how his life had been dramatically changed:

8.14 Ron: As I saw myself suddenly instead of being on top of the world with the best of everything and two beautiful children um an understanding and caring wife with a lover with um with this feeling of you know Oh good God um and I felt that I'd regained my honesty by being able to be open with my wife [about sexuality and extra marital affairs] um my family knew who I was so I really didn't feel that I had to hide myself from anybody, except perhaps with my wife's family who were on the other side of the world, ... um ... suddenly I felt that um from this highly privileged position um feeling well because of my good health um ... I presented well um that *suddenly I became a pariah I became a danger to um everybody else basically who I could touch um and I became a very different colour.*

Interviewer: Where did those ideas come from?

Ron: Oh well it came from the fact um the disease that I had was irreversible it was um transmissible and it was allied with um a morally questionable area of sexual activity; morally questionable not for me specifically but in the eyes of society at large ... *Oh I was like a leper you know ... That I was like a loaded gun that um that I could inflict um — and in fact would inflict um — harm and death upon people who had sort of sexual contact with me ...* he [previous lover] and I were in fact both, that *we were both pariahs ... I could not be safe any more.* Not even ... with my children. *Because my blood, my blood literally was tainted ... I can go out and kill somebody ...* instead of what I considered to be a healthy beautiful thing, I rejoiced in my own body. I enjoyed my body with relation to other people's bodies. I liked my body, you know, and then it became a — well first of all my penis became a useless appendage except with regard to ... [ex-lover who was also HIV-positive]. [Emphasis added] (Ron, 1 1066-1101; 1199-1221; 1841-1903)

In this extract Ron uses metaphors, a popular method of conveying the meaning of new experiences, to demonstrate the radical change to his self-image brought about by his diagnosis of seroconversion and the effects of certain elements of the early common sense discourse. Having successfully negotiated a difficult period in his life including openly acknowledging to his wife that he was engaging in homosexual affairs and enjoying the physical pleasure he derived from his body, Ron was forced to reconceptualise his self-image. Although he was asymptomatic, Ron was so influenced by the strength of the belief in the virulent nature of the new disease that he uses the leper metaphor, which is steeped in strong connotations of being a social outcast, to describe his perception of himself. The fatal nature of the disease is symbolised in Ron's use of the gun metaphor; as a 'lethal weapon' he could inflict death on anyone who had close contact to him.

The above extract also demonstrates the interfusion of different aspects of knowledge and myths about HIV/AIDS. The original belief in the transmission of the disease through homosexual practices is supported by Ron's reference to his penis becoming "a useless appendage". Implicit in this comment is Ron's belief that he could only be sexually intimate with others, like his then lover, who are also HIV-positive. The reference to not being safe even with his children suggests Ron was also influenced by the initial public hysteria concerning spreading the disease through routine daily activities (e.g., sharing eating utensils). The tainted blood metaphor reflects the developing knowledge of how the infection was spread. As medical knowledge about HIV/AIDS developed it became apparent that it was not simply a sexually transmitted disease but a virus that was spread through infected body fluids.

The impact of the early discourse elements about the effects and outcome of the new disease are provided by another informant. Geoff had also been through a particularly difficult time prior to his diagnosis of seroconversion. After disclosing his homosexuality he experienced a difficult separation from his wife and children, resigned from a job he enjoyed, moved interstate to avoid discrimination and condemnation from relatives and former friends, established a new lifestyle and identity within the gay community of a large city and began a cohabiting relationship with another man. Geoff did not suspect he might be infected with HIV when he sought medical attention from the outpatient department of the local hospital for an extremely high temperature in mid 1985. He was subjected to discrimination by hospital staff when he acknowledged he was gay; they refused to treat him and sent him to another hospital specialising in HIV/AIDS. Geoff comments that after diagnosis of his seroconversion:

8.15 Geoff: I went through a really rotten time and I'm, I'm surprised to say, well embarrassed to say that I became suicidal. I actually took lots of medication which I shouldn't have taken.

Interviewer: What led up to that?

Geoff: Oh, just a long period of feeling quite worthless and trying to deal with I'm HIV positive and I can't, that *I can't even sleep with my lover any more* and dealing with it and I think it really was everything that happened with my break-up, the marriage, and my whole lifestyle um everything leading up to um finally here I've got a relationship which is what I want with a man, I'm happy, and then suddenly being told that "You're HIV positive" um was quite devastating to me at the time. [Emphasis added] (Geoff, 1 514-536)

The perceived virulent nature of the new disease led Geoff to believe that now he had been diagnosed as HIV-positive he would no longer be able to be sexually intimate with his partner. Since Geoff could see no worthwhile future for himself, and in conjunction with the difficulties he had experienced in the past (some of which were still impacting on his life), he could see no alternative but to attempt suicide.

A similar reaction to seroconversion is provided by another informant diagnosed in 1987. Although he had no symptoms indicating that he was ill, his reaction is similar to that reported in the above extract, thus indicating that it too is based on the general understanding that no treatment or cure was available:

8.16 ... [my] reaction at that time was, well there's, *there is nothing at all that can help you, because there is not even any sort of life-extending drugs*, and I think that was a big shock and it was a time -- I think the first deaths were occurring in larger numbers and so I guess I felt quite, quite demotivated by the whole thing, just in a state of shock for about six months. [Emphasis added] (Stan, 1 192-199)

However, one informant reports that he had no adverse reaction to his diagnosis of seroconversion. This particular informant came from a very accepting family who had known about, and affirmed his sexuality for many years. He recalls his reaction at the time of diagnosis:

8.17 I kind of had it in the back of my mind that I would not come out with a negative test, but that didn't prevent me from going in anyway, and sure enough it was a positive result. Uhm -- which didn't thrill me -- because I think I half expected it -- ahhh -- so I didn't kind of sit down and cry -- and the doctor said "Do you need counselling?" -- This, that and the other thing, which I didn't really feel that I did, -- ahhh -- not having any idea when I was infected, or how early it was, or anything else, -- ahhh -- so -- I kind of just -- you just dealt with it. You just thought -- well this is, kind of, your lot. Well the doctor was kind of obviously expecting me to fall to bits, I think -- and -- I -- he was, I think, he was genuinely concerned that I would need some counselling of some kind or another, but I -- think that basically I'd had friends already that had been ill -- ahhh -- nobody was -- obviously knew what the impact was going to be and the ramifications of how many people were going to die etc. -- ahhh -- and I guess I just -- thought that I could deal with it with the peer group that I had. (Keith, 1 25-83)

This informant's response is so different to that of all other informants in the current study that initially it appears as though he is using denial to avoid the reality of his seroconversion. However, there is sufficient evidence in the remainder of his narrative to

support the conclusion that his self-image and personal philosophy (discussed in more detail in Chapter Eight) is so strong that he is able to acknowledge his HIV status and get on with living his life to the best of his ability.

Influence of friends' experiences on self-image

Interpreting the experience of others, and then retelling these anecdotal experiences, is simultaneously a method of transmitting elements of the common sense discourse to other members of the community and a mode of reinforcing these same discourse elements to the storyteller. In telling the story the narrator hears his/her own voice which tends to reinforce the validity of the words being spoken. This regularly occurred with the early period of HIV/AIDS for two reasons. Firstly, the absence of a reliable body of knowledge based on research into the topic forces people to glean information from whatever source possible in their attempts to understand and develop meaning about a new phenomenon. Individuals then make interpretations of this information and relay their interpretations to others.

Secondly, and perhaps more importantly for members of the gay community, the new phenomenon occurred to a range of people who were close friends or acquaintances. Discussing experiences and interpretations with friends also has a validating effect on the anecdotes. For example, one informant recounts his interpretation of the experiences of two of his close friends whom he thought were so convinced, after receiving their diagnosis of seroconversion, of their inevitable rapid decline to death that they literally gave up living, thus reinforcing the strength of the early discourse belief about the disease and its rapidly fatal outcome.

8.18 Stan: It was just the end of the year [1987], he found out and he went through this whole trauma of, you know, I'm going to die and I might as well give up life and just literally was just going downhill so rapidly ... I was watching him and seeing a bit of myself, my fears, *so I quickly was sort of focussing on him* and saying, "Well, you know, *you've got to get on with life*" and so on and I was probably really telling myself the same thing.... I think I was watching myself and what he was doing, saying I'm learning a lesson here, you know, *he's got to pull up his own socks and look after himself a bit, he's got to want to live* um it's too premature, the time will come but it's too early, why is this happening and er, and just, you know, and just shook him by the, by the neck and said "Come on, get going, get going".

Interviewer: So in fact, in getting him to do that — you're able to get yourself to do that as well?

Stan: Yeah — That's, that's quite true, yeah, quite true, and, and I think a lot of the, a lot of the things that I had him do were things that I was almost — I

have a psychology background, but it's almost like you observe someone's behaviour and you say "Does that work? Oh well that's fine, well I'll try that"... I had a good friend who was. he was a well known doctor who was diagnosed as being positive and died about two, two and a half years ... *he was too scientific and too fatalistic*, that he wouldn't believe that there was a possibility that his body could, recover from some of the things and he died literally semi-healthy, right, *there was no reason for him to go. He wouldn't eat, he wouldn't do things, he'd just given up, that was it.* [Emphasis added] (Stan, 1 259-264; 275-280; 514-540; 1278-1295)

This extract also demonstrates part of the process of reconceptualising a new self-image. At the time of initial diagnosis Stan had a self-image that he was in a hopeless situation and that he would die within a relatively short period from the effects of the new disease (see extract 8.16 page 247). However, through observing his friends and their experiences he began to reconceptualise his self-image as getting on with life and not giving up too soon. His focus began to change from one of dying to one of living as best he could.

Elements of the discourses of hope and moral culpability are also demonstrated in the above extract. In the absence of indications that neither of his friends experienced symptoms of illness Stan's comments imply that he believes that both friends gave up hope and this is the reason why they deteriorated so quickly. Furthermore, in the second story there is implicit support for the belief that his doctor friend was accountable for his own death because he would not take responsibility to do "things" to prolong his life. In essence Stan is supporting the generally accepted myth about personal culpability and responsibility for one's ill health and death. As Foucault (1971, 1977, 1981, 1994) argues, it is this 'support' and continued promulgation of beliefs by individuals who are themselves ill that gives such beliefs their power.

Focusing on the other

A focal point in the mainstream media's construction of HIV/AIDS is its presentation of the origin and transmission of the virus in language that evokes an almost primal focus on the 'other'; the foreigner (e.g., Africans or Haitians), the morally defined 'deviant' (homosexuals, injecting drug users and prostitutes), and the 'already damaged' (people with haemophilia) (Aroni 1992; Crawford 1994; Schiller 1992; Treichler 1987). Since discussion of HIV/AIDS began in the media in 1981 the public at large has fluctuated between short-lived panic about the disease spreading, particularly among the heterosexual

community, and regarding it as the “curse of the other” (Altman 1986). Locating the source of a lethal epidemic disease in populations perceived as culturally different is a practice that predates modern health research (Brandt 1985; Slack 1988). Schiller (1992) suggests that this paradigm of the contagious cultural other has two functions. Firstly, it delegates the origin of the disease to the cultural other, who is seen as different and immoral. Secondly, it supports the belief that the disease is highly contagious so that the other must be separated from the general public. In addition, Crawford (1994) claims that it maintains a separation between those who are healthy and those who are unhealthy.

Support for the continuation of this common sense discourse belief is reflected in the current study. An informant who became infected during the early years of HIV/AIDS in Australia makes the comment:

8.19 There are arguments that it was in Africa, it's in Haiti, it's rife in heterosexual communities everywhere else. And that homosexuals actually brought it back — I mean, I don't know. There's arguments that it's a man made disease. I mean there's all that kind of American research — hysteria — yeah — that it's out to get the homosexual and wipe them out. (Keith, l 1855-1870)

Further evidence of this focus on the other is implied in Mark's comment in extract **8.11** (page 241). Mark's initial understanding of the disease, derived from media reports, was that it was an “alien thing”. Implicit in this statement is the belief that the virus is not routine or ‘normal’ and, therefore, happens to ‘others’ rather than an ‘ordinary’ person. As Mark indicates, his understanding of the disease only changed when he began to have a personal experience of the disease - first with his close friends and then himself becoming infected.

Since homosexuality is still widely discredited within the Australian community, HIV/AIDS is still considered as a highly stigmatised disease and a phenomenon that does not occur to the ordinary person. Rather it is perceived as a disease of the other. This is supported by informants' narratives. For example, one informant comments:

8.20 ... it's always been a homosexual problem ... I think that's just how it's been perceived. It's a bit like the gay plague [syndrome]. (Keith, l 1798-1845)

Keith also believes that the community still has negative attitudes toward homosexuals and, as a result, the community continues to perceive HIV/AIDS to be a problem of others

(homosexuals, and, to a lesser degree, prostitutes and intravenous drug users) and is not too concerned with the issues associated with the disease:

8.21 ... it's one of those things homosexuals get — and I still believe the community sees it as a homosexual disease and, therefore, they're not too concerned, generally ... But I think there's still that — that — attitude out there, that negative attitude to homosexuals anyway. (Keith, l 589-597)

Contained within this extract is the implicit belief that not only does the community see it as a homosexual 'problem' and, therefore, a problem of 'others', but also, as a 'curse of the other', they think that as normal members of the community they are not at risk of becoming infected.

Evidence that, at the time of interview, this is still a belief within the common sense discourse in Australia is provided by current informants' understanding. For example, one informant who was diagnosed in 1985 indicates that, at the time of his seroconversion, the community believed the disease belonged to a specific group - homosexuals. Furthermore, some eight years later the same attitude is prevalent. Mitch makes the comment that he believes the community still perceives HIV/AIDS as:

8.22 ... a poofter's disease basically. Um — *it's still very much that attitude actually* um so when you see things in the paper about um — just recently there was — someone was saying it was basically still a male homosexual disease, well OK fine, but the majority of people are going to think that because at this stage that's all that's been affected um — *I think the — general public's attitude is still pretty bad*. Er the gay attitude is not as bad as I used to think it was. I used to think every — every young gay person had a thing against anyone who had AIDS. [Emphasis added] (Mitch, l 2353-2364)

Implied support for the continued existence of the early belief that only certain types of people (homosexuals) became infected is also contained in informants' narratives. This focus on homosexuals, in 'understanding' the phenomenon of HIV/AIDS, evokes elements of the common sense discourse of homosexuality, particularly the stigmatising beliefs associated with perceived deviance, promiscuity and otherness. For example, in discussing the issue of whether family members suspect their HIV status one informant said of his parents:

8.23 ... it would be a matter of them to think "Oh well, you know, OK, you know, he's — he's gay but that wouldn't happen to him not the other thing, that just wouldn't happen to him". That's how, that's how they would be thinking of it *which is how I would have thought about it once upon a time*. [Emphasis added] (Mitch, l 2604-2612)

This focus on the other has implications for how individuals react to diagnosis of their seroconversion and their attempts to live with the infection.

The dilemma of who becomes infected - me or the other?

Although each of the current informants had a self-image as a gay man, and selectively disclosed information about their sexual identity, each also accepted this particular self-image as 'normal' rather than deviant. For example, in the previous extract (8.23 page 251) Mitch acknowledges that, despite personally accepting his homosexuality since adolescence, and living openly in gay relationship for several years, he was also influenced by beliefs within the common sense discourse that only certain types of homosexuals were at risk of infection. Implicit within the statements in this extract is the belief that infection only occurs to the other. Herein lies a dilemma. Beliefs within the common sense discourse suggest that, as deviant others, all homosexuals will become infected with the virus. However, Mitch does not perceive himself to be a 'typical' homosexual. More importantly, Mitch does not perceive himself to be 'the other'. He presents evidence to support this conclusion when discussing what he believes is his sister's attitude. Since Mitch thinks his family does not consider him to be the stereotypical gay person, he believes that they would not suspect that he would become infected with "typical gay person's disease":

8.24 I think she suspects I'm gay, I think she always has, but as far as the AIDS thing's concerned, no, I don't think any of them [family members] would even think about it because in their mentality still *it's something that happens to other people, to gay people, or to queers or, you know ... I don't think they'd see me as the typical gay person, therefore they wouldn't expect me to get a typical gay person's disease.* And that's the way most people will think about it, so I think. [Emphasis added] (Mitch, l 2650-2678)

The implication in Mitch's comment is that not only does he not perceive himself to be a "typical gay person" but also he does not consider himself to be an example of the other - a stereotypical, deviant homosexual:

8.25 I don't see myself as a screamer or one who likes to dress up in make-up or that sort of thing or carry on like a -- a bit of a girl or — whatever. (Mitch, l 2692-2697)

Mitch's comments in these two extracts indicate that he believes that the common sense discourse of homosexuality stereotypes the "typical" gay person as a deviant with blatant characteristics (e.g., effeminate, wear dresses, and use make up) that immediately identifies their membership of a culturally discredited group. Again, implicit in this statement is the

stereotypical link between the belief that deviants within the gay community, such as “screamers”, those who like to “dress up” or those who act like “a bit of a girl”, are promiscuous and, therefore, are the people most likely to become infected.

Further support for the belief that only the stereotypical, ‘deviant’ gay person would become infected with the ‘homosexual disease’ is provided by another informant. In response to the letter from his parents (see extract 8.3 page 238) Stan indicates that he was shocked by his parents comments on two levels. Firstly, that they knew about his sexuality, despite his efforts to withhold that information from them. Stan did not want his parents to know about his sexuality because he believed that they would reject him if they knew his “guilty secret”. Stan had arrived at this belief because of the way he interpreted his father’s responses to Stan’s childhood experience of being accosted by a pedophile, and the general stigma associated with homosexuality. Secondly, and more importantly, he was shocked that they would think that he was the ‘type’ to contract this “weird” new disease:

8.26 I guess I was shocked that they would, that they would know I was gay, and secondly that they would think I would, you know, get some kind of a weird disease. (Stan, 1709-718)

Stan’s response was to write back and reassure his parents that, although he was homosexual, he wouldn’t get HIV/AIDS:

8.27 I wrote back to them and said um oh, you’re right, I’m homosexual, etcetera, etcetera, but, you know, how dare you suggest that I’m, you know, going to get sick with this thing, it’s all bullshit, I’m in a, I’m in this relationship.... I was so strongly — when they suggested that that’s a danger in 1982, whenever it was, — that I had a holier than thou attitude that *I wasn’t a, a, a scumbag or a sleaze ball*, I wouldn’t pick up sexually communicated diseases and therefore, you know, don’t even suggest that to me. [Emphasis added] (Stan, 1614-620; 1708-1718)

Although a belief within the common sense discourse of homosexuality is that all homosexual behaviour is deviant and, therefore, as deviants all homosexuals are members of the morally corrupt, contagious cultural other, Stan, like Mitch, does not perceive himself to be the other. Both these men have a self-image as a ‘normal’ gay man. Furthermore, they distinguish between their own self-image of normality and that of the ‘other’ within the gay community who are perceived as ‘deviant’ (i.e., the “screamer”, the “bit of a girl”, the “scumbag”, and the “sleaze ball”) and more likely to become infected with the virus. Both these men experience internal conflict as a result of these beliefs. Their

statements imply that they believe that it is only deviants within the gay community who become infected. However, both men must face the fact of their own seroconversion. As a method of dealing with this internal conflict both men choose to 'distance' themselves from the common sense discourse. (This issue is discussed in greater detail below - see page 262).

The experience of being the other

Attributing the social identity of the other to those who become, or are thought to be, infected with HIV is a common practice within the wider community. Informants provide a number of examples of situations which, at a surface level, are familiar and have a known configuration of meaning (e.g., seeking emergency medical attention, routine interaction with friends). However, to the informants' surprise, interaction has not proceeded as expected. The outcome of these social interactions were interpreted by informants as non-infected people creating or maintaining social distance. On some occasions this distance was physical and at other times it was emotional. For example, one informant describes his interaction with staff at a local hospital outpatient department prior to his diagnosis of seroconversion in 1985:

8.28 I thought I'd just go to the hospital. I was hot, boiling ... and the first question they asked me was, "Are you homosexual?" I said, "Why are you asking me that? But yes" and I was comfortable answering yes. I was immediately moved into a single room and left *and I thought treated quite, literally treated — poorly*. I found myself just put in a taxi next day in the morning after being there all night and sent to ... [specialist hospital]. [Emphasis added] (Geoff, 1854-875)

In this incident Geoff, himself a nurse, describes his attendance at the outpatient department of his local hospital; a familiar situation with a known configuration of meaning. He was expecting routine interaction with the medical staff whom he thought would investigate the cause of his high temperature and provide appropriate treatment. As a part of this standard investigative process Geoff was expecting the staff to ask questions relevant for this purpose. He was not expecting to be asked about his sexuality. Geoff interprets his affirmative response to this question as the trigger that resulted in the medical staff redefining the situation. Geoff considered the medical staff's response of moving him into a single room as unusual. He also interpreted their action as isolating and "poor".

It appears from Geoff's description of the incident that the medical staff began operating from a different perspective once Geoff was identified as a homosexual. Geoff, as a patient, was no longer the social object toward which the medical staff were acting. Instead, the situation was redefined by the staff as one which included the possibility of a highly infectious disease. Consequently, the staff began acting toward this new social object. In the absence of data from the medical staff involved it is not possible to identify the actual reason for their actions. However, at least two alternatives exist. First, in acting toward the infectious disease as the social object, the staff may have engaged in what was considered appropriate medical action by isolating the infected person in a single room to decrease the risk of cross infection of other emergency patients. Second, staff may have been acting toward the social object of Geoff as a homosexual and, therefore, a member of a socially devalued group. In this later scenario staff may have redefined the situation as not only medically threatening but also personally threatening and placed Geoff in a single room to create distance between Geoff as a physical or moral threat and themselves.

Whatever the motivation for the medical staff's response it is important to consider Geoff's interpretation of their actions for it is Geoff's interpretation and redefinition of the situation that influenced his responses. Although feeling "comfortable" about acknowledging his sexuality, Geoff was not comfortable with what he thought was the medical staff's response. It is apparent that during the incident Geoff did not interpret the staff's actions as efficient management of infection control. Instead he began thinking of himself as devalued by the response of the medical staff. He then interpreted their action as a slight against him: he perceived their actions as indicating that he was the devalued other, from whom staff wished to maintain social distance.

Another informant describes his experience of being admitted to hospital for eye surgery in 1986:

8.29 I was one of the first openly HIV people to be operated in a public hospital in ... [Australian state] My private health insurance meant that I could only afford a shared ward. I was put in a private room. Theatre nurses refused, for an hour, to operate on me. They said, "Send him off to ...[named hospital]. (Kyle, 12538-2548)

Similar to Geoff's experience outlined above, Kyle interpreted his experience as being socially isolated by some members of the medical staff. However, this is not an isolated incident for Kyle. He describes another experience of what he perceives as discrimination which occurred in 1988. Kyle believes this discrimination also arose as a result of his HIV status. While on his way to work Kyle was involved in a car accident and injured his back. When the ambulance arrived he informed them that he had "bad blood". The ambulance men were profuse in their thanks for this information and Kyle was taken to a large inner city hospital. Kyle takes up the story:

8.30 It was a Tuesday morning at a quarter to nine. We're not talking Saturday night, road casualties — I wasn't taken into Casualty. *I was put into a linen closet ...* there was no buzzer to call for a nurse, right, and I was busting for a wee. I didn't want to wet myself ... so I had to — with the top of my back and the bottom of my legs, manoeuvre the gurney to the wall — pull myself along the wall without trying to move my back, and open the door and I asked a nurse for a bottle and she said, "Why do you need it?" *I was treated with the utmost contempt. I was treated like dirt. I fulfilled my moral and legal and safety obligations by telling the ambulance men.* They were wonderful. I mean, possibly because of the fact that I wasn't bleeding, but the fact that I turned around and said, "Hey guys I've got bad blood", I mean, that could mean hepatitis or anything else. They could take the necessary precautions. But see, the thing was — *I was left in that linen closet for two and a half hours.* [Emphasis added] (Kyle, 12637-2700)

This incident is similar to Geoff's in extract **8.28** in that there was a known configuration of meaning at the outset of the interaction. Kyle responded by role-taking. As a patient Kyle believes he completed his "moral and legal and safety obligations" by informing the ambulance officers of his "bad blood". The ambulance officers responded as Kyle expected and he interpreted their responses as "wonderful": they did not appear to redefine the situation in response to his "bad blood" comment but continued to act toward the social object Kyle as accident patient. However, Kyle's interpretation of the hospital staff's responses is very different. It is obvious from the above extract that Kyle interpreted the staff's reactions as responding to the social object Kyle as person with HIV/AIDS and not Kyle as accident patient or infectious patient. Kyle interpreted the staff's response in isolating him in "a linen closet", and the nurse's response to his request for a urine bottle, as communicating contempt for him because of his devalued HIV status.

The assigning of the social identity of otherness can be experienced in subtle or symbolic ways. For example, one informant, who was diagnosed with HIV prior to his then partner's diagnosis, felt isolated by the manner in which his partner dealt with his subsequent diagnosis:

8.31 I was on drugs to put me to sleep because I just wasn't sleeping and my *other half* would sort of go to sleep like that (SNAPPED FINGERS) ... things turned sour when he [partner] was diagnosed as HIV-positive. I mean, his attitude was, 'Oh hell! Bad luck. We can't do anything about it. Why worry about it?', which wasn't good enough for me. I sort of felt like I really wanted to talk at times but we never did.... And instead of probably looking at each other for support I sort of think I pulled away from ... [ex partner] a fair bit because I didn't feel he understood. Um he seemed to carefree about it [Emphasis added] (Mitch, l 563-583; 1394-1397)

The term "other half" symbolises the internal dilemma Mitch is experiencing. He was devastated by his diagnosis of seroconversion (see extract **8.2** page 235) and, at times, needed to talk about his experiences with his partner. However, Mitch interpreted his other half's (then partner) reaction of not needing to talk about his own diagnosis as coping well. Mitch then interpreted his own reaction as dysfunctional; since he needed to talk about his experiences and his partner did not, Mitch reasoned that there must be something wrong with him. Mitch acts toward himself as object and how he is "coping" with seroconversion and compares his reaction to that of his then partner, who was also HIV-positive. Mitch makes judgements about how that self is responding and concludes that it is he who is the outsider, the other, who is not coping well.

The practice of socially distancing individuals infected with HIV is not restricted to members of the general community. It is also evident within the gay community. For example one informant explains that when he was diagnosed with HIV:

8.32 Some people were supportive and others weren't ... I have a fair mix of friends both gay and straight ... and some of the gay people were quite repelled by it, more so than straight people I told. They were really reactive, which was interesting, and they gossiped so the word got around, and I could feel that sort of feeling that it was, you know that I was a social outcast. (Stan, l 202-224)

It is apparent from this extract that Stan felt comfortable with disclosing his HIV status to selected gay and straight friends. However, he was much less comfortable with this knowledge being available to other individuals. He interpreted the actions of those

individuals who found out about his HIV status as judgmental and socially isolating. This supports the findings of Minichiello (1992) that although disclosure of HIV status can be therapeutic such disclosure is selective and requires a suitably receptive audience who are “supportive, encouraging, empathetic and non-judgmental”. However once this information is disclosed this individual has no control over the secondary disclosure of this information by confidantes.

Assigning the social identity of the other, and thus creating social and emotional distance, is not restricted to diagnosis of seroconversion. It occurs throughout the illness experience, particularly with the appearance of obvious physical symptoms. An example of this is eloquently provided by one informant who talks about a number of his experiences with the disfiguring skin lesions of Kaposi’s Sarcoma. This issue is of such importance for this informant that he raises it in the early stages of the interview and revisits the topic at frequent intervals throughout the interview. The major problem for this informant was that the visibility of his lesions results in him becoming a social outcast. He makes the comment:

8.33 Kyle: I realised that our society is this — the gay society is aesthetically based. Now I only had three lesions but they were — it was horrendous.

Interviewer: What was horrendous?

Kyle: The horrendous fact was that I had seen Kaposi’s patients at ... [named hospital] in a really, really bad way — and I don’t know whether you call it thinking with your dick — but I — nobody would find me attractive. Nobody would talk to me. That was my preconception. (Kyle, l 336-338)

Kyle’s fears were realised when he attended a warehouse party. Under the lights of the main party room the lesions were not particularly visible. However, Kyle was ‘outed’ by the fluorescent lights in the toilets:

8.34 In ’89 I was up in ... [named city] and I had Kaposi’s — and there was a warehouse party at ahhh — the ... [named venue], and they have downstairs toilets and the toilets have fluorescent lights, and Kaposi’s just — magnifies under fluorescent lights, and I was standing at the wash basin after washing my hands, it would have been about midnight, ... and as I was walking up the stairs some queen turned around and said “Well don’t go near him dear, he’s got Kaposi’s”. And then I promptly didn’t go out for six months. Literally! Because — well — I mean, I just did not go anywhere. I would go to work; I would go shopping; I would go to places where I felt totally secure. (Kyle, l 353-371)

The visibility of KS lesions lessens with treatment but the stigma associated with this particular opportunistic infection does not fade with the treated lesions. Verbal disclosure of KS also results in social isolation. Kyle relates an incident that occurred to him after he had been receiving treatment. He had used a tanning lotion to camouflage the remaining skin shading caused by the lesions and went to a local swimming pool that was also a known gay meeting place:

8.35 The radiation treatment had an effect ... and in the summer of 1990 — 90/91 — I went to ... [named public swimming] pool. Admittedly I used pre-tan accelerator — uhm — I didn't go in public — ahhh — until I had a reasonable tan — but I was blond haired and tanned again — and life was wonderful. I mean, I was getting checked out a ... [named] pool — it was wonderful. And I actually met a guy there — and talking to him and everything else — you know, I mean, he would come — everyday, And this guy would chase me from each section over a period of days. And we didn't have sex or anything — uhm — you know, he came around one night and he said "Why — " because he rang me and said I want to see you, — because I gave him my phone number, and you know, I thought well he hasn't got the address, "Why won't you follow this through?" And I said "I'm HIV." — He said "There's nothing wrong with being HIV." — I said "I've got Kaposi's." — He backed off like you would not believe. — I mean, literally backed off — and so — uhm — anyway — ahhh — I became — dare I say secretive and furtive. (Kyle, 383-427)

Kyle is aware of why KS lesions have such a distancing effect on other people. Based on his experiences he provides a number of reasons, and also attempts to rationalise why people respond by maintaining social and emotional distance. At the same time he is attempting to convince himself that their reaction is not personal:

8.36 I don't know if you've seen some of the boys that have really bad Kaposi's? They're raised — thick, purple-black lesions. Now, by having those on your body, — and the gay community being — aware — they are suddenly confronted with two possibilities; a) *This person that I'm getting to know will possibly die; am I prepared to get involved in such a late — uhm — date, into this person's life*, b) it reminds them of the probabilities — if they're HIV themselves, of what they may face — in the future. They don't know what — you know, if you've been HIV for two years and you don't show any opportunistic infections, there's no test to determine, say, that you're going to end up with Pneumocystis, there's no test to determine you going to, say, Kaposi's, and being this aesthetically based society — I mean it is hard but then you've got to face the fact too ... that it is nothing personal because I might be talking to you, you may have a dear friend or somebody who's gone through agony and died of Kaposi's, which can be a very painful death and it may have only happened two months ago — and you're talking to me and you see the Kaposi's and that may bring back memories that you're still learning to cope with. [Emphasis added] (Kyle, 491-538)

In this extract Kyle identifies what he believes is an important reason why members of the gay community avoid social contact with him; they are influenced by the fatal nature of the disease. Kyle believes that the visibility of his KS lesions identifies him as someone who not only has an infectious disease but also one that has a fatal disease. It is Kyle's interpretation of other people's behaviour and their supporting reasons (i.e., rejecting him because his KS lesions remind them of their mortality or prior painful losses) that influences his behaviour (i.e. using tanning lotion to hide the lesions and becoming furtive).

Reconceptualising self-images

Reconceptualising self-images is an important process for individuals living with HIV/AIDS. It begins when individuals suspect that they may be infected with the virus and recurs at various times throughout their illness experience. Reconceptualising self-image involves a complex amalgam of interactions between individuals' perception of elements of the common sense discourse and a number of other symbolically designated objects such as current self-image, the presence (or absence) of symptoms, experiences of close friends and acquaintances, significant others (e.g., partners, friends, family of origin). As discussed in Chapter Two common sense discourses are securely installed as the 'natural' order and as such are more difficult for individual members of the community to resist or challenge. The influence of such discourses is so pervasive that it can initially overwhelm an individual's previous self-images. For example, one informant indicates that prior to his diagnosis of seroconversion he felt very comfortable with his homosexuality (see extract **8.14** page 245). He had recognised from adolescence that he was gay, and openly discussed it with his parents when he was sixteen. Prior to diagnosis of seroconversion he was able to ignore the social discrediting of homosexuality and describes the personal fulfillment he achieved through his sexual activity as:

8.37 I mean physical contact to me had always been a — an enormous joy um — I mean, — to me it was a rejoicing in life and being able to um — to have physical contact was not — it wasn't something um dirty disgusting or anything like that. It was something that just a joy this was something that I was I always looked upon as being sort of — — I looked upon it as being um the — as being um highly desirable not just desirable um you know desire of sex sort of thing but from a from a point of view of personal expression um that it was a higher form of personal expression — a sexual relationship. (Ron, 1 1224-1252)

Prior to his seroconversion Ron had a self-image of a gay man, content and well satisfied with his life and "on top of the world". However, his diagnosis forced Ron to confront this

particular self-image. With confirmation of his infection Ron was suddenly overwhelmed by the power of elements of the discourses of HIV/AIDS and homosexuality to label discourse subjects (infected homosexuals). Ron's self-image changed dramatically. He began to perceive himself to be a "pariah", a "loaded gun" with the potential to kill others close to him, and a social "leper" with "tainted blood" (see extract **8.14** page 245). When he and his former partner separated Ron thought that, as a result of his HIV infection, he would not be able to have another intimate relationship with another man. He thought no one would want to have a relationship with him.

Another informant had similar difficulty with reconceptualising his self-image because of his perception of the social identity of the other being ascribed to PLWH/A. After a difficult separation from his wife Geoff moved interstate, began the task of re-establishing himself in another city (including establishing his identity in the gay community), participated in postgraduate study and established himself in a stable gay relationship. Although he experienced some difficulties with his self-image as father to his two children who remained with their mother, Geoff's self-image as a gay man was happy and contented; he was living in a gay relationship and enjoying a lifestyle in which he found personal fulfillment. However, when he was diagnosed as HIV-positive Geoff's world fell apart. The discrediting power of early beliefs about contagion and socially unacceptable sexual behaviour led Geoff to perceive himself as a threat to the safety of others, particularly those with whom he was sexually intimate:

8.38 I felt almost, I suppose you call it plague syndrome, where I shouldn't sleep, even sleep with him [partner] anymore ... I felt that I would be rejected sexually, our intimacy would change and that was more of my own problem. (Geoff, 1750-752; 1229-1231)

At the time of interview Geoff was still struggling with reconceptualising his self-image and distancing himself from the social identity of the other. Throughout the interview Geoff makes a considerable effort to present himself as coping well with his illness. It appears that he does not want to be seen as not able to deal effectively with the issues in his life and, therefore, be labelled as a dysfunctional other. Whenever emotional issues arose during the interview Geoff describes the situation and then quickly adds that he thought he "coped very well with it" (suicide attempt), "I've dealt with it" (fear of dying), "I adapted to that very well" (possible rejection from sexual partner), "but I think we're dealing with it

in a positive way” (the stress associated with his deteriorating health and frequent hospitalisation). The ambivalence Geoff experiences with his self-image is best illustrated by a comment he makes just prior to the conclusion of the interview. Geoff talks about the difficulties he and his current partner are having with his deteriorating health and what the future might hold:

8.39 Geoff: He’s [partner] 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’s been a lot of fear about the future?

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

It is apparent in this extract that Geoff begins to disclose a negative comment about the relationship and his coping style. It appears that Geoff interprets the interviewer’s attempt at clarification as a form of censure. In response to his interpretation of the interviewer’s comments as possibly critical of his behaviour Geoff quickly indicates that it is not happening at the moment because they have “dealt with it”, but there have been problems in the past with fights, yelling and screaming at each other.

Challenging the common sense discourse

Individuals attempt to avoid accepting the imposed identity of the other, with its implied moral condemnation and sense of culpability, and in doing so challenge the power of the common sense discourse. The most common practice is to distance themselves from elements of the discourse and, consequently, avoid the process of symbolically designating themselves as a discourse subject (i.e. a PLWH/A): If an individual does not perceive themselves as a PLWH/A then they are not a discourse subject and consequently not subjected to the influence of the CSD. There are a variety of techniques used by informants to physically or symbolically distance themselves from the discourse of HIV/AIDS or the concept of the other. Three methods identified in the current study are a) creating symbolic distance, b) focusing on the experiences of friends, and c) focusing on living. These methods may be used individually or in combination with each other.⁴ These distancing techniques also enabled individuals to challenge the applicability of the common sense discourse to their subjective experience.

Creating symbolic distance

In responding to the elements of the common sense discourse concerning the rapidly fatal nature of the virus some individuals engaged in the process of re-evaluating their priorities in life. As part of this re-evaluation process two informants undertook significant travel that involved movement away from their routine environment, significant others, family of origin, friends and support networks. For example, one informant, whose initial reaction is described in extract **8.16** (page 247) drove to a tropical holiday resort, a round trip of over 7,000 kms, to:

8.40 ... try to get my life in order and go away and think about things and I did and I came back saying "*Alright, I'm still here [alive], and my job's still here, so get on with it*". [Emphasis added] (Stan, l 313-320)

In physically distancing himself from his routine life in his home town, and symbolically distancing himself from the early discourse beliefs, Stan was able to focus on his actual subjective experience rather than the generic experience as outlined by the generally accepted elements of the common sense discourse. He recognised that his reality was that he had no symptoms and, as a consequence, there was no reason for him to 'give up' and passively await his inevitable death. Stan decided that he was going to take what control he could in his life. Stan makes the comment that although this process took about twelve months:

8.41 ... I realised I had inner strength and *was going to worry about living as best as possible*. All wasn't lost. And my motivation changed and I got quite strong again in terms of handling the problem. [Emphasis added] (Stan, l 265-270)

Stan decided that contrary to the common sense discourse, with its focus on dying from effects of the virus, he was going to actively focus on living his life to the best of his ability. On his return from this trip Stan continued to maintain distance from the power of the common sense discourse by focusing on his friends' experiences and learning what he could do to avoid similar experiences (This issue is discussed in detail below.)

Similarly, another informant, in re-evaluating his priorities decided he wanted to travel overseas. Although not feeling positive about his HIV status prior to embarking on his trip Mitch symbolically distanced himself from the common sense discourse. In response to his diagnosis Mitch felt "dirty" and would not disclose his HIV status to friends or even casual

sexual partners. During his overseas trip Mitch engaged in social interaction with other individuals with HIV who had a completely different attitude to living with the infection.

He indicates that:

8.42 ... while I was over there *I just sort of got hit in the face with all these different attitudes*, how they treat their friends over in Europe...It was in Austria where I met a guy who had a lot of friends who really supported him and he never told me that he was, that he had AIDS, but I sort of guessed that's what it was and one of them told me at the end when before I left — but um — it — *I came back with this whole different attitude that there's nothing wrong with letting your friends know....* Going overseas I realised everyone's not the same. When I came back I told a couple of my good friends and that was terrific that I told them.... *meeting people overseas who showed me that you don't have to be so frightened about this*, they had friends helping him, he had friends helping him and that made me think differently when I came home.... I was more, *I was much more inclined to want to tell people*. And let them know [about HIV status] and therefore — keep them as friends hopefully. [Emphasis added] (Mitch, 1964-989; 1042-1047; 1498-1517)

Through symbolically distancing himself from the common sense discourse of HIV/AIDS and engaging in social interaction with a group of people, some of whom were PLWH/As, as opposed to interaction with a specific support group of PLWH/As, Mitch was able to modify his symbolic representation of HIV/AIDS. More importantly, he was able to reconceptualise the most important symbolically designated object - the self - and reconceptualise a new self-image as someone who was not “frightened” of disclosing his HIV status. Returning to Australia with this new self-image enabled Mitch to engage in different social interaction. Mitch recalls that rather than being a “moper”, “depressed” and “hysterical” as he had been prior to his overseas trip, he came back:

8.43 ... full of enthusiasm to get out there and share with the world ... and then I met ... [current partner]. (Mitch, 1978-1981)

Other changes also occurred in Mitch's self-image: He no longer perceived himself to be a 'victim'. He took more control of his situation, informed his parents of his sexuality, changed his employment to a position that provided opportunities for reducing his stress levels and increasing his opportunities for further overseas travel.

The lack, or cessation, of symptoms allowed other informants to distance themselves from the common sense discourse of HIV/AIDS. For example, Mitch, whose initial reaction to

diagnosis was dramatic (see extract **8.2** page 235), began to symbolically distance himself from the common sense discourse when his initial symptoms abated. Although he originally thought he would be dead ‘within two months’, once the visible symptom (i.e., diarrhoea) abated he ceased perceiving himself as ill with a rapidly deteriorating, fatal disease. In no longer perceiving himself to be a discourse subject Mitch’s hysterical reaction subsided and he was able to be more in control of his life. He did not engage in “denial” as he continued to understand that he was infected with the virus. However, in the absence of symptoms he interpreted his experience as differing to that defined by the common sense discourse. In distancing himself from elements of the common sense discourse Mitch perceived that he still had “some life still in front of me”. Mitch describes his situation:

8.44 As I said, business was sort of picking up and things were looking good and — then I can remember how it happened was one night *I had this bout of uncontrollable diarrhoea and it just didn’t go away and so after a week I was convinced I had AIDS* I was convinced that it was this [AIDS], and so it kept going of course, and my turning point came I think after four months. Now in that time I was a real moper. I just, you know, didn’t want to do anything ... so about four months later though I started taking some stuff that had a lot of fibre in it because someone said, “Oh maybe you’ve got the runs because you’re not getting enough fibre” ... and like *within a day I’d lost my diarrhoea so as far as I was concerned I was back on top of the world. It wasn’t so imminent any more ...* I’d started taking this stuff called Metameusil and I was crapping normally and of course I felt great, you know. Sort of went away for Easter and ... at last *I could put it in the back of my mind because I’d realised by then that I wasn’t going to die immediately* and I thought, ‘OK. I’ve had my test. *I know I’m HIV but I do have some life still in front of me*’. And my attitude by then was — because I was beginning to control my — hysteria about it, I kept thinking, ‘Well the time may come when I have to be a bit like this anyway but why do it now, you know, while I’m OK let’s get on with being OK’. [Emphasis added] (Mitch, 1516-639)

Mitch’s distancing himself from some of the effects of the common sense discourse was further assisted by his overseas travel (see extract **8.42** page 264).

This situation is similar for other individuals who do not have overt symptoms of infection. For example, in the absence of symptoms Mark has difficulty “believing” he is infected (see extract **8.12** page 241). At a cognitive level Mark acknowledges that the diagnostic test confirms his HIV status. However, it is clear that Mark interprets the common sense discourse of HIV/AIDS as indicating that someone with HIV/AIDS must have some

physical indication that they are infected. Since he has no such symptoms he is experiencing difficulty conceptualising himself as either HIV-positive or ill. Clearly Mark's conception of someone with HIV/AIDS is at odds with his personal experience. Consequently, he has difficulty conceptualising himself as ill.

Another informant used the principles and practices of a self-awareness program called *The Forum* to symbolically distance himself from the common sense discourse of HIV/AIDS. Brian maintained that through this particular self-awareness program he took "control" of his life and was able to "choose" to respond to all situations with a positive attitude. He explained the process of taking control for himself as:

8.45 ... accepting that I am going to react -- uhm -- I look at it this way; human beings react or respond -- I use the word respond when I'm talking about myself, so -- you and I, we're responding now. In fact we've been an unbroken stream of response -- all our lives. Not a microsecond goes past when you don't respond. If you cease to respond, you're dead. So, to my way of thinking, how I look on it for myself is that to live is to respond. I mean even in a dead coma, if -- ahh -- you lift the eyelid and shine a torch in you'll get some sort of contraction of the pupil indicating that the person is still responding, so I totally accept that I can not not respond. And having said that, the issue of control comes in -- in accepting that you can't not respond, but accepting that once you're aware of that fact, the possibility of choice is then open to you. When we do respond, we do so automatically. We do so like a hand on a hot stove, and largely, I believe, human beings are unaware of response. We go through life being unaware of the process of living. It's so obvious, it's so automatic -- that we're largely unaware of the process. We're largely unaware of going through the motions. So when you train yourself to achieve a certain awareness of responding -- like an ongoing awareness -- like if you -- if you let yourself dwell in the awareness that you're an ongoing response mechanism -- what you can actually achieve is -- that choice that I'm talking about which happens after the awareness of your automatic response. You begin to develop choice. You -- and that's what I call control. You begin to develop an ability to choose ongoingly; how you want to respond next, in any given circumstance.... The program that we did was all about absolute responsibility for oneself.... The program was called the Forum. And in the process of doing that Forum -- uhm -- I developed an awareness -- or a way of looking at the world -- A way of looking at the world that realises that -- you are totally responsible for how you respond. (Brian, 1 210-278; 304-305; 351-358)

At no point during the interview did Brian deny his HIV status. However, in acknowledging his status he did so with a complete absence of affect. Brian attributed this lack of emotional response to his beliefs as expressed above. These beliefs enabled him to engage in daily life without undue concern about his HIV status. His self-image differed

greatly from that implied by the common sense discourse of HIV/AIDS. He continued to live his life to the full, engaging in a full work schedule as well as being involved in HIV-related education programs for medical students.

The effect *The Forum* has on Brian's ability to focus on living rather than dying as a result of HIV is best expressed in his comment:

8.46 And I don't give a stuff if I die tomorrow because I've got to die of something, so that comes from that course; that comes from that program. *Total acceptance of circumstances but me being — the master of how I respond to the circumstances.* [Emphasis added] (Brian, 1972-1977)

Focusing on friends' experiences

One particularly effective method of maintaining emotional distance from the effects of the common sense discourse is by focusing on how friends react to their experience and 'learning' how to respond 'positively'. One informant provides examples of this technique throughout his narrative. Several months after his own diagnosis of seroconversion Stan observed a close friend who "gave up life and just literally was going down hill so rapidly" (see extract **8.18** page 248). This also proved to be a motivating experience for Stan. By focussing on his friend's situation, Stan is able to emotionally distance himself from his own predicament. Symbolically Stan's friend represents the other and, although providing support and encouragement to his friend, Stan is able to maintain a degree of symbolic distance from the effects of the virus. This symbolic distancing from the otherness of his friend fulfils an important function for Stan. It reinforces his original self-image as 'normal' and not the other (see discussion of extract **8.27** page 253). While he is able to maintain this social distance, whether real or symbolic, he is not challenged to reconceptualise his self-image to incorporate the other identity of either an individual infected with HIV or seriously ill.

Furthermore, Stan's advice to his friend to "get on with life" implies that the friend is 'responsible' for his current situation; if he possessed sufficient 'self-control' and 'self-discipline' the friend should be able to stop his current slide and, if not able to 'cure' himself, at least take control of his illness experience rather than simply submitting to it. At the same time Stan is accepting the validity of this belief and reinforcing it for himself. This is

another example of supporting the common sense discourse of culpability (see discussion of extract **8.18** page 248).

Stan provides another example of maintaining the focus on friends rather than himself when he describes how “they” reacted to his friend’s deterioration:

8.47 ... my room mate who was, who had got quite sick with a rapid deterioration um we got on to AZT when it was an experimental drug and went to Canberra and all sorts of things and, you know, we got very er very aggressive and er um managed to er, you know, to get things done, and I suddenly felt ‘Well, there is something, you take that upon yourself and manage your life’ and I don’t just want to sit here and be gloomy. (Stan, l 393-408)

It is important in understanding the meaning of Stan’s comments in this extract to appreciate the two meanings of the word ‘Canberra’. Firstly, it is the name of Australia’s national capital city and in the context of the above extract means the physical location that Stan and his friend visited to gain approval for use of an experimental drug (a return trip of over 1200 kms). Secondly, the name refers to the seat of Federal Government and it was to the Commonwealth Department of Health that Stan had to make personal representations for access to AZT. The fact that Stan indicates that “we got very aggressive” implies that final approval was only obtained after some sort of ‘battle’ with bureaucrats.

In the first part of this extract, use of the term “we” indicates that Stan is focussing on his friend’s need for the drug and he is simply helping a friend. However, in the latter part of the extract Stan uses the personal pronoun “I” demonstrating that he has learnt from this experience that he can take some control over his “illness” if, and when, the time arrives. A little later in his narrative Stan confirms his tactic of observing others who are ill, making his own interpretations and then responding in ways to focus on living effectively with the infection and, at the same time, distancing himself from the general focus on deterioration and dying. At the same time he is reinforcing beliefs within the discourse of culpability. He makes the comment:

8.48 I was watching myself and what he was doing, saying I’m learning a lesson here, you know, he’s got to pull up his own socks and look after himself a bit, *he’s got to want to live* it’s too premature, the time will come but it’s too early, why is this happening and er, and just, you know, and just shook him by the, by the neck and said “Come on, get going, get going” ... but it’s almost like you observe someone’s behaviour and you say “Does that work? Oh well that’s fine, well I’ll try that”. [Emphasis added] (Stan, l 514-540)

Focusing on living

Some individuals challenge the common sense discourse by developing a self-image as 'living with', rather than 'dying from', the infection. This changed focus also leads individuals to distance themselves from other PLWH/As. Examples of maintaining distance from other people who are living with the infection and its consequences are provided by several informants. For these informants the distancing process is not a function of denial but rather a reaction to two issues; the lack of relevance of the common sense discourse to their personal experience and focusing on living rather than dying and death. For example, one informant describes his reaction to the response of some of his friends who are also HIV-positive and appear to have given up on life and are now waiting for the 'inevitable':

8.49 I'm amazed at friends of mine who've stopped working and they're on bloody government handouts and things and they're perfectly OK. There's nothing wrong with them. That irritates me a little bit and I sort of feel that's the last thing I'd want to do is give up like that and do nothing. (Mitch, l 2775-2787)

Mitch also participated in a support group some time after his diagnosis of seroconversion. At the time he attended he was still searching for someone with the answer to restoring his health. Mitch did not find the group helpful although he acknowledges that this type of group may work for other people:

8.50 The one I — got in touch with that time I got pissed off with again but it was just a silly little group of people privately doing this thing, I didn't get anything out of it.... I don't really want to sit around and talk about our problems I suppose. Maybe what that group was doing was probably what they needed. You know I said they just tended to — sit around and talk about nothing. Well maybe that was good for them. It wasn't for me at the time because I was looking for at that stage I suppose I was still hoping someone would tell me Hey there's a way out of this and you know. (Mitch, l 3200-3203; 3264-3279)

Mitch interprets the focus of his group of friends and the support group as inappropriate for his needs. He interprets their reaction as focusing on the illness experience and waiting for death. What Mitch wants to do is focus on living with the infection to the best of his ability. His focus on living, rather than dying, is also demonstrated in his choice to attend private consultations at his general practitioner's clinic rather than the public sessions held at a specialist hospital. Mitch makes the comment:

8.51 ... [named hospital] [has] just got that connotation about it. I know the doctor I see has ... sessions there and a lot of my friends go there to see him but I don't want to. I associate that place with — I suppose with death and AIDS and you

know, I don't want to be reminded of it. I'd rather go to a clinic and see him privately.... I like the way I handle it because it keeps me going. I don't mope around all day and I feel fairly normal but *I'm also not silly enough to think that it's [HIV/AIDS] not there.* (Mitch, 1 2828-2839; 3165-3171)

In this extract it is clear that Mitch's response to his HIV infection is not one of denial. He is fully aware of his HIV status but chooses to focus on living as well as possible rather than focus on illness, disability and impending death. The impact this has on his self-image and experience of living with HIV/AIDS is discussed further in Chapter Eight.

Another informant provides an example of distancing himself from the common sense discourse. He also distances himself from people who are HIV-positive because he interprets their behaviour as inappropriate. Keith originally undertook the diagnostic test because "everyone was taking it and it just seemed the thing to do". He recalls that he wasn't particularly upset as he had no symptoms and continued getting on with his life. He was an active member of the gay community and was influenced to join a support group because "it was the thing to do". Keith was disappointed with the support group and finally left as he perceived it's focus as a waste of time for himself:

8.52 I joined the People Living With AIDS Support and it was so full of shit, and the people were so up themselves, and so — politically motivated that I just thought "What a waste of time." Two hours in a meeting and, you know, fifty minutes devoted to who should be in the room while they pass a vote. You know, why bother. I've got better things to do — ahhh — so, no, I find all that — let them be politically motivated and let them do all that, that's fine, but — not [for me] any more, (Keith, 1 1064-1080)

This extract also demonstrates Keith's personal philosophy of living with HIV/AIDS. At the same time he indicates the common sense discourse's lack of relevance for his subjective experience. Keith initially responded to the belief within the common sense discourse that PLWH/As needed to meet together to gain mutual support through the illness experience. At that time Keith wanted to find out about other people's experiences of living with the virus so that he might learn ways of getting on with his life. However, the group's focus on politics and 'illness' did not meet Keith's needs. At the time Keith's perception was that there were too many things he still wanted to do with his life to concern himself with 'illness'. There is little doubt that Keith's ability to focus on life rather than illness was influenced by the fact that he had a lack of symptoms indicating infection. Keith did not

remember experiencing specific symptoms of initial infection, nor had symptoms begun to develop by the time he attended the support group.

Wanting to maintain distance between self and other PLWH/As is not restricted to being asymptomatic. One informant discusses how much he dislikes having to continue daily treatment visits to hospital for two reasons; he can not “do the things that give me self-esteem, self-awareness, and make me happy” (Kyle, l 841-843), and he finds being with others receiving treatment distressing because it reminds him of his probable future. Kyle believes that the design of the hospital’s day centre is “criminal” because treatment is provided ‘publicly’ rather than in private. As a consequence he is ‘forced’ to observe others being treated who look so ill and distressed. In describing one situation Kyle compared the other patient’s appearance with that of his former partner who “looked better an hour after his death” than this particular patient. Kyle also provides a cogent reason for wanting to distance himself from his perceived future.

8.53 ... it's distressing for me — because yes I'm going to go through it — but I'm going to go through it in a situation where, also too, over the last couple of years — not only have I seen my friends die — I don't have many friends left [VERY SOFTLY SPOKEN], as in gay friends. Because they're all dying — and I don't want to die alone — — I mean, quite frankly, to see anyone die is horrific enough... sometimes you see three people who are acquaintances in one week in the death notices. It's quite frightening. Uhm — yes I'm scared — when I say scared of dying, I'm scared of pain, and I'm scared of relying on other people. I've never had to rely on anybody else — — and suddenly I'm finding that. It's quite frightening. (Kyle, l 1056-1090)

In this situation Kyle interacts with his imagined self. He “sees” his future as deteriorating and becoming dependent on other people for his routine daily care. Kyle also “imagines” himself dying and reacts to this social object (his future) with fear; fear of pain associated with dying and fear of becoming reliant on others.

Summary

The media has exerted considerable influence on the publicly created context which informs how people talk about and come to understand HIV as a disease and illness experience. Initially HIV/AIDS was presented as a virulent, rapidly fatal, sexually transmitted disease of promiscuous gay men for which there was no known treatment or cure. Despite the development of medical knowledge the initial focus of media attention on

the acute disease model of HIV illness, the fatal consequences of the virus and the process of people dying from the effects of the virus has continued. The close relationship between the new disease and socially marginalised groups, particularly homosexuals, has meant that the social issues of morality, sexuality and participation in socially defined deviant subcultures have been confounded with the medical aspects of the disease and significantly influenced the social construction and meaning of HIV/AIDS as a disease and an illness. This is compounded by the strong social and individual motivation to represent any individual who is sick as different, or as the unhealthy other. The popular prejudices against homosexuals has resulted in HIV/AIDS as being perceived as “the curse of the other”. Consequently, gay men living with HIV/AIDS have been doubly discredited.

Those individuals diagnosed during the early years of the disease were initially influenced by beliefs within the common sense discourse of HIV/AIDS. They believed that they had no future, because they thought that their health would rapidly deteriorate and their illness experience would consist of increasing bouts of debilitating infections that would restrict their ability to live a dignified life. Furthermore, they believed that they would die an undignified death within a relatively short time. These individuals were so influenced by the common sense discourse that they thought their HIV status precluded them from any further intimate relationships. Initially, individuals perceived themselves as “a leper”, “a lethal weapon”, “a social outcast” and “out of control”. This posed a major dilemma for individuals who, on diagnosis, were defined medically and socially as unhealthy despite the fact that they might not necessarily experience any symptoms. Individuals had to face the task of not only reconceptualising their self-image as a seriously ill person but also as one who has an incurable, fatal disease.

Although mainstream media focus is still on the process of dying as a result of infection with HIV more recently diagnosed individuals had difficulty reconceptualising their self-image as being ill. This change has been brought about by interaction with friends who have been infected by the virus for a number of years but have not yet died. Although these recently diagnosed informants knew they had seroconverted, in the absence of specific symptoms they found it particularly difficult to conceptualise themselves as being ill. Since their subjective experience concerning seroconversion did not include physical symptoms they found it difficult to believe those elements of the common sense discourse relating to

rapid decline in health and eventual death. Although from the professional perspective these individuals may be labelled as 'in denial', since they appeared not to be actively engaging in the process of emotional acceptance of their impending death, this is not an accurate interpretation of the situation

All individuals within the current study experienced difficulty reconceptualising their self-image as the other. Although openly living in gay relationships informants did not have an image of themselves as 'deviant' or as the 'stereotypical' gay man: they did not consider their lifestyle as that of the other. Many of the informants were surprised on receiving their diagnosis because they had a self-image as an average gay man and thought only deviants - the "scumbags", "sleaze balls", "screamers" or those who like to "dress up in make-up" or "carry on like a bit of a girl" - were at risk of becoming infected.

The common sense discourse focus on the other also impacts on how informants engaged in social interaction. In their attempts to avoid the imposed identity of otherness informants engaged in a variety of methods of distancing themselves from the common sense discourse. These practices include creating symbolic distance from the common sense discourse, focusing on friends' experience of illness and learning what works and what does not work in coping with the illness experience, and focusing on living rather than the restrictions of 'illness'. The importance of these distancing strategies is that it enables individuals to challenge the relevance of the common sense discourse for their own experience. At the same time this process enables individuals to develop their own symbolic designations of the various 'objects' associated with their experience of living with HIV/AIDS - to develop their own 'reality'. This individual defining of the situation serves as a general frame of reference within which each individual assesses the particular lines of conduct in relation to their experience of living with HIV/AIDS.

Another important impact of the common sense discourse on the individual's social interaction is to whom disclosure of their HIV status is made. Irrespective of when they were diagnosed (i.e., during the early years of the disease or more recently) all informants were particularly afraid of being rejected by significant others - rejected sexually by partners and as a person by families. This fear of rejection influenced their decision

whether to disclose their HIV status not only to family of origin but also casual sexual partners.

The fact that some members of the gay community react to the other classification ascribed to those individuals living with HIV/AIDS suggests that it is not the 'unhealthy' status of the individual nor their perceived immoral turpitude or deviancy that is responsible for the application of otherness and the subsequent creation of social distance. The otherness classification is a function of the physical threat of the disease rather than socially prescribed aberrant behaviour. Moreover it is a function of responding to the life-threatening nature of the disease. The social distance created as a result of applying the other classification to individuals living with HIV/AIDS serves not to distance members of the community from facing issues of immorality but rather to distance them from confronting mortality.