Life Goes On: Living with HIV and AIDS in Singapore

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AIDS is a global disease and Singapore has not been spared of it. Increasingly, AIDS has become a major medical and social concern in Singapore, and has been the subject of a number of studies there. However, there is a paucity of local research on the lives of patients with HIV/AIDS (PWAs) in their social interactions. Unlike previous works, this ethnographic study seeks to correct this omission and undertakes a more holistic and humanistic approach to the research of HIV/AIDS in Singapore — by placing in the foreground the voices and experiences of PWAs, and situating them in the larger social and institutional contexts of Singapore within which AIDS acquires its meanings and connotations.

Introduction

Since 1985, when the first case of HIV infection was reported in Singapore, numerous studies have been undertaken on the medical, epidemiological, and social aspects of the disease in that country. For example, there have been studies focusing on the level of awareness of the disease on the part of the public (Emmanuel, 1991; Singh, Fong & Ratnam, 1991, 1992; Bishop, 1996) and among those in high-risk groups, such as prostitutes and gays (Ratnam, 1986; Kok, Ho, Heng and Ong, 1990); the legal and policy implications of AIDS in Singapore (Iyer, 1993); the attitudes, knowledge and experience of the disease amongst doctors and nurses (Lee, Yong and Tan, 1989); the practice of safe sex to prevent the spread of HIV (Chan, Cheong and Lim, 1993); the role of the volunteer, non-governmental organization (NGO), Action for AIDS (AfA), in the provision of social services in Singapore (Leong, 1995); and how society responds to AIDS within the framework of social control (Wong, 1989). Recent major studies include surveys on the level of AIDS awareness amongst youth and human resource professionals, and their attitudes towards people with HIV/AIDS (Lim and Tan, 1998; Lim and Loo, 1999). So far, however, there has been a paucity of research in Singapore on persons living with HIV/AIDS (PWAs) with regard to their experiences of the illness.

This crucial lack in the study of PWAs in Singapore is, perhaps, reminiscent of the initial situation in global AIDS research between the mid 1980s and the mid 1990s when HIV and AIDS were thrust into the medical and public limelight. During that period, studies on AIDS were dominated by biomedical and epidemiological agenda and concerns (Parker, 2001:165) It was only in the early 1990s — with an increasing number of
anthropologists and sociologists researching the subject, and often conducting indepth ethnographic studies — that the range of HIV/AIDS research began to broaden. It came to include concerns such as the lived experience of PWAs, the interpretation of cultural meanings of HIV/AIDS, social determinants of sexual behaviour, and the political economics of the pandemic (Parker, 2001:166; also see Farmer, 1992; Alonzo and Reynolds, 1995; Schoepf, 1992a, b; 2001; Herdt, 1997; Muecke, 1992; Nichols, 1985; Baumgartner, 1986; Weitz, 1991; Sandstrom, 1990; Kotarba & Hurt, 1995; Baer, Singer, Susser, 1997).

The latter trend is, however, not evident in the case of HIV/AIDS research in Singapore. So far, there is still a lack of indepth sociological and anthropological research into the various aspects of the lived experience of PWAs. In taking an initial step to correct this omission, I strive here to present a more holistic and humanistic picture of HIV/AIDS in Singapore. I do this by placing in the foreground the voices and experiences of PWAs in their social interactions, and by paying simultaneous attention to the public discursive realms of Singaporean society.

Methodology

When this study was first proposed, I was warned of the potential difficulties involved in AIDS research in Singapore, in particular, with regard to having access to respondents. In Singapore, AIDS is still a disease shrouded in much secrecy, and confidentiality is strictly observed; the disease is often associated with “deviant” behaviour frowned upon by society, such as sexual promiscuity, homosexuality and illegal drug use. There is a strong stigma still attached to AIDS in Singaporean society, such that the identity of any person who has contracted the disease is best kept secret so as to shield him or her from possible negative evaluations by the rest of the society. Numerous studies done in Singapore (Emmanuel, 1991; Bishop, 1996) and in other countries (see Weitz, 1989; Herek and Glunt, 1991; Bolton, 1992; Kayal, 1993) indicate that PWAs are often socially ostracized and physically discriminated against. In other words, the very presence of generally averse social reactions to AIDS in society warrants the concealment of AIDS patients’ identities.

As such, it is no wonder that before this research was carried out, the lived experiences of PWAs in Singapore had not received the level of attention by local researchers that it should. It is likely that the perceived difficulties in gaining access to informants in this climate of secrecy had, among other factors such as personal biases, deterred social scientists from embarking on studies of the psycho-social aspects of AIDS patients.

The data for my research was obtained mainly through two avenues: indepth interviews and participant observation. I conducted indepth interviews
with four seropositive persons who were relatively healthy and had not yet developed full-blown AIDS at the time of this research. This was a group that had eluded me for a long time; it was only after I became a volunteer with AfA that I had access to it. Two of the PWAs were introduced to me by other more experienced volunteers whom the PWAs knew well; one interviewee I got to know whilst visiting the Communicable Disease Centre (CDC) in Singapore; while the last of the PWAs was assigned to me as a “buddy” as part of my volunteer work. The first three PWAs were bachelors in their late twenties and early thirties, while my “buddy”, Dan (not his real name) was in his mid-fifties, married and with no children. All four of them were infected through sexual contact. Two interviews were conducted in Mandarin, one in Hokkien (a Chinese dialect), and one in English. The face-to-face interviews each lasted an average of one hour and fifteen minutes, were semi-structured, and guided mostly by open-ended questions. Participant observation was made possible through my involvement in the activities organized by the AfA, and my frequent interaction with Dan in his social and familial life.³

HIV and AIDS in Singapore

AIDS is a global disease, and Singapore has not been spared from it. According to the latest UNAIDS estimates, there are currently 40 million adults and children in the world living with HIV/AIDS, out of which 6.6 million are in the Asia-Pacific region. As of the end of October 2003, a total of 2,034 Singaporeans were found to be infected with the virus,⁴ and 776 have died from it (The Straits Times, 25 November 2003). A vast majority of those infected are men, while the number of women and children infected with the virus has been increasing over the years (see AfA website: http://www.afa.org.sg/astats.htm). Unlike the situation in North America and South America, where the mode of transmission has been predominantly homosexual encounters, in Singapore the virus is mainly transmitted through heterosexual contact, with the age groups 30–39 years and 40–49 years most affected by HIV/AIDS.

In response to the first outbreak of AIDS in Singapore, the National AIDS Control Programme was formulated in 1985 under the purview of the Ministry of Health (MOH). Its main functions include public education, legislation, protection of blood supply, managing the infected, counselling, disease monitoring, and training and research activities. Two committees were set up to assist the programme. The first was the AIDS Task Force, which advises the MOH on medical and scientific matters; and the second was the National Advisory Committee on AIDS, which provides community feedback and advises the MOH on AIDS education for the public.

From the beginning, education and prevention have been the two
main foci of the Singapore government’s programme in dealing with the disease. Efforts have been directed at both the general public and to those most at risk of infection. To increase AIDS awareness among the youth, a structured AIDS education programme was implemented in 1993 for students in junior colleges and pre-university centres. AIDS education is also being provided for all national servicemen. The MOH utilizes all forms of communication for its education programme, including pamphlets, posters, exhibitions, talks and the mass media. As the mode of transmission in Singapore in recent years has shifted from homosexual to heterosexuals contact, the key message relayed to the public for many years was concerned with the dangers of casual sex and sex with prostitutes; it was maintained that the best way to prevent infection was to remain faithful to one’s spouse. This message is very clear in one of the early advertisements that warned against AIDS: “NO CASUAL SEX, NO RISK, NO AIDS”. Thus, promiscuity was portrayed as the dominant type of behaviour that puts people (especially men) at risk. At the beginning, therefore, the state’s AIDS education was imbued with a heavy moralistic overtone. Although the approach might have been able to “scare” some people from engaging in risky behaviour, it also presented some serious problems.

First, the public was not made aware through these public education efforts that the virus could be transmitted through other routes, for example, that women were equally at risk of infection if their spouse or lover was promiscuous and/or a carrier. The second insidious problem of the “scaretactic was that it accentuated the social stigma associated with the disease. It cast PWAs as a “deviant” social group, thus, further widening the gulf between them and the public. From 1999 onwards, however, there has been a perceptible change in the tone of the official campaign to educate the public. Probably due to feedback from AIDS workers and an increasing awareness of the sexual habits of Singaporeans, the public education effort since 2001 focused on two things. One is that AIDS does not harm just the infected individual but also brings suffering to his or her loved ones; and two, that “protection”, that is, safe sex, is the “next best defence”. This was the first time where, in addition to the theme of “promiscuity” as the main avenue for infection, the theme of “safe sex” (in the form of contraception, mainly, the use of condoms) became part of the education campaign. This shift in emphasis, tragically, came too late for those who were already infected because of their ignorance of “safe sex”, as was in the case of my interviewees.

In the light of all the educational efforts by the MOH, what is the public’s perception of AIDS in Singapore? Surveys on the public’s perception of HIV/AIDS and of those infected, from the early to mid-1990s, showed that despite the rather swift and intensive response of the MOH in educating Singaporeans, there were still certain misconceptions and false
beliefs about AIDS (see Emmanuel, 1991; Bishop, 1996). For example, a majority of respondents in a survey (Bishop, 1996) thought that “AIDS only affects homosexuals, drug addicts, prostitute and others like them from high risk groups”. Slightly more than half the respondents thought that “AIDS is more likely to be contracted from foreigners than from locals” (58%), “AIDS is a homosexual disease” (53.1%), and “I’m not worried about the spread of AIDS as it has nothing to do with me” (52.9%). Not surprisingly, the social stigma that has plagued AIDS sufferers elsewhere was evident in Singapore as well. Emmanuel (1991) found that Singaporeans tend to put as much distance as possible between themselves and PWAs. An example of hostile opinion can be seen in a letter sent to the local English daily, The Straits Times, in as recently as 2001:

... most of those with HIV are not innocent victims, but are simply bearing the consequences of irresponsible actions... People who rape and murder are punished. Do we feel sorry for them? If the answer is ‘no’, then why should we feel sorry for people who are infected with HIV as a result of a reckless lifestyle?

The question we need to ask now is why views such as these still persist despite the education efforts of the MOH. I suggest that one of the reasons is that the beliefs and conceptions resulting from the initial misinformed social construction of AIDS as being associated with “socially undesirable behaviours” had been largely appropriated by Singaporeans, no thanks to the ways local and foreign media had initially portrayed the disease.

As Wong (1989) has shown, the Singapore media played a crucial role in the social construction of AIDS by, basically, re-reporting news about AIDS from other countries. It was most notably focused on the United States, since that was where the disease was first discovered and named, and gained widespread medical and public attention (see Schiller, Crystal and Lewellen, 1994; Herlich and Pierret, 1993). Thus, in 1984, as news of AIDS was just reaching Singapore, the press reported that the disease was linked to “male homosexuals, haemophiliacs, intravenous drug users and Haitians.” (The Straits Times, 12 December 1984). As it was first discovered in the United States and then in European countries, AIDS was viewed as a “foreign disease”. As Wong points out, because the first reports of AIDS involved other societies, and marginal groups such as homosexuals, it was seen as being far removed from Singaporean society and thought to only affect specific (“deviant”) groups of people (Wong, 1989:40). The social construction of AIDS had spilled over from the United States to Singapore through the media.

Therefore, it is reasonable to conclude that the Singapore public’s basic views and conceptions of AIDS, however wrong or misguided they
may be, have to a large extent been shaped by the initial media reports on the disease when it first aroused attention in Singapore in the first half of the 1980s. These views and conceptions had been so entrenched that, despite more than a decade of efforts by the National AIDS Control Programme and various NGOs in raising AIDS awareness, they were still prevalent in the mindset of the general public well into the mid-1990s. As noted previously, the MOH’s initial moralistic media campaign correctly promulgated the message that the main mode of HIV transmission in Singapore was through heterosexual activities. However, it failed to educate the public on other possible modes of transmission while resolutely refraining from contemplating a public safe-sex campaign. As Allen (1991) notes, such moralizing “texts” are words that kill, as prevention was thwarted by the authorities’ reluctance to address the relevant issues. One could further draw the conclusion that the initial educational effort by the MOH resulted in the further stigmatization of the disease, and accentuated the cleavage between PWAs and the rest of society.

The acute stigmatization prevalent in Singaporean society is reflected by the fact that the disease was given a public face only after more than a decade had passed since HIV was initially diagnosed in the country. During an AIDS conference in December 1998, Paddy Chew became the first Singaporean to publicly acknowledge his HIV status. His short but moving speech to the conference audience, which included the health minister, enunciated with poignancy the difficulties faced by people with HIV, both in dealing with their medical condition and with society’s attitudes towards them:

Having to face the disease alone is one thing. But having to face the emotional and psychological stress without any kind of support is another. The fear and stigmatization of this disease is apparent... Most of the PWAs... are so afraid that many even declined to attend this conference. There is a real fear [of] being associated to anything that could get them identified as a PWA. Paranoid behaviour is a problem for most PWAs and this is due to discrimination they feel they will suffer from.

From the 1980s until recently, while the government was utilizing “scare tactics” inflected with explicit moralizing, civic groups adopted a somewhat different approach. AfA was set up in 1988 and was the first, and most profiled NGO with the main objectives of increasing public awareness of HIV/AIDS and providing various forms of support for HIV carriers. Its initial constituency was HIV-infected gay men but in line with the demographic change in the pattern of HIV infection, it now provides services to cater to all HIV carriers. Since the mid-1990s, AfA’s focus has shifted from AIDS education and prevention activities to offering PWAs welfare
programmes and financial assistance. The difference between its approach and that of the government’s can be seen from the types of programmes it conducts. Since its inception, AfA has taken a non-judgemental and “realistic” approach to HIV prevention. For example, in contrast to the government’s early unwillingness to deal with the issue, the promotion of safe sex has been one of AfA’s key strategies in its education efforts. While the government was proclaiming the dangers of promiscuity to the public, AfA members and volunteers were distributing pamphlets to night club patrons and prostitutes to highlight the importance of using condoms in preventing infection. As pointed out earlier, it is only in the past couple of years — and in large measure, due to AfA’s constant feedback and lobbying — that the health authorities have come to realize the limits of their previous approach. They have begun to utilize the media to educate the public on the importance of safe sex in HIV prevention, albeit grudgingly qualify it as the “next best defence”.

The importance of the role of civil groups cannot be overstated. Especially over the last five years, there has been an increasing number of organizations catering to the different needs of HIV carriers. Volunteers from educational institutions, church groups such as the Catholic AIDS Response Effort (CARE) and other congregations are involved in wide-ranging activities, such as fund raising, being “buddies” to HIV carriers, counselling, peer support, giving free legal and medical advice, hospital visits, and education campaigns. In 2000, a project called “True Love Waits” sought to raise AIDS awareness among the Chinese community, culminating in a sell-out Mandarin pop concert. Meanwhile, to commemorate World AIDS Day every November, both government agencies and NGOs organize a series of exhibitions and AIDS awareness programmes, culminating in the AIDS Walk held in Singapore’s main business and shopping district.

The efforts by civic groups and the government to raise public AIDS awareness are beginning to show some positive results. In a couple of recent surveys, researchers found that most of the respondents are aware of the main modes of HIV transmission and show a lesser degree of aversion to those with HIV/AIDS, as compared to earlier studies (Lim and Tan, 1998; Lim and Loo, 1999). What is revealing is that 71 percent of respondents are aware that HIV/AIDS is not primarily confined to individuals with a particular sexual orientation, which is a significant shift from the dominant perception in the 1980s and early 1990s that AIDS is predominantly a gay-related disease. However, the same surveys indicate that a substantial proportion still have ambivalent attitudes towards PWAs. This calls for continuing efforts in public education; not just at increasing the level of AIDS knowledge, but also in changing people’s attitude towards AIDS sufferers.
Living with HIV in Singapore

Becoming a Patient with HIV/AIDS (PWA)

Assessment of Risk
I have previously highlighted that when HIV and AIDS first received public attention in Singapore, the media played a crucial role in the social construction of HIV/AIDS through its inherent ability to shape public perceptions and opinions. This has resulted in two problems with regard to the Singapore case. First, public attention was diverted from the fact that it is in engaging in certain behaviours with someone already infected with the virus that puts individuals at risk, regardless of whether that someone belongs to any “risk group(s)”. Second, this perception not only allowed people to have a false sense of security in believing that the virus only strikes certain groups of people, but also perpetuated the social cleavage that separates the public from the “deviant others”, hence, allowing the latter to be stigmatized (see also Quam, 1990).

The unfortunate consequence of this misconstrued view is borne out by the experience of the PWAs I interviewed. For example, Dan had thought that he was not at risk because he did not visit prostitutes or share needles in his drug use:

I didn’t think I was at risk. I slept around, I’d never thought, you know... because I didn’t go to prostitutes. I didn’t share needles. I’d always thought that I would never get it, you see. I slept with women, but they are not prostitutes... slept with professional women.

Teo was diagnosed with the disease a few years ago. Prior to that, he was an odd-job labourer and frequented brothels whenever he had a chance to go overseas. When he visited sex workers, he used condoms only occasionally as he was not well informed on AIDS and safe sex. He says:

With regards to HIV at that time, really, I only knew the name, but didn’t know what it actually was. At that time, I understood it as a “homo”, “gay” disease. We were very naive then, since we didn’t engage in such activities [gay sex]... We thought it only prevailed in places where there were many Westerners.

Even those who know about the dangers of contracting the disease, but are uncertain that they could actually be infected, construct theories that explain why they are not really at risk despite particular types of behaviour (Weitz, 1991:54). Jack and his friends knew about the existence of AIDS but did not care much about getting infected when they visited prostitutes. According to him: “When we were having a good time, we did
not think about AIDS, although we heard about it. But we thought, it is impossible for me to get infected; millions of people around, so what are my chances [of getting the disease]?”

**Acquiring PWA Status**

In medical terms, one acquires an “AIDS identity” when one is tested “positive” for the AIDS virus. Currently, the two most widely available HIV tests in Singapore for initial screening are the antibody (or the ELISA) test and the antigen test. Further tests such as the “Western blot”, P24 antigen, and Polymerase chain reaction (PCR) are employed to confirm the initial results. Until 1991, anyone who wanted to get tested could only do so at two venues: a private practitioner’s clinic or a government polyclinic. They could get the results between two to fourteen days. In Singapore, AIDS is a “notifiable” disease, that is, any doctor who diagnoses someone with the virus must notify the MOH so as to allow it to monitor the spread of the disease. Under the provisions of the Infectious Diseases (Amendment) Act, the Director of Medical Services is empowered to require any person with HIV or AIDS to undergo counselling or comply with safety measures, and the person can be subjected to a fine and imprisonment if he or she fails to comply. Given the above provisions, some individuals may be reluctant to have a HIV test for fear of the attention they would inevitably get from the authorities if their result turns out positive. The danger of this situation is that those who are actually carrying the virus, but are uncertain of this because they are reluctant to go for HIV testing, might continue with risky behaviour and further spread the virus. In lieu of this, AfA started the Anonymous Counselling and Testing site in 1991 at the clinic of the Department of Sexually Transmissible Diseases. Unlike the testing provided by other clinics, this service allows a person to walk in, receive counselling, undergo the test, and then “disappear” without having to divulge his identity. The aim is to encourage those who think they are at risk to come forward for testing.

One factor that deters people from going for the HIV test is the heavy social stigma that is attached to AIDS; they might not want to face the consequences of a positive diagnosis (*The Straits Times*, 30 October 1997). Another problem is that those who engage in high-risk behaviour might not even be aware that they are vulnerable to infection, thus, they feel no need to get tested. This is an unfortunate consequence of the authorities’ initial reluctance to educate the public on the issue of safe sex and on the use of condoms to protect against the risk of HIV infection. For example, Teo did not learn that he had been infected until he developed symptoms and had to be hospitalized. Jack did not go for a HIV test even though he visited prostitutes and engaged in unsafe sex. He was told of his condition after seeing a doctor at the National Skin Centre for a skin problem:
My skin problem troubled me again, and my doctor could not determine the reason for it and referred me to the National Skin Centre. After the blood test, they were supposed to contact me after seven days about the results [of the diagnosis of skin problems]. But when they called me after five days I knew something was amiss... Then the doctor told me that I had contracted the AIDS virus. I was dumbfounded.

**Adjusting to a New Social Identity**

Being infected with the AIDS virus per se does not transform an individual into a PWA; one acquires that identity only upon a positive diagnosis. In other words, a person gains an AIDS identity only after he is medically defined and officially recognized as a sufferer of AIDS. Jack’s identity as a PWA was realized and validated only when the doctor at the National Skin Centre informed him about his blood test results, not when he was infected. Therefore, viral infection alone does not make someone a PWA; it is also a social process that involves interpersonal interaction and definitions. Jack became a PWA because he was “defined” by the medical authority as such. This process of identity construction entails both interpersonal and subjective transformation:

> Within the interpersonal realm, the newly diagnosed ‘AIDS patient’ is resituated as a social object and placed in a marginal or liminal status. On the subjective level, this separation produces a crisis, or a disruption of the PWA’s routine activities and self-understanding. [He] is prompted to “make sense” of the meaning of his newly acquired status and to feel its implications for future conceptions and enactments of self. (Sandstrom, 1990:274)

Among my respondents, the experience of receiving one’s diagnosis and its immediate aftermath vary. Teo was filled with grief and intense hopelessness. He recounts his experience:

> I was already feeling hopeless when I was being tested. Feelings of grief and other problems plagued me. How should I put it? After knowing the result, you have to put up with pressures from all sides, family, society, friends. Should I let others know? Would they look down on me and ostracise me? Or would they offer sympathy? One can’t be sure. My feelings and thoughts went through a roller coaster ride... I planned for the worse. I told my family, if I can’t stand up and live normally within one month, I’ll end my life. That’s right, I’d kill myself. I did not want to be a burden to my family.

Jack was seized by shock and incredulity when told of his condition. Fortunately for him, the rude impact of the news was cushioned by the counselling efforts of the doctor who broke the news to him. He assured him that all was not lost, and that he could still live a relatively normal
life for at least a few years if he took good care of himself. Dan’s experience was completely different. As his condition was diagnosed while he was in the Drug Rehabilitation Centre (DRC), he not only had to contend with the devastating impact of the diagnosis, but also received considerably less humane treatment from the Centre’s authority:

I was in the DRC, and they put me in the punishment cell for three days, the moment the result came back. They did not even tell me why. Of course I was very angry. But then it’s their strategy, for whatever reason. It was hard to accept, but I had to come to terms [with it].

Dan’s experience reveals that the stigma and misconceptions associated with HIV/AIDS not only prevailed in the wider society, but was also widespread within government institutions. Like other inmates at the DRC who had been tested positive for HIV, Dan had to use a separate sets of utensils and crockery of a different colour from those in general use. Apparently, the authorities at the DRC were unaware that HIV cannot be transmitted through sharing utensils. The inmates soon came to know why the utensils were colour coded; the result was that those seen using these utensils were immediately marked out by their HIV status, and were stigmatized and generally avoided.

**AIDS and Social Relationships**

The trauma felt by PWAs upon receiving a positive diagnosis of the disease signifies the start of the process of constructing a new identity; this is very often fraught with difficulties, intense feelings, uncertainty and dilemmas. At this juncture, the PWA acquires a new identity and is resituated as a social object in a web of relationships that obliges him to construct new interpretations and seek meanings so as to “make sense” of his new status. In other words, a seropositive individual tries to personalize the illness so as to integrate the meaning of his condition to various aspects of his social life. However, this process does not involve just the PWAs but also significant others, such as family members and friends. As symbolic interactionism informs us, social events and objects are produced and acquire their enduring meanings through continual social interactions and cultural definitions (Couch, 1989). It is, therefore, necessary to understand the effects AIDS has on the social relationships of PWAs so as to gain better insight into how the disease is experienced.

**Familial Relationships**

Most people will turn to their families for emotional, financial or other types of support following diagnosis of a serious illness or other types of
trauma (Weitz, 1991:103). Because of the strong social stigma still attached to AIDS, and the abounding misconceptions about the disease — particularly with regards to the modes of transmission — a person diagnosed with HIV faces the prospect of averse reactions from family members. Numerous research findings and media reports have alerted us to the ostracism that PWAs face by their families when the latter find out about the diagnosis. For example, some families refuse to come into social contact with members infected with HIV for fear of contracting the disease themselves (see The Straits Times, 5 October 1997). PWAs have experienced moral condemnation especially if their families’ religious beliefs frown upon “deviant” behaviour, such as casual sex, homosexuality and drug use. These are activities that the PWAs might have engaged in and contracted the AIDS virus through (see Sontag, 1988; Weitz, 1991). For example, at the time of the interview, Dan had only told his mother about his condition but not his siblings because “they’re very ‘straight’, and they’re not so educated, and they’re very religious people, so I don’t want to talk to them about it. I felt that a lot of religious people think that this is a curse from God.”

At the other end of the spectrum, there are also families that offer the crucial support much needed by PWAs for their emotional, financial, and medical well-being, when the initial fears have been allayed and doubts clarified. Teo recounts the reactions of his family upon hearing the news that he was HIV positive:

When my family got to know about it, they convened a family meeting. Every family member got to know of my condition. They were to decide whether to keep me and to take care of me in my medical needs, or to ‘let me go’, that is, let me take my own life. They were not so worried about how the other relatives would see them because of my illness, it was just on the matter of how to best take care of me that they were unsure about. But I can tell you frankly, they were also afraid [of the disease], not that there wasn’t any fear, as they did not know much about AIDS at that time, and were unsure what to do. But when they’ve decided to take care of me, they gave me encouragement and support.

Teo was once bedridden in the Intensive Care Unit, with his condition so bad that the medical staff had given up hope on him. However, with the staunch support of his family, Teo’s condition took a dramatic (he called it “miraculous”) turn, and at the time of the interview, he looked like any healthy person living a normal life. There was not a hint of his previous brush with death.

Lee was not so fortunate. His relationship with his family had already been strained even before he was diagnosed with HIV; it was further jeopardized after he became a PWA. When I visited the CDC on one occasion, I saw him bathing and washing his clothes at the Patient Care Centre
(PCC). He did not have a home to go back to. All his belongings were packed into two bags and stored in a cupboard at the PCC, where he would stay during the day. In the evenings, he had to leave the CDC and find a place to spend the night. For a few months, he had been sleeping at bus stops, public housing void decks, construction sites and even in an abandoned hut in a cemetery. For people like Lee, who have no home to call their own, family support is non-existent. This adds additional stress to an already problematic condition. Lee lamented in Hokkien:

I need a place for me to rest, to apply medicinal cream for my skin problem. That’s why I asked my family, my mother, to let me go back for baths, to apply cream, after that I’ll just leave . . . But they didn’t allow me back . . . I wandered everywhere, I’ve been to most of the coffee shops . . . one can’t have no place to stay. If I have a place to stay, I’d be able to apply my cream, have my meals, shower, sleep, and work. Others [PWAs] have homes, have places to hide themselves. I don’t have! The government can’t help me, where do you suppose I could go? How can I have any confidence? I tell you frankly, what confidence?!

The contrast between Lee’s and my other respondents’ dispositions was stark. Without the support of family members or a home to go back to, Lee struck me as a person who was disillusioned and disappointed with life despite receiving considerable help from the medical social workers at the CDC. He seemed stripped of any confidence of living. On the other hand, Teo, Dan and Jack, all of whom have received considerable family support, displayed much hope and a willingness to fight the disease. Despite the daunting difficulties they had to face, they displayed evidence of positive thinking and a zest for life. Even the very self-confidence I saw in them during the interview points to the importance of family support in an illness as biologically devastating and socially stigmatizing as AIDS. Often, it makes a difference between life and death, as exemplified by Teo’s case.

It is some comfort to know that in Singapore, although there have been quite a number of cases of PWAs having been rejected by their families, they are still exceptions rather than the rule. In most cases, families usually give at least some degree of support to AIDS sufferers and try their best to help them live as normal a life as possible (see Emmanuel, 1991). In fact, relationships with family members could actually be strengthened following disclosure of AIDS infection. Dan, who was the only married person among my four respondents, noticed an improvement in his relationship with his wife:

Q: So the news didn’t affect the relationship?
A: No. It actually turns better. I think my wife loves me more now! [laugh] I think so. She’s doing a lot of things for me now that she did not use to do before. And I’m very fortunate.
Singaporeans with foreign spouses infected with HIV had to contend with an additional difficulty in the form of Singapore’s immigration law. Under Section 8, sub-sections 1 and 3 of the Immigration Act, foreigners with HIV/AIDS are deemed “prohibited immigrants”. Previously, foreign spouses infected with HIV were given social visit passes to enter Singapore. However, from mid-1998, the authorities tightened the law and refused entry visas to these people, compounding further the emotional sufferings of PWAs and their families. The authorities’ apparent callousness in the strict enforcement of the law caused a major public outcry, led by AfA, that protested against the measure and lobbied for it to be relaxed. The matter became serious enough to warrant the attention of the Prime Minister, who subsequently intervened to resolve the issue in favour of allowing entry to foreign spouses infected with HIV.

**Relationships with Friends**

As with family members, PWAs are also concerned about their friends’ reactions to their medical condition. There is also the consideration of which friends to reveal the news to. Typically, PWAs only reveal their condition to close friends, since they can be more certain that these friends would not have adverse reactions and might very well offer emotional support. Dan told two of his closest friends that he is HIV-positive, and received much support from them: “I don’t have a problem with them. . . . they are very concerned, they help me in their own ways, their very best. They’ve been a great help. When I get a cough or something, they’ll wonder whether I should go and see a doctor. That’s very nice. . . . I’m very fortunate that I have good friends.”

However, other PWAs are not so fortunate. As misconceptions about AIDS still persist and fear of the disease still prevails, friends might abandon a PWA when they learn of the diagnosis. This was what happened to Lee; his so-called “friends” left him after he told them of his condition, thus, he was deprived of support from both family and friends: “Last time I had ‘bad’ friends, I didn’t walk the right path. This illness can’t be cured, everybody runs away when they see it. Now, there is no one to offer me comfort.”

It is relatively easier to conceal one’s HIV status from friends when one is still asymptomatic. Feelings of uncertainty and dread will arise when physical symptoms start to manifest themselves. Six of Jack’s closest friends knew about his condition, and they have all had been very supportive. However, he was rather apprehensive about how his other friends will react once he starts showing symptoms. His worry is also indicative of PWAs’ general wariness about the public’s response to the disease:

I seem okay now, no symptoms, no physical changes. But two years down the road, when the medicine cannot help me, the illness will be unstable
To protect themselves from being stigmatized, PWAs often have to devise strategies for “cover and concealment” such that knowledge of their “spoiled identities” may be kept to a small social circle, a manoeuvre Goffman (1963) calls “passing” in his classic work on stigma. I had first-hand encounters with one of these strategies through my participant observation as an AIDS volunteer. Once, Dan and his wife invited me to their place for a Christmas party, to which he had also invited other friends. It was likely that I would be asked how I had gotten to know Dan, and I could not tell the truth for the sake of keeping Dan’s HIV status hidden. That is, I could not say that I had been assigned by AfA to Dan as a “buddy”. Dan and I got together and devised a cover story: if I was asked, I would say we had met at a local bar some time ago and had been tennis partners since. The cover story was put to good use that day, and Dan’s AIDS identity was kept under wraps.

Work Relationships

When Teo was diagnosed with HIV, he was already incapable of working. Dan got to know about his condition when he was at the DRC; since he was discharged, he had not been working because he found it difficult to work while keeping the numerous medical appointments at the CDC. Those PWAs who choose to work following their diagnosis face possible stigma and discrimination if others learn about their illness. In 1992, *The Straits Times* (13 March) reported that a hotel had sacked a porter who had the AIDS virus; the reason given by the management was that it provoked fear amongst the staff. A survey of 236 human resource managers found that workers infected with HIV would get short shrift, and would not be promoted. Though the managers were generally well informed on AIDS, this did not translate into a favourable attitude towards infected employees. For example, nearly 60 percent of the managers reported that they would take precautions to protect other workers, and about 50 percent would dismiss the infected worker rather than upset the other staff. The results of the survey indicate that the managers’ attitudes were influenced by misinformation and irrational fears (*The Straits Times*, 25 March 1997). The two examples are cited to highlight the discrimination PWAs are likely
to suffer at the workplace; their positions are all the more precarious as the current employment law does not protect them from dismissal based on their HIV status.\textsuperscript{1}

In view of this, PWAs normally choose not to inform their employers of their illness. Lee had been working as a security guard but kept his disease from his employers. Jack was a delivery man at the time of interview, and had not informed his employer of his illness either. He said; “When we look for a job, it is not possible for us to tell them, ‘I have this disease, would you hire me?’ Completely no hope!” To avoid being stigmatized at the workplace, PWAs typically would not reveal their condition to fellow workers, for as Teo rationalizes: “The lesser the number of people know of your diagnosis, the safer it is for you. The society still cannot accept this illness.” As with the case of relationships with friends, it is easier for PWAs to conceal their illness from their colleagues when they are still asymptomatic. They will also have to resort to information control and various strategies to obscure their “spoiled identity” and to “pass” off as being normal.

Re-construction of the Self: Building and Embracing an AIDS Identity\textsuperscript{13}

Individuals diagnosed with the AIDS virus not only face problems and changes in their social relationships, but their very self-conceptions and understanding of their lives also undergo dramatic transformations. Being infected with HIV is one of those traumatic experiences that threatens “core assumptions about the resilience of the self and challenges fundamental perceptions of life experiences, meaning and order.” (Borden, 1991:434) As such, acquiring the status of “infected person” prompts individuals to “make sense” of their new identity, to integrate the illness into their daily lives, and to re-construct a more viable sense of self (Kotarba, 1984). The following life story serves to highlight the various salient features that are involved in the process.

The Case of Jack

Prior to his diagnosis, Jack had been leading what Singapore society might deem a “deviant and undesirable” lifestyle. In joining secret societies in his teens, Jack had his fair share of what he called “bad” activities, such as getting involved in fights and illegal dealings. For some time, he earned his living as a pimp in the red light districts. Finally he got addicted to drugs, and was arrested and incarcerated at the DRC where he served the full term of 18 months as he “was the worst of the lot”. As a first timer, he was not given any work to do at the DRC, thus, he spent most of the time in his cell. With much time to spare, Jack started to practise daily
meditation three times a day, for an hour per session. During one session just before his release from the DRC, he suddenly felt “enlightened”. He recalled: “I felt that the things I did in the past were wrong, I wanted to start anew. After my release I pursued another path, I refrained from illegal business even as I could easily have earned lots of money. Then I slowly embraced the Buddhist faith, went to Buddhism class, and started to understand things.”

Three years later, while meditating on the beach, a thought suddenly struck him: Jack felt that his life was about to end soon. He was very puzzled by the thought: “I was sitting at the beach after my meditation, looking at the sky, and it seemed to beckon me to ‘go back’. I told myself, ‘not possible, I still have a lot of things to do.’” Soon after that episode, he started having skin problems and was referred to the National Skin Centre for a check-up. It was then that he was diagnosed with HIV. “The doctor came over and told me ‘Unfortunately, you have contracted the AIDS virus’. I was dumbfounded.” He was referred to the CDC for medical treatment and counselling. His assigned counsellor, who was also a volunteer for AfA, suggested to Jack that he join Life Goes On (LGO), a support group for PWAs under the umbrella of AfA. He recalled:

Because I’m quite open, I said okay. Because the more people you get to know, the more things you can learn to help you manage [the illness]. So I attended some lectures organized by LGO, joined their activities, and soon I was in the committee to help out... I can say I have gained a lot. I got to know what are the right medications to take, what things I should do. I received a lot of education, a lot of knowledge.

The one activity that Jack found most meaningful and suitable for him was visiting the AIDS patients in the CDC wards. He felt that these people needed much emotional support; they seemed to him unable to pull themselves together and start living. As Jack said: “They seemed to be in a daze, unable to wake up.” This observation prompted Jack to visit them as often as he could so as to counsel and motivate them. He often used himself as an example of how a seropositive person could fight the disease and lead a relatively normal life if he could view things in a positive light:

Sometimes when I visit the ward, some people don’t seem to know how to take care of themselves. It is only when you tell him, then he will know. Then you tell him, ‘I’m also HIV positive’, he will feel strange, and will think how come you are still so healthy. I’ll tell him, ‘Actually you still can lead a good life, I used to be like you, bedridden with the disease. If you take care, you could live up to five to 10 years. Must think positively, must relax, must eat well, must have more knowledge.’
Through his work with the patients and through reflecting on his life, Jack felt that he was \textit{fated} to be infected with the disease and thought that he was on a \textit{special mission} to help patients in the ward, to give them advice and motivate them to overcome the disease. This belief allowed him to "make sense" of his life and give new meaning to it. Rather than a "curse from God", AIDS was symbolically and experientially seen as a "blessing". His religion played an important role in this identity transformation:

I'm a Buddhist. I don't feel anger in getting this disease, because nothing can be changed by feeling regretful and angry. Just let the past go. Buddhism teaches us to look forward, to do what we have to do. I personally feel that I'm fated to have this sickness. I won't say it's a punishment, I think it's all 'arranged'... I see a lot of Catholics coming here to help, but there are no Buddhists, and there are a lot of Buddhist patients here. That's why maybe I've been 'arranged' to come here to help them.

Jack's life story serves to highlight the identity work that PWAs frequently engage in after a validating diagnosis. The identity work allows them to personalize the illness through the process of \textit{embracement}. As Snow and Anderson (1987) point out, embracement refers to "verbal and expressive confirmation of one's acceptance of and attachment to the social identity associated with a general or specific role, a set of social relationships, or a particular ideology." Therefore, by joining support groups such as LGO, and by drawing on religious beliefs, PWAs like Jack slowly come to accept their condition and embrace their new identity as PWAs. Through their participation in the activities organized by these support groups, and through increasing awareness of the medical and social aspects of the disease, PWAs integrate the illness into their lives and give it an entirely new meaning. In a rather paradoxical way, though religious pronouncements have contributed significantly to the social construction of AIDS as a stigmatized disease, religious beliefs could, on the other hand, be subverted to the PWAs' advantage to allow them to feel that they are "chosen" with a "special mission". The process of embracing their illness, thus, makes possible the transformation of an otherwise traumatic experience into one that imbued with positive or redemptive meaning. At the same time, it \textit{empowers} the individual with the capacity to transcend the feelings of grief, guilt, and death anxiety that are usually associated with the disease.

\textbf{Conclusion}

The main concern of this paper is to infuse humanism into HIV and AIDS research in Singapore, as reflected in both the subject matter and the general style of presentation of the data. Through this paper, I strive to put
in the foreground the voices and experiences of PWAs in their dealings with the disease within various social contexts. At the time the fieldwork was undertaken, the PWAs I interviewed in Singapore were not fully aware of the dangers associated with AIDS and its mode of transmission, therefore, they had not taken the necessary precautions when they engaged in “risky” heterosexual activities. They had had a false sense of security, thinking either that they did not fall into the “risk groups”, or that they were not susceptible to infection as the thought of contracting the virus was extremely remote. One of the possible explanations for this “not-me” syndrome (see Quah, 1992) I have suggested could be attributed to the misconceptions that have prevailed as the result of the initial social construction of AIDS by the media in Singapore and abroad.

The social construction of AIDS as a stigmatized disease has affected the way in which the wider public in Singapore views the disease in general, and PWAs in particular. As such, when individuals receive a positive diagnosis (which itself is a social process through which they gain a new identity), it necessarily entails transformations in interpersonal relationships and self conceptions as PWAs seek to make sense of and react to the new social situations they find themselves in. Referring to the acute anxieties and emotional stress PWAs have to face, Paddy Chew, the first and only Singaporean to publicly acknowledge his HIV status, notes that “[the] disease is not the main killer. It is the human aspect, the lack of human warmth, the absence of human care that has actually contributed to the many deaths and suffering.”

Due to the persistent stigma and misconceptions associated with HIV and AIDS, PWAs are uncertain as to how family and friends would react to their illness. In order to avoid facing negative reactions, they only reveal their condition to very close friends and family members whom they feel would offer them support. For my interviewees, most of them had received support from these groups, which is a crucial factor that mitigates their emotional and physical suffering. Such support goes a long way in helping PWAs cope with their medical condition, and mitigates the debilitating effects of the initial positive diagnosis. On the other hand, the lack of familial and peer support only compounds the problems that PWAs have to face, and deprives them of the necessary confidence to live with and fight the disease. Courageous efforts by civic groups such as AfA, and by individuals offering various forms of support to the PWAs further strengthen their will to confront the disease and encourage them to continue living a meaningful life. PWAs hesitate to reveal their illness to those who are not very close to them, and are very unlikely to inform their employers for fear of losing their jobs. To conceal their “spoiled identities” from others, PWAs are constantly on guard and often devise tactics to “pass” off as being normal, a manoeuvre that is relatively easier only when they do not display obvious physical symptoms. As a result of this preoccupation with
secrecy and concealment, PWAs are plagued by tremendous stress in their social interactions.

The stress and strain of concealing one’s AIDS identity in social interactions could be mitigated by the identity work in the subjective realm that entails a transformation of the self. The process involves PWAs embracing their new identity and integrating it into their daily lives, so as to give both their illness and their lives entirely new meanings. Given religion’s role in the social construction of AIDS as a stigmatized disease, it is rather paradoxical that religious beliefs are often used by PWAs in Singapore to rationalize their illness in a positive light. This study has shown that “personalizing” the illness and embracing an AIDS identity could empower PWAs with the capacity to transcend the various debilitating traumas and negative feelings that usually come with a positive diagnosis.

Notes

1. This paper is based on fieldwork undertaken between 1997 and 1999. I want to thank Dr. Vineeta Sinha, Department of Sociology (National University of Singapore), for her encouragement and supervision from 1997 to 1998. My heartfelt gratitude goes to those PWAs who did me the honour of sharing their experience with me. Due to concerns with anonymity, it is regrettable that I have to use pseudonyms instead of their real names. I will never forget my drinking and tennis sessions with Dan and the conversations we have had. To all the AIDS activists in Singapore, people like Roger Winder, Sheung, and Munjeet of AFA, and Iris Verghese, I salute all of you for the immeasurable work you have done and for being a constant source of inspiration.

2. I will discuss this issue further in the next section.

3. It should be pointed out that all the respondents I managed to get in touch with after some difficulty were men. A gender-sensitive approach calls out for future effort, when the Singaporean public becomes more willing to engage in discussions on sexual issues, and when the stigma associated with HIV/AIDS abates.

4. This number is misleading, as it reflects only those cases known by the health authorities. According to the figures of UNAIDS, the more accurate number of infections is around 3,400.


6. The moralistic tone of the government came as no surprise as it tied in nicely with its “anti-Western” rhetoric in the late 1980s and early 1990s, when the governing People’s Action Party was preoccupied with shaping a unique “Singaporean Identity”. In 1988, the then Deputy Prime Minister Goh Chok Tong mooted the idea of a set of shared values to buttress Singapore’s “Asian values” system against over-Westernization and de-culturation. One of the values, “family as a basic unit of society”, was partly intended to discourage Singaporeans from engaging in the “alternative lifestyles” seen in many developed (read Western) countries, such as casual sexual and single parenthood (see
The Straits Times, 6 January 1991). Since AIDS was first discovered in and gained prominence in the West, it acquired its stigmatized status in the eyes of the government as it was linked with “sexual promiscuity”, “deviant lifestyles” and “undesirable Western influence” — all encompassed within the anti-Western/“Singaporean Values” discourse (I want to thank Daniel Goh for bringing this to my attention).

7. This important role that the media plays in the social construction of the illness, and its power of shaping beliefs and opinions has been attested by the World Health Organization’s surveys on Knowledge, Attitudes, Beliefs, and Practices. It indicates that, regardless of the number of AIDS cases in the countries being surveyed, the population was always first informed through the media (see Herzlich and Pierret, 1993:61).

8. Paddy Chew later went on to star in a one-man play about his experience as an AIDS sufferer. He passed on soon after the last session was staged. At the time of writing, Paddy remains AIDS’ only “public face” in Singapore.

9. Despite living in a “developed” country, most PWAs in Singapore still cannot afford the optimum medical treatment. The MOH assiduously resists pressure from AIDS workers to offer subsidies so as to allow more PWAs to be able to afford the medical treatment. Responding to findings by AfA that three-quarters of those with the virus could not afford the costly but most effective anti-retroviral treatment, a MOH spokesman commented: “Anti-retroviral drugs are expensive and, more importantly, not a long-term solution for HIV and AIDS patients . . . It is hence not prudent for the Government to use public money on such subsidies, as the drugs are not a cure for AIDS.” (The Straits Times, 27 November 2001).

10. See Lim (1997) for a study of AIDS volunteers in Singapore. For an indepth study of AfA, especially with regards to the response of Singapore’s gay community and its crucial role in the AIDS effort, see Leong (1995).

11. An encouraging development was reported in 2001 whereby a manager of a department store revealed to the Singapore media that it hired HIV-infected persons, and the company’s effort in educating other staff members about AIDS.


13. See Sandstrom (1990) for another account of how PWAs construct and negotiate the meaning of their illness and the types of identity management they engage in.

References

Action for AIDS. Website: www.afa.org.sg
Living with HIV and AIDS in Singapore


