

**WOMEN AND AIDS:
A STUDY OF ISSUES IN THE PREVENTION OF HIV INFECTION**

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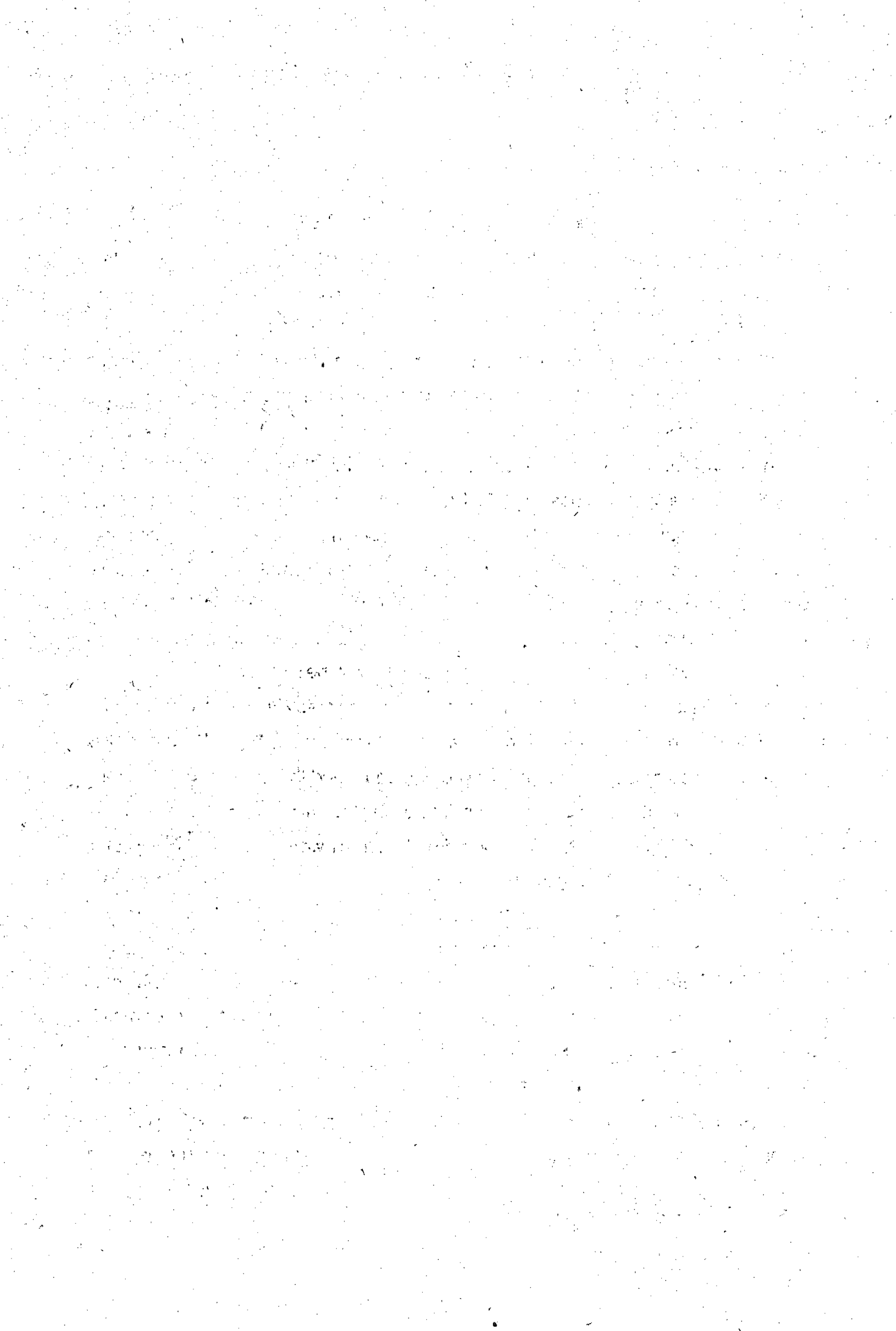
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The work for this thesis was started during the heady days after the release of Nelson Mandela and the unbanning of opposition political organisations. It drew to a close in the bleak aftermath of Chris Hani's assassination. It has not always been easy to sustain momentum and maintain perspective on the significance of the research during the last stages of writing. The thesis is dedicated to the hope that in the new South Africa we will have the energy and space to attend to problems like AIDS.

And for my father, who died June 1993



ABSTRACT

There is worldwide recognition of the magnitude of the AIDS problem generally and the particular concerns regarding prevention and care which this raises for women. Social constructionist and feminist analyses have done much to extend understanding of the issues beyond the biomedical realm to include social accounts of the constitution of AIDS knowledge, meanings and responses. However, these frameworks have not easily translated into realistic responses to the seeming paradox of women being seen as responsible for HIV prevention, while they lack the power in gender relations to implement safe sex behaviour. Therefore, this thesis aimed to explore in depth the experience and meaning of AIDS for South African women, to map their accounts in relation to existing depictions of the problem, and to identify constraints and opportunities for action which these raised. A further intention was to generate realistic and appropriate prevention options both through and arising from the research process. Preliminary work involved two pilot studies. Firstly in-depth interviews were conducted with HIV-infected women. Then an overview of the status of AIDS prevention and care facilities for women in South Africa was completed by means of interviews with key informants in medical, research and organisational settings. These studies highlighted the complexity of issues involved and confirmed the need for an approach which linked understanding to intervention. The main study aimed to explore the range and interplay of discursive themes which South African women drew on regarding AIDS, and the implications of their positioning in relation to these representations for AIDS interventions. To achieve this, fourteen focus group discussions were held with 95 subjects, the majority of whom were women from a number of relevant settings: antenatal and sexually transmitted disease clinics, nutrition centres, women's and youth branches of community political organisations, and employment categories of domestic workers, teachers and university students. The transcribed and translated texts were analysed to identify dominant and alternative discourses and their consequences. And the process both within and between groups was studied to contextualise the analysis and explore the potential for group interventions. In keeping with the literature on social constructions of the problem, two main interpretative repertoires regarding AIDS

emerged: one which involved the medicalisation of AIDS and the other to do with the stigmatisation of AIDS. Discourses of gender were also prominent: on the one hand there were depictions of men having the power to determine sexual relations, while on the other women were seen as being responsible for prevention of HIV infection. A further dimension to the problem was the current stage of the epidemic in South Africa, which seemed to foster notions of AIDS as a silent and invisible epidemic, with HIV-positive people needing to keep their status hidden. Although these representations were not unchallenged, the pervasive sense was of denial of own risk and feelings of fear and fatalism. However, the thesis argues that alternative positionings and resistances together with shifting material conditions allow for both long-term and strategic interventions. It also stresses that effective AIDS work must involve both women and men collectively. In addition, the use of groups was found to offer promising opportunities for combining AIDS research with education and support.

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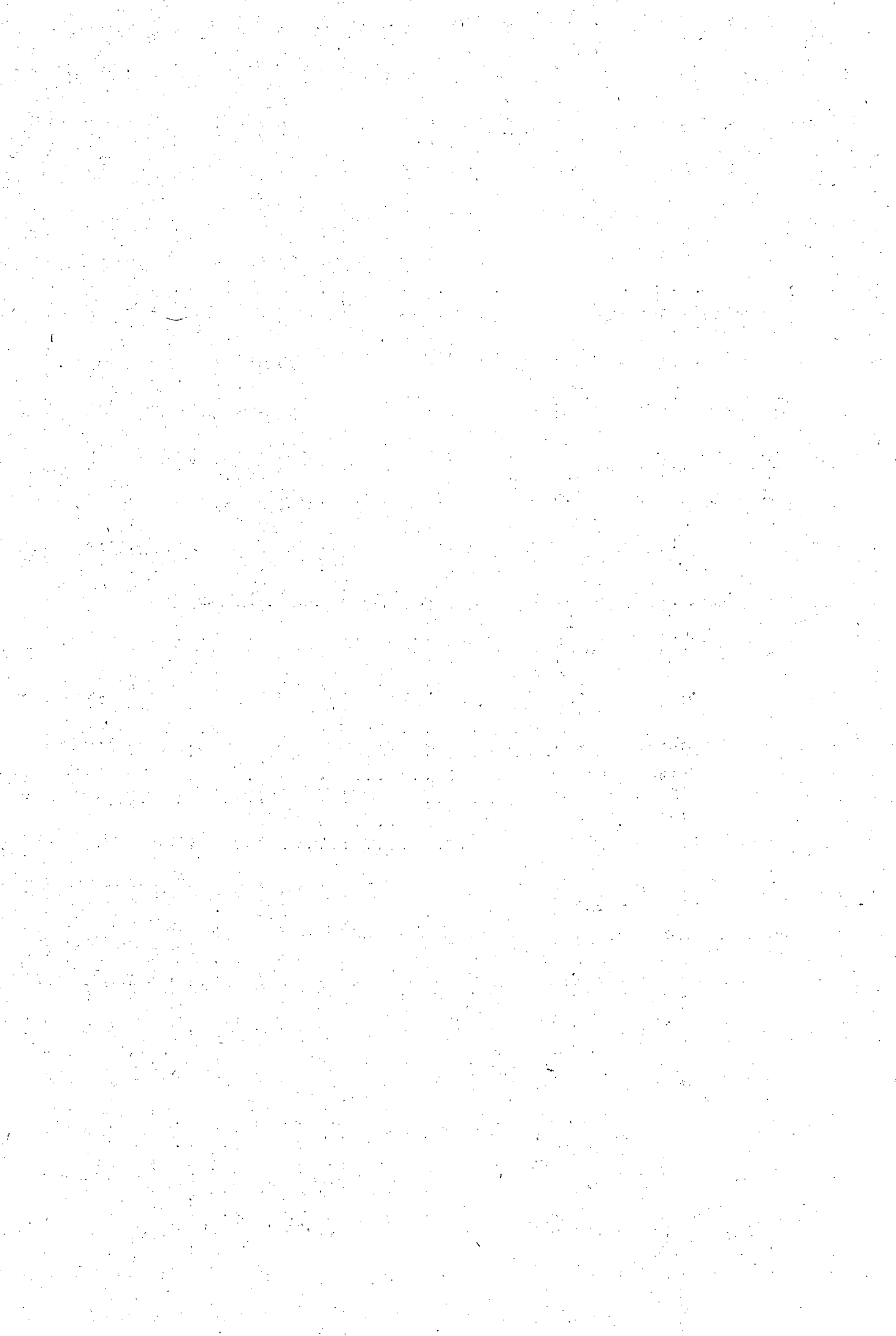
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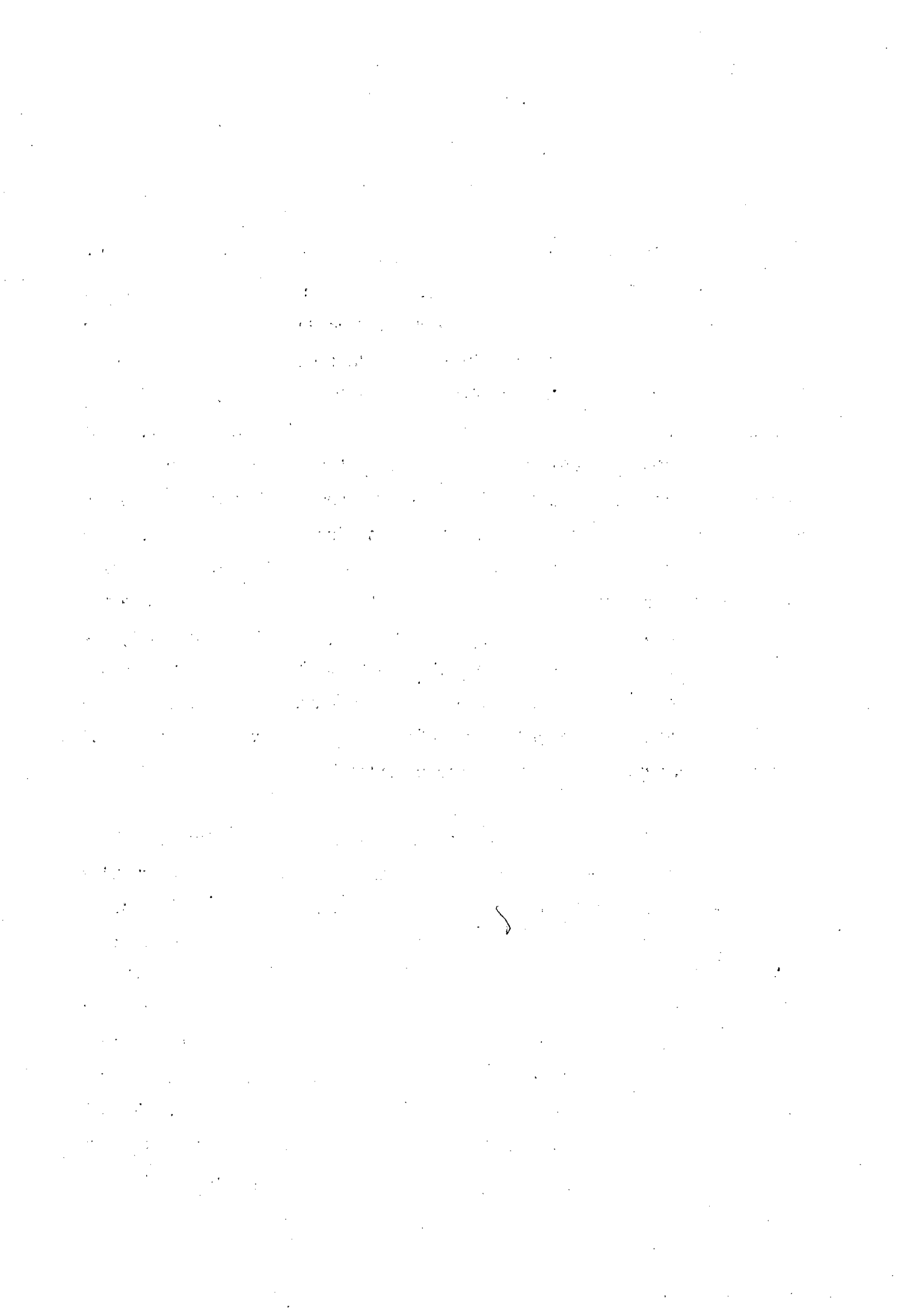
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INTRODUCTION

It is already somewhat of a truism to state that in its relatively short history, the Acquired Immunodeficiency Syndrome has come to be recognised as a major world problem. On the one hand this epidemic, with no available cure, has emerged in a modern society in which major threats to public health are largely unknown except in developing regions. At the same time the medical profession has increasingly come under fire for their incursions into everyday life. Modern medicine has thus been posed with an unexpected and disconcerting challenge. At the same time, the Human Immunodeficiency Virus appears not to be an indiscriminate, neutral virus: some people seem more likely to become infected than others, while who you are also seems to affect reactions to you once infected. It presents as a disease of many faces: of innocent, tragic children; of promiscuous, deviant homosexuals; of cynical, infective prostitutes; of unsuspecting, suffering haemophiliacs. Furthermore, given the history of which groups were first seen to be infected with the virus, as well as the major modes of transmission, AIDS has readily been depicted as a disease of stigma which only affects other, marginal people. The implications of these biomedical and social dimensions of the problem will be explored in this thesis.

One group which has increasingly featured in the ranks of the plethora of '*others*' whom the disease is believed to affect, is women. The mere trickle of references in the international literature on women and AIDS a few years ago has multiplied into an intimidating deluge. Much of this work recognises that for women AIDS raises particular concerns related to epidemiology and natural history. Also, their position in society generates specific problems for prevention and care; as a woman in an education workshop was heard to say : '*What have I got to put a condom onto?*' However, what is striking about much of this work on women and AIDS is the assumption that it is the job of women to take responsibility for safe sex, despite their seeming lack of options. This spotlight on women also occurs alongside a virtual silence on a comparable attention to '*men and AIDS*'. In elaborating on these

contradictions, the thesis will suggest that paradoxically a focus on women is needed in order to take the focus off women alone.

My own entry into AIDS work came via two routes. The one was academic research using survey methods, which generated information about target groups in the early days of the epidemic in South Africa. At the same time I was involved in voluntary organisational work, where we were continually confronted by the daunting task of introducing AIDS awareness and prevention in communities. And the two strands of endeavour often, but perhaps not surprisingly, had distressingly little to say to each other. So the rather ambitious impetus to this project was a commitment to address both issues of understanding and of intervention.

In view of the multifaceted nature of the problem, the models for understanding the phenomenon of AIDS are likely to be complex, convoluted and untidy; while for the same reasons, any responses to the problem must be nuanced, diverse and flexible. At the level of analysis, some work has already been done on the social constructions of the problem of AIDS. This approach takes account of prevailing public depictions of the disease, their interaction with current social structures, as well as their impact on available options for response. Also, such a model allows for investigating the ways in which different members of society, who are after all the individuals who will become infected/practise safe sex, make sense of and interact with the varying accounts of the problem. However, it is significant that the bulk of such work has occurred at the macro-level, involving analysis of state responses to AIDS and national media campaigns. There has been far less documented investigation of the nuance and detail of individual or group engagement with these representations of AIDS. Moreover, the possible interventions regarding the problem which such an approach suggests are not clearly articulated.

At the same time, feminist work on gendered power relations and the political economy of sexual relations also contributes to an understanding of the conditions which influence women's responses to the issues. These analyses emphasise the central role of a broad social transformatory perspective, both in understanding the issues and in

suggesting meaningful responses. Yet they too are less helpful in developing specific concrete and strategic choices for women.

Thus, while both constructionist and feminist perspectives provide rich and nuanced frameworks for approaching the problem of AIDS for women, they are perhaps rather thinner on micro-level explorations of their arguments and on generating realistic and appropriate interventions.

On the other hand, most of the considerable work on AIDS prevention has come from other directions. Recognising the urgency of the crisis, researchers have drawn largely on experience in the field of health education. However, frequently such work has been based on unclear theoretical underpinnings, or is located within a traditional social psychological paradigm, which views safe sex as a matter of individual choice: behaviour change as a result of objective information to adjust negative attitudes and alter misperceptions. Thus, such an approach seems to overlook some of the dense interplay of factors related to AIDS. And at a more practical level, research into the validity of these models has thus far been inconclusive, while implementation of their principles has also not led to the expected changes in behaviour.

In the light of this situation, two initial studies aimed to pick up some of these threads. By beginning with an in-depth focus on women living with HIV/AIDS, I hoped to explore some of the texture and detail of the experience and meanings of the disease for women. And by looking at what was happening at the practical level of interventions for women, I intended to start engaging with concrete AIDS prevention options. Overall this preliminary work confirmed the value of the direction of investigation and produced a clearer and more sharply focused sense of the scope and direction needed in the following stages.

In the main study then it seemed important firstly to identify how South African women saw the problem of AIDS; to map their accounts in relation to prevailing representations of the problem elsewhere; and to identify constraints and opportunities for action which these might produce. At the same time this analysis of discourses

needed to be more than an academic exercise; if it was to provide a meaningful challenge to traditional views of health education, the work would need to feed concretely into debates about practical AIDS prevention activities. So a further intention was to actively pursue realistic and appropriate intervention options, both through and arising from the research process. However, such a practical application of constructionist understandings of AIDS is still largely uncharted terrain and thus an exploration of possibilities. As such it was unlikely to produce neat solutions, but rather to sketch a landscape.

The focus of the research should also be seen against the broad background of current approaches to AIDS in South Africa. The thesis will outline how the broad political context and the stage of the epidemic presently in South Africa make the problems especially urgent but largely inaccessible. So there is also the need to expand the debate, initiate talk about AIDS, engage in public discourse beyond the realm of media horror and survey research.

OUTLINE OF THE THESIS

- ✓ Chapter One provides an overview of the problem of AIDS. It identifies the extent of the problem internationally and in South Africa, by indicating how the numbers of HIV-infected people have grown substantially and how patterns of infection have shifted. It also looks at the nature of the problem, through a review of biomedical and especially social features of the disease. It then focuses specifically on the problem of AIDS for women, with a detailed study of the literature on the particular medical and social concerns and implications for women.

- ✗ Chapter Two focuses on responses to the problem of AIDS. Firstly some policy aspects of the epidemic are discussed, and then a number of health education approaches are evaluated and their implications for AIDS education highlighted. This is followed by a review of international and South African responses to the problem for women. The section ends with a detailed description of two South African studies and

their implications: one which investigates the provision of AIDS services to women, and the other which documents the experiences of HIV-positive women.

Chapters Three and Four deal with the main study. Chapter Three sets the scene for later interpretation of findings, by discussing methodological considerations, especially the use of discourse analysis, and motivating for the particular focus of the study. It then outlines the research process, by describing in some detail the procedures followed in selection of subjects, fieldwork and analysis. It concludes by elaborating on the context within which to consider the results which follow: through a description of the sample and by analysing a variety of group factors, both within and across groups, and in relation to the researcher.

Chapter Four begins the identification and discussion of repertoires of discourses found in the study, by focusing on discourses of AIDS. It elaborates on the medical discourse and its ramifications, then turns to discourses of sexual stigma and the variety of stances on the 'other'. It further identifies some of the responses of women to these positions and raises implications for AIDS interventions. The process is continued by focusing on gender-related discourses. It explores the dominant and alternative discourses on gendered power relations, which depict men as having power in sexual relations and so able to determine behaviour in this sphere. On the other hand women are regarded as having responsibility for AIDS. Some of the dilemmas of this paradox and their consequences are raised.

Chapter Five brings together the different strands of the research in a model of how to understand present depictions of AIDS by women. Through recognising possible shifts in the particular South African context and prevailing discourses, it suggests some spaces for effective AIDS prevention activities. This concluding section also comments on the value of such an approach and expresses some reservations about the overall process.

Finally a comment about terminology is necessary. Although legislated racial discrimination has largely been scrapped, it has had a pervasive influence on the lives

and experiences of all South Africans, an impact which does not simply terminate together with the laws. So the classificatory categories of '*African*' and '*Coloured*' are employed to reflect this legacy, while the term '*black*' is used to refer collectively to all people of colour.

CHAPTER ONE

THE PROBLEM OF AIDS

In multiple, fragmentary and often contradictory ways we struggle to achieve some sort of understanding of AIDS, a reality that is frightening, widely publicized, and yet finally neither directly nor fully knowable (Treichler, 1987, p. 263).

THE EXTENT OF THE PROBLEM

It is ten years since the Human Immunodeficiency Virus (HIV) which causes the Acquired Immunodeficiency Syndrome (AIDS) was first identified. During this relatively short period of time, the number of people affected by the disease has grown substantially and the patterns of spread have shifted considerably.

Since the first cases of AIDS were seen in the USA in 1981, the pandemic has spread rapidly to most countries of the world. The World Health Organisation (WHO) reports that in 1982, 1,668 cases were officially identified by 17 countries. This had risen to 24,591 cases in 68 countries by 1985, and 100,410 in 138 countries by 1988 (Panos, 1988). By the end of 1992, 611,589 cases were reported by the WHO, although they claim that the real figure was more likely to be about 2,500,000 (Cape Times, 18/1/93; WHO, 1993).

However, known AIDS cases represent only a fraction of those infected by the virus. Estimates of the number of HIV-positive (HIV+) people are more than ten times higher. By May 1992, the WHO estimated a cumulative adult HIV+ total of 10 to 12 million, with about two million in North and South America, seven million in Africa, one and a half million in Asia and 600,000 in Europe (Kanki & Coutinho, 1992; WHO, 1993). They predict that this total will have risen to 15 to 20 million adults and 10 million children by the year 2000, at a rate of 5,000 new infections a day. (Cape Times, 30/11/92; The

Epidemiology Monitor, 1991). However, even these estimates are considered to be conservative, and the Harvard International AIDS Centre calculates that as many as 110 million men, women and children will carry the HIV by the turn of the century (Cape Times, 6/6/92).

These latter discrepancies highlight the problems of arriving at accurate reporting of known cases, estimations of those already infected as well as predictions of future scenarios. Both inaccurate test results and under-reporting probably influence official numbers of AIDS cases (Berkley, 1990; Kingman, 1988; Sabatier, 1988; WHO, 1993). While doomsday predictions of dramatic decreases in population, especially in Africa (Anderson, May; Ng & Rowley, 1992), have not materialised, it is clear that the epidemic has expanded rapidly with far-reaching consequences for millions throughout the world.

Together with this picture of increasing numbers, is a changing pattern in the epidemiology of the disease. Initially, three major patterns of infection were identified: Pattern 1 occurred mainly among homosexuals and intravenous drug users (IVDU) in the USA and Western Europe; Pattern 2 was found among heterosexuals and those receiving contaminated blood, in Africa (Savarit, DeCock, Schutz, Konate, Lackritz & Bondurand, 1992), the Caribbean and parts of South America; Pattern 3 included mixed modes of infection and was predominant in Asia, the Middle East and Eastern Europe, although numbers were low (Frankenberg, 1989; Panos, 1988). However, these distinctions no longer hold, as shifts have occurred along a number of dimensions. Firstly, while the bulk of cases came originally from the USA, more than half of HIV+ people are now estimated to be in sub-Saharan Africa (Berkley, 1990) and since 1987 there have been dramatic increases in the number of infections in South-East Asia (Ford & Koetsawang, 1991; Kanki & Coutinho, 1992; WHO, 1993). Thus, while cases in the USA accounted for 65% of the world total in 1988, this had fallen to about one third of cases by 1992 (Cape Times, 18/1/93; Panos, 1988).

Secondly, although AIDS was initially seen as a gay disease, especially in the USA and Europe, heterosexuals now account for an increasing percentage of infections. In

Africa, more than 80% of HIV spread is considered to be heterosexual (de Zaluondo, Masenga & Chen, 1989). Furthermore, minority groups have been heavily hit by the epidemic. Commercial sex workers (CSW) have often had high rates of infection and IVDUs now account for a large percentage of those infected in Europe and the USA (Flaskerud & Nyamathi, 1989; Mantell, Schinke & Akabas, 1988; Saalfeld, 1990). People of colour are also more severely affected than whites. In the USA, African Americans and Latinos, although only 19% of the population, account for 40% of AIDS cases. This is probably linked both to high rates of IVDU and socio-economic factors which increase risk of infection (Mays & Cochran, 1987; Sabatier, 1988).

A further development in the shifting epidemiology of AIDS has been the world-wide increase in rates of infection among women and so also children (Kanki & Coutinho, 1992; The Epidemiology Monitor, 1991). While women accounted for about 25% of cases in 1990, this had already grown to 40% by 1992 (Cape Times, 6/6/92); and in Africa, equal (if not greater) numbers of women are becoming infected (Ankrah, 1991; Berkley, Naamara, Okware & Downing, 1990; de Zaluondo *et al.*, 1989).

Finally, the discovery of the HIV-2 in 1986 in West Africa compounds the picture still further. This virus appears to differ from HIV-1 in a number of ways: lower rates of sexual and perinatal transmission have been reported, as well as longer periods of incubation before AIDS symptoms development (Kanki & Coutinho, 1992; M'boup, 1991).

In South Africa, while the epidemic initially expanded more slowly than in other African countries, trends have been similar. The first AIDS case was identified in 1982, and the disease spread in the beginning among white male homosexuals, where the rate of infection has now begun to level off. In 1987 AIDS was first diagnosed in blacks and since then the major expansion has been among urban black heterosexuals, in patterns similar to the rest of Africa (Schoub *et al.*, 1990). By March 1991, 683 AIDS cases had been reported of whom 41% had died (Cape Times, 18/3/91). Rapid increases in infection were being found. At Baragwanath Hospital there were 16 new cases identified in the second half of 1988. In the same period in 1990, this figure had

risen to 133 (Friedland, Klugman, Karstaedt, Patel, McIntyre & Allwood, 1992). In addition, two seroprevalence surveys in rural Natal/Kwazulu showed more than an overall doubling in prevalence of HIV infection within six months (Abdool Karim, Abdool Karim, Singh, Short & Ngxongo, 1992). As elsewhere all figures and estimates have to be regarded cautiously as there have been many problems associated with reporting of AIDS cases and predictions of future spread in South Africa (Cape Times, 19/1/93; Medical Research Council, 1992; Toms, 1990).

As a result, attempts to estimate rates of HIV infection have varied. In 1990, the doubling time for infection was calculated to be 8,5 months, and on the basis of this it was expected that between 317,000 and 446,000 blacks would be infected by the end of 1991 (Levine, 25/11/90; Padayachee & Schall, 1990). However, the Department of National Health and Population Development (DNHPD) total figures for the end of 1991 were 300,000 HIV+ with a doubling time of 14 months. They further estimated that 400 new infections were occurring daily and that the rate of spread was slowing down (Cape Times, 6/5/92; St Leger, 1992). In addition, the current Minister of Health reported over 1800 AIDS cases by 1993, with 659 infections in 1992, 64% of which were the result of heterosexual transmission and 31% perinatal. She further expected that one in five of the population would be HIV+ by 2010 (Cape Times, 1/3/93).

A number of prediction models have also been developed. In one of these, estimates were of 180,000 HIV-infected by 1991 and up to 5,2 million HIV+ by 2000 (Broomberg, Steinberg, Masobe & Behr, 1991). A more recent model yields a scenario of about 130,000 adult AIDS cases in the year 2000 and about 200,000 by 2002 (Doyle, 1993). With such predictions for the future and current AIDS cases at 1803 (DNHPD, 1993a), the epidemic clearly will have far-reaching psychological, social and economic implications for South Africa.

THE NATURE OF THE PROBLEM

BIOMEDICAL ASPECTS

Although HIV is a relatively new condition, a prodigious quantity of biomedical research has been undertaken, so that much is already known about the virus. However, despite the development of tests to identify antibodies to the virus, no cure has as yet been discovered. A number of treatment options are currently undergoing extensive clinical trials. The best known of these drugs, zidovudine (AZT), has been shown to alleviate symptoms in people with AIDS, although there is recent evidence of its inability to slow the progression from HIV to AIDS or improve chances of survival (Brown, 1993; Graham *et al.*, 1992; Hamilton *et al.*, 1992; Radford, 1993). Traditional herbal remedies are also being explored in Africa (Konotey-Ahulu, 1989; Rutayuga, 1992; Scheinman, Nesje, Ulrich & Malangulia, 1992). In addition, lifestyle factors which depress efficient functioning of the immune system, like stress, smoking and alcohol, have also been isolated as possibly influencing progression of the disease and survival chances (Baum & Nesselhof, 1988; Cape Times, 10/5/93; Richardson, 1987). No vaccine has as yet been made available, but there is hope that this will change in the next few years (Burke, 1991; Hirsch & Lange, 1992). However, researchers warn against undue optimism: it has become clear that different strains of the virus will not all respond to a single vaccine; that clinical trials will take considerable time; and that costs and distribution problems will limit availability precisely in those areas with highest rates of infection (Brandt, 1988b; Burke, 1991; Earickson, 1990; Valdiserri, 1989). Brown (1993, p. 16) in an overview of the Ninth International Conference on AIDS in Berlin, summed the current position up as follows:

Vaccines, which offer the only realistic hope to stop the disease, are midway between fantasy and reality. Many are being tested for their physiological effects, and by 1995 some will be tested in live populations. Really useful vaccines - cheap, oral, one-dose, highly effective, and not requiring refrigeration - are decades away.

The role of sexually transmitted diseases (STD), especially those accompanied by genital ulceration, in HIV infection has also been well-established (Cates & Bowen

1989; Clumeck, Carael & van de Perre, 1989; Ogunseitán & Mariasy, 1989; Wilson & Lavelle, 1990). It appears that people with pre-existing STDs are two to seven times more likely to become HIV infected than people who have not had an STD and are also more likely to pass on the virus (Population Reports, 1990). Tuberculosis (TB) also has significant links with HIV infection. The WHO has warned that this '*forgotten epidemic*', with which an estimated one third of the world's population is infected, is on the increase (The Weekend Argus, 24/25 April, 1993). A recent report in the USA found the largest annual increase of TB cases since 1953, especially in the 25-44 year age group (Jereb, Kelly, Dooley, Cauthen & Snider, 1991). These increases are thought to be related to the lowered immunity brought about by HIV infection. TB is one of the few opportunistic infections which can be transmitted to the general population and it may accelerate the progression of HIV infection to AIDS. Moreover, TB like HIV appears to have its greatest impact among the socially and economically disadvantaged. Thus there is particular concern about this problem in Africa, where it is by far the most common infection in HIV+ people and has resulted in renewed increases in TB rates. (Gilks, 1992; Maartens, 1992; Panos, 1988).

PREVENTION

A crash program to promote condom use, treat other sexually transmitted diseases, operate needle exchange programs, maintain a safe blood supply and increase AIDS education could cut in half the rate of increase expected by the turn of the century. That would save millions of lives, and it's worth doing (Guardian Weekly, 18-24 June, 1993).

In the absence of a vaccine or effective treatment for HIV infection, it is widely recognised that behaviour change can help prevent transmission of the virus (Baum & Nesselhof, 1988; Bayer, 1992; Becker & Joseph, 1988; Osborn, 1986; Quinn, 1990). More specifically, it is recommended that in order to avoid sexual transmission, individuals abstain from sexual intercourse, remain monogamous with an uninfected partner, use condoms for each penetrative sexual encounter or adopt sexual behaviour which does not involve exchange of body fluids (Berer & Ray, 1993; Panos, 1988).

The identification of such guidelines for practising safe sex has taken the issue of AIDS beyond the realm of biomedicine. Behavioural and social scientists increasingly have become involved in the development and assessment of education initiatives (Baum & Nesselhof, 1988; Morin, 1988). As Osborn (1986, p. 289) noted:

It became clear early that the languages of the natural sciences were nowhere near broad enough to encompass the range of problems posed by the peculiarities of the epidemic, and that we would all have to learn a much more universal language if we were to achieve both useful and socially acceptable measures of containment and control.

Much research was initially carried out to establish the AIDS-related knowledge, attitudes, beliefs and practices of individuals and target groups, as well as the extent of behaviour change to safe sex.

Early findings were that many people had reasonable knowledge about AIDS, but that this was often accompanied by misperceptions about especially transmission of the virus. Moreover, knowledge about AIDS and safe sex frequently did not lead to appropriate behaviour change (Adamchak, Mbizvo & Tawanda, 1990; Becker & Joseph, 1988; Quinn, 1990; Siegel & Gibson, 1988; Valdiserri, Arena, Proctor & Bonati, 1989), but rather '*appear[ed] to be a necessary but not sufficient condition to facilitate behavior change*' (Morin, 1988, p. 839). Whether people considered themselves to be personally at risk of infection was thought to be an important variable in altering behaviour (Baum & Nesselhof, 1988; Morin, 1988; Siegel & Gibson, 1988; Wellings, 1988). However, while some studies have supported this hypothesis (James, Gillies & Bignell, 1991; Sherr, 1988; Strebel & Perkel, 1991a), others have not (Dolcini, Coates, Catania, Kegeles, Fullilove & Hulley, 1991; Weinstein, 1989). Also, many engaging in potentially risky behaviour do not necessarily perceive themselves to be at risk (Dolcine *et al.*, 1991).

The use of condoms is widely regarded as a crucial component of AIDS prevention, although there has been some debate about the effectiveness of condoms for HIV prevention especially at the individual level (Feldblum & Fortney, 1988; Gordon, 1989; Perlman, Kelaghan, Wolf, Baldwin, Coulson & Novello, 1990; Schopper, 1990). Generally condom use is low, even amongst those with adequate knowledge (Rickert,

Jay, Gottlieb & Bridges, 1989; Siegel & Gibson, 1988). This is particularly true of less developed countries. A worldwide review of available data found that no more than 1% of couples in developing countries were then using condoms (Goldberg, Lee, Oberle & Peterson, 1989); in a study of 722 Zimbabwean males, 5% were using condoms at the time of the survey (Mbizvo & Adamchak, 1989); while in Rwanda none of over 1000 sexually active adults reported use of condoms (Carael *et al.*, 1988, reported in Taylor, 1990). Moreover, many negative attitudes and beliefs about condoms have been identified (Kegeles *et al.*, 1991; Mbizvo & Adamchak, 1989; Strebel & Perkel, 1991b; Valdiserri, 1989).

Despite these indications that awareness of AIDS has not resulted in effective prevention strategies for many, there have also been substantial behaviour changes in some allegedly high-risk groups. In the gay community especially, there is evidence of marked shifts in behaviour, although this has often involved modification rather than elimination of risky practices and maintenance of safer behaviour is sometimes a problem (Bayer, 1989; Becker & Joseph, 1988; Ehrhardt, 1988; Freudenberg, 1990; Homans & Aggleton, 1988; McCusker, Stoddard, McDonald, Zapka & Meyer, 1992; Quinn, 1991; Valdiserri *et al.*, 1987). Also commercial sex workers and IDUs have changed behaviour to reduce risk of infection (Alexander, 1990; Deren, Fortu & Davis, 1993; Krieger & Appelman, 1986; Ngugi *et al.*, 1988; Valdiserri, 1989). However, some data on couples discordant for HIV suggests that even where risk of infection is extremely great, unprotected sex occurs (Skurnick *et al.*, 1991).

In South Africa too, a number of studies of knowledge, attitudes and practices have been conducted. As elsewhere, these provide not a comprehensive overview of the population, but information on selected sub-groups, some (like university students) selected for ease of access rather than necessarily high-risk behaviour (Skinner, 1992). Most have focused on youth and findings have been similar to other regions. While awareness of AIDS is often good, it is accompanied by inaccurate information. Although many youth are sexually active, few perceive themselves to be at risk or have modified their behaviour appropriately (Mathews, Kuhn, Metcalf, Joubert & Cameron, 1990; Perkel, Strebel & Joubert, 1991; Strebel & Perkel, 1991a; Preston-Whyte &

Zondi, 1991). Work among migrant workers has found some evidence of reasonable awareness of AIDS, high rates of STDs and varying levels of condom use (Ijsselmuiden, Padayachee, Mashaba, Martiny & van Staden, 1990; Jochelsen, Mothibi & Leger, 1991). Gay men have shown good AIDS knowledge, varying responses to the threat of infection and concerns about stigma and homophobia toward the local gay community (Isaacs & McKendrick, 1992; Schurink & Schurink, 1990). It is also apparent that homosexuality among black men is not as rare as is often publicly claimed (de Jager, 1992; Maluleke, 1990; Nkoli, 1991).

This extensive research into behavioural dimensions of AIDS goes a considerable way towards describing relevant current patterns of knowledge and behaviour. However, information is not necessarily generalisable to wider populations. Also most studies have used survey methods which are sometimes less effective for capturing nuance and meaning, especially in the area of sexual behaviour. Nevertheless, they have implications for the development of education strategies, which will be discussed in Chapter Two.

SOCIAL CONSTRUCTIONS OF THE PROBLEM

From the above, it is abundantly clear that AIDS is a major medical problem. However, it has also been widely recognised that the epidemic is much more than a matter of symptoms, diagnosis and pharmacology. Many social scientists have analysed how AIDS occurs within particular historical, cultural, political and economic contexts, which result in varying depictions of the disease (Fitzpatrick, 1984; Holland, Ramazanoglu & Scott, 1990b; Ingstad, 1990; Taylor, 1990). These social meanings and consequences influence individual experience, public views and policy formation; a process which in turn reflects the values and pre-occupations of the society. As Weeks (1989, p. 2) has stated:

AIDS has become the symbolic bearer of a host of meanings about our contemporary culture: about its social composition, its racial boundaries, its attitudes to social marginality; and above all, its moral configurations and its sexual mores. A number of different histories intersect in and are condensed by AIDS discourse. What gives AIDS a particular power is its ability to represent a host of fears, anxieties and problems in our current post-permissive society.

Language is crucial to this process of negotiation of meanings. (Grover, 1989; Patton, 1990b; Treichler, 1987). While these social constructions are often confused, contradictory and multiple, Plummer (1988) has suggested that there are two central discourses which organise much of what he calls 'AIDSPEAK': one focuses on the medicalisation of AIDS and the other upon the stigmatisation of AIDS.

As was discussed above, the dominant paradigm for understanding AIDS has been a **medical** or scientific one. Predominantly, research has been concerned with clinical features, statistics and technological solutions to the problem, a search for the '*magic bullet*' (Brandt, 1985). From this perspective, the disease has been constructed as an epidemic, which draws on associations with large-scale death and disaster. Comparisons have been drawn between AIDS and the plague, as well as earlier epidemics of TB and cancer (Alcorn, 1988; Patton, 1985; Weeks, 1989). In what Treichler (1987) calls the '*epidemic of signification*', frequent use is made of military metaphors to describe the impact of and appropriate responses to the virus (Brandt, 1988a; Sontag, 1988). The media has played a central role in communicating this model of the disease to the public, a model which has understandably evoked strong emotional reactions of fear for many (Kitzinger & Miller, 1991; Patton, 1990a; Watney, 1987; Wellings, 1988). As will be discussed later, such fear is often counter-productive for appropriate prevention of infection.

These writers have highlighted the ways in which such depictions of AIDS serve to entrench the power of medicine and science in everyday life. This has occurred at a time when medicine was on the one hand considered to have overcome all major health problems, while on the other hand was increasingly coming under attack for the way in which it was extending control over social life (Brandt, 1988b; Gilman, 1988; Illich, 1975; Patton, 1985, 1990a; Sontag, 1988; Young, 1987). Patton (1990b, p. 57) elaborates further:

AIDS science privileges the domain of the objectively researchable (viruses, Western biomedical treatments, sex data as compiled in epidemiological study) over communicative and symbolic community processes. The dominance of science as **the** logical paradigm rationalizes systems of social control which predate the HIV epidemic, especially systems which silence or distort the speech

and culture of "minority communities" by constructing them as lacking in the forms of discourse which enable people to "make sense".

On the other hand, as the number of HIV infected people grew, the disease quickly developed a wide range of **stigmatising** associations. One of the most pervasive was the depiction of AIDS as a sexually transmitted disease and comparisons with syphilis. In this way AIDS was seen as the result of sexually excessive and degenerate individual behaviour, which originated among aliens (syphilis was often referred to as the French pox), who were consequently to blame for their affliction (Brandt, 1985, 1988a; Gilman, 1988; Horton & Aggleton, 1989; Sontag, 1988; Valdiserri, 1989).

The fact that the first cases of HIV infection and death from AIDS were identified among male homosexuals in the USA, further contributed to the process of stigmatisation. Early writing about the virus identified gay behaviour as central to risk of infection and the term Gay Related Immune Deficiency (GRID) was coined for the condition. This gave rise to widespread homophobia, as infection was once again viewed as the result of deviant and promiscuous behaviour, and even just retribution (Patton, 1985; Plummer, 1988; Treichler, 1987; Watney, 1987, 1988).

This view of AIDS was consolidated as HIV infection was also identified in other socially deviant groups. Sex workers were considered to be reservoirs of infection, spreading the disease to '*innocent victims*', their male clients (Gilman, 1988). Intravenous drug users soon were identified as a major high-risk group, especially in the USA and Western Europe. Once again, illegal behaviour of a socially-deviant subgroup was associated with HIV infection (Holland, Ramazanoglu & Scott, 1990b; Valdiserri, 1989).

Public response to these initial constructions was described by some writers as **moral panic**. Weeks (1989, p. 5) explained the concept as follows:

Moral panics occur in complex societies when deep rooted and difficult to resolve social anxieties become focused on symbolic agents which can be easily targeted. Over the past century sexuality has been a potent focus of such moral panics.

As a result, instead of those with the disease being regarded with sympathy, they induced reactions of fear and avoidance in many. These reactions were analysed in terms of prevailing social values among the New Right in the USA and United Kingdom (UK). However, although the notion of moral panic has been valuable in deconstructing responses to the disease, Watney (1988, p. 59) has suggested that:

It is better to think in terms of AIDS commentary, rather than assuming the existence of a coherent univocal 'moral panic' on the subject. We are here considering the circulation of symbols, of the raw materials from which human subjectivity is constructed. AIDS has been mobilised to embody a variety of perceived threats to individual and social stability, organised around the spectacle of illicit sex and physical corruption. It has been used to stabilize the figure of the heterosexual family unit which remains the central image in our society with which individuals are endlessly invited to identify their collective interests and their very core of being.

Thus, in this view, traditional values were seen to be undermined by permissive social movements like the hippie generation, gay liberation, the women's movement and black consciousness (Krieger & Appleman, 1986; Patton, 1985; Sontag, 1988; Watney, 1987; Weeks, 1985). At risk was the beleaguered notion of the nuclear family and the advent of AIDS was seen as legitimating the call for a return to such values and the ostracising of those threatening its survival (Earickson, 1990; Horton & Aggleton, 1989; Watney, 1989). The implication of this was the need to control seemingly deviant sexuality (Brandt, 1988a; Grover, 1989; Watney, 1987).

A further dimension to stigmatising those infected with HIV developed as the disease spread outside of the initial groups. In the USA other minorities also showed unusually high rates of infection. First Haitians and then African Americans and latinos became identified as '*high-risk*' groups. Thus the image of AIDS being a disease of the marginalised was expanded to include people of colour and thereby reinforced (Dalton, 1989; Sabatier, 1988; Weeks, 1989) and for a while AIDS was seen to affect primarily the four H's: homosexuals, haemophiliacs, heroin addicts and Haitians (Gilman, 1988; Treichler, 1987).

Finally, HIV also acquired racist dimensions. What had originally been predominantly a white gay disease in the USA soon grew to include large numbers of heterosexual

Africans. Depictions of a rampant epidemic among promiscuous Africans were reinforced by claims that the virus had in fact originated in Africa (Chirimuuta & Chirimuuta, 1987; Kitzinger & Miller, 1990; Packard & Epstein, 1991; Sabatier, 1988; Sontag, 1988).

Overall then there were powerful tendencies to view AIDS as a disease of stigmatisation. The implication of these depictions was to establish the problem elsewhere, a contamination affecting *others*, who had brought about the condition by their deviant lifestyle. In other words, HIV infection was their own responsibility and they were to blame for their state, and in some instances even deserved punishment (in the form of isolation) for this. Furthermore, by constructing AIDS as something that happened only to such outsiders, the majority could deny their own vulnerability to infection and project their fears onto these others, confirming the gap between the innocent '*population at large*' and guilty minorities (Alcorn, 1988; Brandt, 1988b; Gilman, 1988; Horton & Aggleton, 1989; Patton, 1990a; Plummer, 1988; Weeks, 1988).

The result of these social constructions of AIDS was slow and often moralistic responses from governments, calls for testing and isolation, eventually substantial amounts of money for biomedical research, activism from gays, discrimination and legislation; as will be discussed in the next chapter.

'MOTHERS AND WHORES': THE PROBLEM OF AIDS FOR WOMEN

Most of what is known about biomedical aspects of AIDS is based on research among gay males, and much of the work on social constructions of the problem has also focused on the issues as they relate to this group. However, as patterns of infection altered to include significant numbers of women, there was a growing awareness of the need to investigate the epidemiology of AIDS among women and the special problems it raised for them.

Throughout the world there has been a dramatic increase in the extent of HIV infection among women (Kanki & Coutinho, 1992). Estimates of the WHO were that by 1990, one third or up to three million of the eight to ten million people HIV-infected throughout the world were women (Panos, 1990). Further, they expected that by 2000, the number of infected women would equal that of men (Petros-Barvazian & Merson, 1990). In addition, AIDS was already the leading cause of death for 20-40 year old women in major cities in the USA, Europe and sub-Saharan Africa, and during the 1990s the disease was expected to kill about three million women and children (Chin, 1990).

In the USA, the first cases were identified in women in 1982. As they occurred in IDUs and CSWs, little attention was paid to AIDS as a problem for women, other than their being vectors of transmission to heterosexual men (Campbell, 1990; Hankins & Handley, 1992). Women have remained a relatively small percentage of the total of HIV-infected people, with seroprevalence rates of between 0 and 4.3% for sentinel groups (Shapiro, Schulz, Lee & Dondero, 1989). Nevertheless, the number of AIDS cases among American women has increased 600% since 1986, and the growth rate currently is two and a half times faster among women than men (Rodin & Ickovics, 1990). Minority women are consistently worst affected, with over 70% of cases among women of colour (Campbell, 1990; Carpenter, Mayer, Stein, Leibman, Fisher & Fiore, 1991; Flaskerud & Nyamathi, 1990; Guinan & Hardy 1987; Jones & Catalan, 1989). It has been estimated that African American women are thirteen times more likely and latina women nine times more likely to be HIV-infected than white women (Mays & Cochran, 1988b).

In sub-Saharan Africa, women constitute a far greater percentage of those infected. One in forty women are thought to be infected, and by 1992, the WHO estimated that four million women and one million children in sub-Saharan Africa were HIV+, accounting for 90% of the world total (Merson, 1991; Panos, 1990). While distribution across the continent has been highly variable, the ratio of male to female infection was initially calculated to be 1:1 (de Zalduondo *et al.*, 1989). However, more recent studies consistently have found the rate of infection greater in women than men (Ankrah, 1991;

Berkley *et al.*, 1990; Decosas & Pedneault, 1992; Mariasy & Radlett, 1990). More specifically, at a voluntary and confidential public HIV testing service in Uganda, overall seroprevalence among 872 clients was 28%: 35% among women and 24% in men (Muller, Barugahare & Schwartland, 1992); and among women of child-bearing age in urban Rwanda, HIV infection now accounts for 90% of all deaths (Lindan *et al.*, 1992).

As in the USA, the first infections in South Africa were among white gay males, but as the disease in the black population began to spread rapidly after 1987, women made up an increasing number of those infected. By the end of 1992 it was estimated that women accounted for about 180,000 of the total of 320,000 HIV-infected people in South Africa (DNHPD, 1993a). Thus, while the first national HIV survey of women attending antenatal clinics in 1990 revealed an estimated seroprevalence rate of 0,76%, this had risen to 1,49% a year later, and 2,69% by 1992, with the highest rate among 20-24 year olds (DNHPD, 1992, 1993b). The same trend was evident in rural Natal/Kwazulu, where an anonymous HIV seroprevalence survey found 1,2% of cases HIV-1 infected, with women having a 3,2 times higher prevalence than men. The rate had increased to 2,5% six months later, with most cases in the 15-30 year age group for women (Abdool Karim, 1992; Abdool Karim *et al.*, 1992). Furthermore, forecasts of HIV prevalence among all adult females are about 4% by 1995, 12,5% by 2000 and 20,5% by 2005 (Doyle, 1993). Apart from these significant increases in infection rate and the predominance among younger women, the South African picture is also characterised by strong links between STDs and HIV infection. In a study of 2682 STD clinic attenders in Natal, 3,2% of women and 1,9% of men with STDs were HIV+ (O'Farrell, Windsor & Becker, 1991).

BIOMEDICAL FACTORS

As recognition of the extent of the problem among women grew, research into the natural history and co-factors of AIDS for women began to produce a clearer picture of the impact of the disease.

Women have different absolute and relative risks than men for many diseases, including AIDS. Unlike men, for women the chief mode of transmission of HIV is heterosexual. In the USA and Western Europe, IDU accounts for substantial numbers of infections too, while contaminated blood is also a risk factor in some areas (Campbell, 1990; Carpenter *et al.*, 1991; Cochran, 1989; Cohen, Hauer & Wofsy, 1989; Hankins & Handley, 1992; Murray, 1991). Information on woman to woman transmission is still limited (Chu, Hammett & Buehler, 1992; Leonard, 1990).

There is also evidence that women are consistently more likely to become HIV-infected through heterosexual transmission than heterosexual men are (Mantell *et al.*, 1988; Panos, 1990; Rodin & Ickovics, 1990). It has been estimated that heterosexual transmission from men to women is three to five times more likely than from women to men (Anastos & Palleja, 1991), and in a study of 563 couples, the European Study Group on Heterosexual Transmission of HIV (1992) found that male to female transmission was 1.9 times more effective. While the reasons for this greater risk of infection are not entirely clear, researchers suggest that there is a larger pool of infected men, so that women are more likely to come into contact with an infected partner; and that transmission might be more efficient from men to women (Guinan & Hardy, 1987; Jones & Catalan, 1989; Wellings, 1989). In this regard, there is increasing evidence of the possibility of a greater physiological vulnerability in women (United Nations Development Programme, 1992). It is also thought that the number of exposures to an infected partner increases risk of infection (Padian *et al.*, 1987).

Of further significance is the fact that women are often infected up to ten years younger than men, with 79% of female cases in women of childbearing age (Mantell *et al.*, 1988; Ray, 1990; Rodin & Ickovics, 1990; Shapiro *et al.*, 1989). In addition, women frequently appear to have a poorer prognosis once infected and die sooner than men (Berer & Ray, 1993; Jones & Catalan, 1989; Mantell *et al.*, 1988; Rodin & Ickovics, 1990). However, evidence seems to indicate that there is not a significant difference in natural history of the disease between men and women (Carpenter *et al.*, 1991; Kanki & Coutinho, 1992). Rather, because of the absence of a women-specific case definition of AIDS, women may be diagnosed later than men and, therefore,

appear to have lower survival chances. Also, it is likely that women have less access to health services than men and so present for medical help later (Hankins & Handley, 1992).

Another major feature of HIV infection in women is the fact that transmission can occur perinatally from mother to infant. This in fact forms the chief mode of transmission for infants and is estimated to account for 78% of such infections in the USA and 63% in the UK (Guinan & Hardy, 1987; Jones & Catalan, 1989; Murray, 1991). Although the rate of transmission varies worldwide between 14% and 52% (Kanki & Coutinho, 1992), roughly 30% of babies of HIV+ mothers are infected (Global Programme on AIDS, 1992; Merson, 1991). Evidence from twin studies is that infection can take place during the birth process (Goedert *et al.*, 1991). It may also occur postnatally (van de Perre *et al.*, 1991). Thus, breastfeeding may place an infant at risk too, with estimates of transmission by breastfeeding 16% in prenatally infected women and 26% in postnatally infected women (Kanki & Coutinho, 1992). The GPA (1992) therefore suggests that the mother may be more infectious if she seroconverted postnatally and the risk of transmission lower if she was already infected at delivery. Generally, however, despite this evidence and because of the overall benefits to the infant of breastfeeding, women are encouraged to continue breastfeeding even if they are HIV+, especially in developing countries (Edwards, 1992; Jones & Catalan, 1989; Kanki & Coutinho, 1992; Panos, 1990).

There has been concern that pregnancy adversely affects the progression of HIV infection in women. However, this does not seem to be the case, at least in the early stages of infection (Panos, 1990). Studies have found that pregnancy, in the absence of HIV-associated symptoms does not strongly influence disease progression (Carpenter *et al.*, 1991; Chin, 1990; Handley & Hankins, 1992).

There are other ways in which AIDS poses particular problems for women. As mentioned earlier, STDs have been shown to increase the likelihood of HIV infection. In women, symptoms are often less apparent, so that STDs are more likely to be undetected, resulting in less efficient treatment and increased vulnerability to HIV

infection (Legion, 1992; Panos, 1990; Standing & Kisekka, 1989). Moreover, women are often perceived by men as responsible for the spread and treatment of STDs (dos Santos & Arthur, 1991). Rates of STD infection are particularly high in developing countries. In Zimbabwe, for example, over 90% of women at a genitourinary clinic had genital infections (Mason, Gwanzura, Latif & Marowa, 1990). A recent study in rural South Africa also found high rates of STD infection in pregnant women (O'Farrell, Hoosen, Kharsany & van den Ende, 1989).

There are suggestions that oral contraceptives, which sometimes produce inflammation and bleeding, as well as intra-uterine devices, may increase chances of HIV infection in women (Berkley, 1990; Hankins, 1990; Panos, 1990). Menstruation has also been thought to be associated with HIV infection, because STDs are more readily acquired during this period (Murray, 1991). Although there is no clear evidence at this stage, some writers have speculated about the possible impact of female genital circumcision and infibulation as risk factors (Hosken, 1987; Mantell *et al.*, 1988; Richardson, 1987; Standing & Kisekka, 1989). Needle infections through injections and transfusions are of particular significance for women in developing countries, who are often more frequently exposed to such procedures (Head, 1992a; Packard & Epstein, 1991; Panos, 1990). In fact, it is estimated that women and children receive 80% of all blood transfusions in Africa (Berer & Ray, 1993; Ulin, 1992).

SOCIAL FACTORS

Thus, it is apparent that women are increasingly becoming infected. They also are at greater risk of infection if exposed to the virus, and carry the added burden of being able to transmit the virus to infants. However, this is not the full picture. There are social and economic factors which have a considerable impact on HIV transmission in women. It is essential, therefore, to explore women's position in society, in order to understand the complexity of the problems they face and in order to approach prevention and care initiatives realistically.

Sexuality and Gender

Central to considerations of AIDS as a problem for women is an understanding of sexuality and gender. The traditional view of psychosexual development was of biologically-based differences between males and females, which were the basis for the emergence of separate sex roles for men and women. These were seen to be the result of intrapsychic processes and social learning and resulted in typical masculine characteristics of strength, assertiveness, rationality, but also biologically-driven sex needs; as opposed to feminine characteristics of softness, dependence, passivity, emotionality and physical attractiveness (Maccoby & Jacklin, 1974; Milès, 1992; Weitz, 1977).

However, feminist writers have challenged this version of fundamental and unchanging differences between men and women. Many have outlined how sexuality is in fact socially constructed and historically located within a matrix of intersecting social, economic and cultural factors (Caplan, 1987; Gagnon & Simon, 1973; Ortnor & Whitehead, 1981; Rubin, 1984). Gender relations then are not natural and biologically determined, but are based on differential relations of power in which patriarchy exerts substantial control over women in a variety of spheres (Smart & Smart, 1978; Vance, 1984; Weedon, 1987). One of the most powerful forms of such social control over women's sexuality is the fear of violence from men (Levett, 1991; Posel & Posel, 1991; Smart & Smart, 1978; Vance, 1984). However, some writers have stressed that this is not a seamless inequality, with women consistently powerless (Holland, Ramazanoglu, Scott, Sharpe & Thomson, 1990b; Hollway, 1984a, 1984b).

These gendered power relations have significant implications for understanding the problem of AIDS for women. In order to avoid infection, women are advised to abstain from sex, practise monogamy or negotiate the use of condoms with their male partners (Ardill & O'Sullivan, 1988; Richardson, 1987). These options reflect a focus on a male, heterosexual construction of sexuality as depicted in the media and serve as a means of reinforcing social control over women's sexuality (Bell, 1989; Juhasz, 1990). Women are consistently portrayed as being responsible for ensuring that safe sex is

implemented (Carovano, 1991; Holland, Ramazanoglu & Scott, 1990a; Juhasz, 1990; Reid, 1991; Richardson, 1990; Thomson & Scott, 1990; Worth, 1989). However, this view upholds the prevailing notion of a male sex drive for which men are not responsible, but which women are expected to curb, and entrenches dominant gendered power relations (Crawford, Kippax & Waldby, 1992; Holland *et al.*, 1990b; Hollway, 1984a; Patton, 1989; Scott, 1987). Thus, women paradoxically are required to exert power and make choices in a domain over which they have notoriously little control and few options (dos Santos & Arthur, 1991; Hollis, 1992). Moreover, these constructions of prevention see safe sex as a matter of individual concern and responsibility (Grover, 1989; Patton, 1989). Finally, for many women sex has frequently been associated with danger (of violence, pregnancy, health risks) so that to talk of safe sex poses somewhat of a contradiction (Holland *et al.*, 1990a; Segal, 1987).

In the light of these factors, feminists have suggested alternative responses to the threat of AIDS. In fact, for some the AIDS epidemic has provided an opportunity to refocus attention on the feminist project and to resume talking about sex (Ardill & O'Sullivan, 1988; Miles, Steinberg, Strelbel & Cooper, 1992). Fundamental to this approach would be the need to substantially change the power dynamics between men and women toward greater equality and more women-centred notions of sexuality (Ardill & O'Sullivan, 1988; dos Santos & Arthur, 1991; Segal, 1987; Hollis, 1992; Kippax, Crawford, Waldby & Benton, 1990). This would involve the legitimating of alternative sexual practices like non-penetration and mutual masturbation (Miles, 1992; Segal, 1987; Scott, 1987; Holland *et al.*, 1990b). In addition, attempts to curtail women's sexuality and the advances of the women's movement by calling for monogamy need to be resisted (Grover, 1989; Kippax *et al.*, 1990; Kutzko, 1988). In Africa, high rates of HIV and STD infection have often been attributed to the '*unbridled promiscuity*' of black women, so that prevention activities become such a means of controlling women's sexuality (Vaughan, 1990). In order to counter these possibilities there should instead be a focus on expanding women's sexual options, enhancing pleasure and desire (Pearl, 1990; Scott, 1987; Thomson & Scott, 1991).

There also needs to be recognition of the fact that women are not uniformly without power in gender relations, that women are actively engaged in constructing their sexuality, that there are contradictions and spaces which can be exploited in negotiating safe sex (Erben, 1990; Fuller, 1992; Holland *et al.*, 1990a; Kane, 1990).

Finally, implicit in this approach must be the understanding that the issues are not seen in terms of individual responsibility and blame, but as opportunities for collective development of appropriate responses. So that while empowerment would need to involve individual behaviour, it also includes collective action at community and social levels (Fuller, 1992; Holland, Ramazanoglu, Scott, Sharpe & Thomson, 1991; Patton, 1989).

Socio-economic Factors

Much of the above debate has been located specifically within a feminist perspective. However for others, these issues have been part of a broader view of the problem. Especially for women of colour in the USA and women in Africa, there has been a recognition that other important variables intersect with gender to compound the picture. They therefore reject an overemphasis on gender, which denies the complexity of power relations and experience differences between women with regard to race and class (Dugger, 1991; Ramazanoglu, 1989; Stamp, 1989).

The problem of AIDS in women has been located within the wider political economy of Africa. Because of their differential positioning in society, economic factors impact on men and women differently, so that women often lack power and social status, and thus access to economic resources. They are usually then poorer than men, more likely to work in the informal sector or to be unemployed (Schoepf, 1991, 1992; Ulin, 1992). Frequently, therefore, they are economically dependent on men (Ankrah, 1991; Campbell, 1990). In Africa, this situation is regarded as the result of a long-term process, whereby the intersection of colonialism and traditional culture gave rise to large-scale migrancy and urbanisation, initially of men but later also of women (Bassett & Mhloyi, 1991; Larson, 1990). This led to the presence in cities of substantial numbers

of economically destitute women and female headed households, which usually had less income than male headed ones (Schoepf, 1988; Ulin, 1992; van der Vliet, 1984). For many women, sexual relationships with men became a valuable source of income, as sexual exchange frequently involved the transfer of material resources (Bassett & Mhloyi, 1991; Caldwell, Caldwell & Quiggin, 1989; Schoepf, 1988; Standing & Kisekka, 1989). The implication of this was that women might come to rely on a number of sexual partners and that for financial reasons they would be less likely to be able to insist on the use of condoms, thus increasing their risks of HIV infection (Caldwell, Orubuloye & Caldwell, 1990; Larson, 1990; Schoepf, 1988).

In South Africa, researchers on migrancy agree on the potential impact of this practice on HIV transmission, but they have different opinions on the extent of networking and risk behaviour (Abdool Karim *et al.*, 1992; Head, 1992a; Ijsselmuiden *et al.*, 1990; Jochelson *et al.*, 1991).

There are other implications of poverty for the spread of HIV. Lack of material resources directly affects health status, so that malnutrition, stress and susceptibility to TB lead to diminished immunity. This increases the risk of HIV infection (Head, 1992a; Packard & Epstein, 1991). Furthermore, poverty frequently results in limited access to health care, as well as reduced access to education and employment. All of these factors are likely to result in minimal exposure to AIDS education as well as care for those already infected (Danziger, 1989; van den Boom & Gostin, 1992). As discussed above, it is women who are more likely to suffer these consequences of poverty and thus be at increased risk of infection.

However, some writers have cautioned against an over-simplistic analysis of economic factors in the political economy of Africa generally (Stamp, 1989), and in approaching the AIDS problem. Firstly, many studies have found that it is in fact women of higher economic status who become HIV-infected (Edwards, 1992; Gwede & McDermott, 1992; Lindan *et al.*, 1992; van den Boom & Gostin, 1991). It has been suggested that it is the wives of men who are more affluent, more mobile and thus more likely to be able to pay for sexual favours, who are first infected (Larson, 1990).

Also, women in single headed households are not necessarily less able to negotiate safe sex because of greater financial need. While for some women single status is unavoidable, others are increasingly choosing not to marry because they argue that this strengthens their economic situation (Jaffe, 1991; Ramphele & Boonzaier, 1988; Mayer, 1971; Schoepf, 1992; Stamp, 1989). These women may in fact be in a better position to insist on condom use. It is necessary too to acknowledge that women do not only have multiple sexual partners for material benefits (Orubuloye, Caldwell & Caldwell, 1990; Pickering, Todd, Dunn, Pepin & Wilkens, 1992). Some may choose to do so for pleasure, and it is after all not numbers of partners but specific sexual practices which increase risk of infection.

In addition, a too narrow focus on economic factors may lead to limited attention being paid to the often contentious issue of traditional culture and the ways in which it is mobilised to perpetuate control over women (Ramphele, 1989; Stamp, 1989; van der Vliet, 1991). In the light of this, there have been calls for male sexuality to receive a greater research focus (Ankrah, 1991; SWAA, 1991), and if necessary, legislation to alter existing practices:

The unassailable facet of African culture, the customary and legal right of males to unlimited numbers of partners, according to his wishes, should now be questioned as a value, because the heterosexual pattern of transmission puts all African men who have multiple partner sexual encounters at risk of HIV. Where culture and tradition, including polygamy, no longer advance a people, these should be jettisoned. In societies where (sic) the single legal partner status dominates, it is with the foundation and enforcement of the law. It is unlikely that the male will voluntarily surrender the privilege of having many sexual partners (Ankrah, 1991, p. 972).

Commercial Sex Work

Mention has already been made of the focus on prostitutes as vectors of HIV infection (Campbell, 1990; Jones & Catalan, 1989). Despite depictions of such women as inevitably being contaminated and infective, actual rates of infection vary enormously (Leonard & Thistlethwaite, 1990; Mantell *et al.*, 1988). A number of studies have in fact found that they are not necessarily at greater risk than other women, and have often responded well to education initiatives (Alexander, 1990; Jones & Catalan, 1989; Ngugi

et al., 1988; Shaw, 1988; Tavanyar, 1988). However, poor women, who are understandably under pressure not to refuse client demands for unprotected sex, are more likely to be at risk, as are women IVDUs, especially users of crack (Anastos & Marte, 1989; Campbell, 1990; Mantell *et al.*, 1988; Schoepf, 1993; Tan, deLeon, Stoltzfus & O'Donnell, 1989). As a result, condom use also varies, and frequently even those CSWs who use condoms consistently with clients do not do so with regular partners (Leonard & Thistlethwaite, 1990; Ray, 1990; Tavanyar, 1988).

There has been considerably less attention paid to the needs and problems (like violence and discrimination) of sex workers, and very seldom has the focus been on their clients (Herasme, Pareja & Bello, 1991; Pauw, 1993; Velten, Kleiber & Jacobowski, 1991). Moreover, early constructions of AIDS as a problem of others, oversimplified the boundaries of commercial sex and failed to recognise the variety of forms and circumstances of sexual exchange for many women struggling to survive with limited resources. For example, a focus on the sex tourism industry of countries like Thailand and the Philippines did not recognise the high rate of sex with prostitutes among local men (Ford & Koetsawang, 1991; Tan *et al.*, 1989). Standing (1992, p. 479) has argued for greater nuance in approaching the issues:

What is needed is to develop, for a given context, a theory of sexual exchange which can account for the circumstances under which individuals exchange particular kinds of resources for sex and the terms upon which these are exchanged. This would allow non-marital, marital, extra-marital and commercialised sexual exchanges to be understood in relation to each other as part of the wider spectrum of exchanges between the sexes.

Pickering *et al.* (1992) have pointed out in this regard that sex workers also engage in prostitution for other than economic need. There are clearly complex issues associated with any analysis of commercial sex work and AIDS (Posel & Posel, 1991), which do not fall within the scope of this study, except as they relate to broader concerns with prevention.

Reproductive Issues

As has been mentioned above, one of the painful aspects of the AIDS problem for women is the fact that they can transmit HIV to infants peri- or post-natally. This again has often led to a focus on women primarily as reservoirs of the disease, rather than in terms of their own needs and problems (ActUp, 1991; Anastos & Marte, 1989; Carovano, 1991; Erben, 1990; Wiener, 1991).

However, this reality raises complicated and often contradictory issues for women regarding reproduction. Once the possibility of perinatal infection was established, the recommendation by the Centres for Disease Control (CDC) and other researchers was for women to avoid pregnancy in order to prevent such infection (Bayer, 1990; Berrebi, Kobuch, Puel & Tricoire, 1990). However, in the absence of a vaccine, this is only a temporary measure, and so places considerable constraints on women. The suggestion of mandatory testing for women wishing to fall pregnant has also raised concerns (Bell, 1989; Franke, 1988; Marte & Anastos, 1990; Patton, 1989; Stevens, Victor, Sherr & Beard, 1989).

In many societies, childbearing is associated with positive social status and indications of worth, especially for women traditionally deprived of much social power (Anastos & Palleja, 1991; Arras, 1990; Levine & Dubler, 1990; Worth, 1989). Moreover, this is not a decision over which women may always have control (Anastos & Marte, 1989; Richardson, 1990).

In addition, it has been suggested that women who are identified as HIV+ should be advised to undergo sterilisation or an abortion if already pregnant. This form of directive counselling, in the face of a tradition of non-directive counselling in reproductive matters, raises many thorny issues. Firstly, both sterilisation and abortion may pose serious moral dilemmas for women (Arras, 1990). Also, the illegality of abortion in some countries produces further obstacles to this option (Levine & Dubler, 1990; Richardson, 1990). Access to adequate health care facilities for the carrying out of such procedures too is a problem for many women (Arras, 1990; Levine & Dubler,

1990). However, there are other more disturbing dimensions to the problem. Most of the women worldwide who are at risk of HIV infection belong to minorities: IVDUs, sex workers, women of colour in the USA and women in developing countries. The call for sterilisations occurs in the context of the history of forced sterilisation and family planning within such communities, and understandably therefore is likely to be viewed with suspicion (Levine & Dubler, 1990; Richardson, 1990). Furthermore, given the strong pro-life lobby in many western countries in recent years, the ease with which abortions are now being recommended for minority women is cause for concern (Bayer, 1990; Campbell, 1990; Marte & Anastos, 1990). For feminists this is an active challenge to the reproductive rights and freedom of women (Bayer, 1990; Chowdhury, 1991; Hollis, 1992).

It appears that for most HIV+ women, knowledge of their serostatus does not in fact influence decisions about sterilisation or abortion, even after directive counselling (Arras, 1990; Denenberg, 1990; Strebel, 1993a). Given the fact that about one third of infants of infected women will become HIV+, the choices women make need to be understood in relation to other considerations (Levine & Dubler, 1990; Marte & Anastos, 1990). Finally, it is significant that most of the debate around reproductive choices focuses only on the behaviour of women and excludes men's responsibility in decision-making (Kurth & Hutchinson, 1990; Sherr, 1993).

A further dimension to the issue of women and reproduction is the fact that for women of childbearing-age who wish to fall pregnant, use of condoms to avoid HIV infection is not a viable option (Denenberg, 1990; Ulin, 1992). There is therefore an urgent need for the development of methods to prevent HIV transmission which do not inhibit conception (Carovano, 1991; van den Boom & Gostin, 1992).

Women in Research

Despite the fact that women make up an increasing number of those infected with HIV, they remain at a disadvantage regarding diagnosis, treatment and care. Rosser (1991) has attributed this to the pervasive male bias in science and medical research.

Generally funds have been limited for research into women-related aspects of AIDS, except when it concerns their role as vectors of vertical transmission. The CDC case definition of AIDS has still based on symptoms as they present in males (ActUp, 1991; Anastos & Marte, 1989). As a result the manifestations and progression of the disease in women are not well understood and gynaecological conditions are not always recognised (ActUp, 1991; Hankins & Handley, 1992; Rosser, 1991). This has led to the late diagnosis of HIV infection and the under-reporting of AIDS cases among women (Anastos & Marte, 1989; Duke & Omi, 1991; Hankins & Handley, 1992; Kurth & Hutchinson, 1990). Moreover, women are frequently not included in drug trials, so that they are less likely to have future access to appropriate vaccine and treatment options (ActUp, 1991; Levine, 1990; Rosser, 1991; Wiener, 1991). There has also been little focus on the development of prevention methods like spermicides which women can control (Gollub & Stein, 1992; Stein, 1990; Voeller, 1992). Finally, ethical issues involving research on women in Africa have been raised, with concern that adequate informed consent is frequently not being sought (ActUp, 1991; Ijsselmuiden & Faden 1992).

Hankins & Handley (1992, p. 967) stress what must be done to rectify the situation:

A concerted effort on the part of clinicians, researchers, funding agencies, and decision-makers is required for redressing the inequities in both the gender-specific knowledge of the natural history, progression, and outcome of HIV disease and the adequacy of medical and psychosocial care for women with HIV infection. The unique features of HIV infection in women have been subject to both scientific neglect and policy void, situations that can and should be rectified with dispatch.

Women as Care Givers

Another significant impact of the AIDS epidemic on women is in their capacity as care givers. It is widely recognised that women are the majority of those in health care roles, both in the formal health sector, where they constitute about 75% of the health services labour force, and informally in the community and at home (Jones & Catalan, 1989; O'Neill, 1988; Panos, 1990). It is also sometimes assumed that this is the '*natural*' task of women as nurturers (AVERT, 1990), and is reflected in the range of motherist

organisations found in parts of Africa (Wells, 1991). There are a number of implications of this situation. Firstly, women usually must add the load of caring for infected family to their already substantial duties in the domestic and formal employment spheres (Schoepf, 1991). These women may themselves also be HIV infected, but because of their many responsibilities may neglect to care for their own health needs (Campbell, 1990). Home care has become a recognised and important part of the management of people with AIDS, and relieves the burden on the often under-funded formal health service (Chaava, 1990). However, in the absence of adequate support being provided, this often leads to exploitation of community and extended family resources (Panos, 1990). Furthermore, with little power to demand the necessary financial and emotional support, many women become isolated and over-extended. They may also have to deal with the stigma of having a person with AIDS in the family (AVERT, 1990; Campbell, 1990).

Sexual Violence

An additional dimension of AIDS as a problem for women is the role of sexual violence and risk of infection. Generally there has been very little focus on sexual violence in research on sexuality throughout Africa (Standing & Kisekka, 1989). More specifically, women who are sexually harassed or raped face the possibility of HIV transmission from an infected assailant (Berer & Ray, 1993; Ehrhardt, 1988; Murray, 1991; Richardson, 1987; Schoepf, 1993; Tapping, 1991). Another facet of violence toward women is that, given their limited power in gender relations, there is the danger that women who refuse sex or insist on condom use or fewer partners may face domestic violence (Anastos & Palleja, 1991; Legion, 1992; Strebel, 1992).

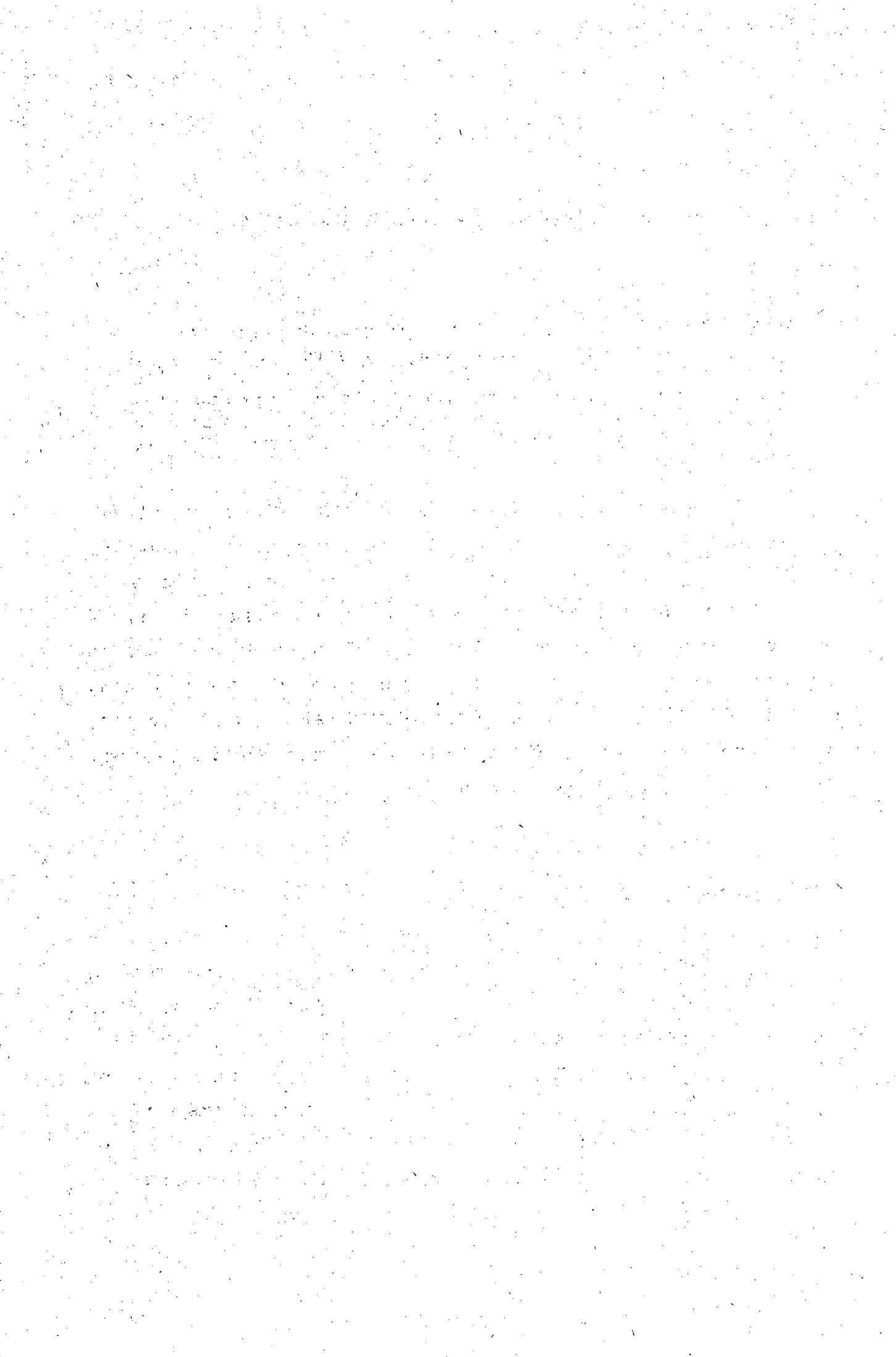
IMPLICATIONS

From the above overview of literature, it is apparent that AIDS poses a problem of considerable magnitude for countries worldwide. The extensive research that has been conducted thus far indicates that there has been manifest progress in the biomedical

sphere regarding knowledge of transmission and the natural history of the Human Immunodeficiency Virus. As a result, a vaccine is expected to be available in the next few years and treatment options have become increasingly sophisticated.

However, as we have seen, this is only one dimension of the AIDS problem. Given its emergence within a specific historical, social and cultural context, the disease also embodies a range of powerful symbols and meanings which influence how individuals and societies understand and respond to it. A central feature of these social constructions of the disease has been the stigmatisation of those infected with the virus. Thus, it is not a condition which is readily acknowledged, making appropriate and effective care of people with AIDS extremely difficult. Furthermore, the fact that most transmission occurs as a result of intensely private or even illegal behaviour makes appropriate and effective prevention also not easy.

It is further evident that for women the disease poses particular medical problems and psycho-social dilemmas, which seem to suggest the need for specific attention and interventions. In the light of what is known and understood about the disease, it is imperative to consider the type of responses which are required to curb spread of the virus and to ensure successful management of its consequences. This will be the focus of the following section.



CHAPTER TWO

RESPONSES TO THE PROBLEM

Whilst AIDS is a serious debilitating disease which demands concern, attention, funding, research and care, it is also a profoundly symbolic event harbouring hosts of new practices, many of which may not be quite as benign as they appear: a medical profession that may control rather than cure, a government that may regulate rather than educate, a media that may disinform rather than inform and a public that may scapegoat rather than understand (Plummer, 1988, p. 47).

In the light of what is presently known medically about AIDS together with our understandings of the social meanings of the epidemic, it is necessary to consider what the responses to the problem have been. This is important to ensure that intended research and interventions are responsibly and appropriately selected and implemented. This section will address these issues. Firstly it will focus on what the policy responses to AIDS have been, from governments and from non-governmental organisations (NGO). Then it will review what has been done in the realm of prevention by assessing health education initiatives. Finally, it will examine what the responses have been to the specific issues for women.

POLICY RESPONSES

In the USA, despite rapid growth of the epidemic and early biomedical research, overall official responses were slow to get off the ground and often hampered by moralistic sentiments and reluctance to tackle sex education (Earickson, 1990; Krieger & Appleman, 1986; Weeks, 1988). This seems to have been because those most affected by the disease belonged to minority groups (Panos, 1988; Shilts, 1987). As was described in the previous chapter, many felt that HIV infection was the just consequence of deviant and immoral behaviour. In addition, because it was predominantly sexual behaviour which needed changing, early prevention messages

focused on messages of sexual control, like monogamy and abstinence, rather than open and direct discussion of safe sexual practices (Brandt, 1985; Weeks, 1988). Another feature of early stages of the epidemic was reluctance on the part of government to direct the necessary funds towards research, care and education (Earickson, 1990; Krieger & Appleman, 1986; Patton, 1985).

A central concern in approaching the AIDS problem has been the tension between issues of **the public good** as opposed to **individual responsibility**. This has involved consideration of public health approaches (as utilised in family planning and STD management) compared to issues of civil rights and liberties of individuals (Bayer, 1989).

On the one hand, public health initiatives have often involved the identification of those infected and attempts to control their spreading the disease further. Some examples of this approach regarding AIDS were the early controversy over whether to legislate closure of the bath-houses frequented by gays, whether to require reporting of identified AIDS cases and the right of HIV+ individuals to confidentiality of diagnosis (Bayer, 1989, 1992; Krieger & Appleman, 1986; Patton, 1985). A central issue was the need for large scale or mandatory testing to identify those who posed a health hazard. Those not yet infected could then be protected from risk of infection: either by encouraging HIV+ people to take the necessary prevention steps, or more extremely by isolating those infected or placing them in quarantine (Bayer, 1989; Brandt, 1988b; Earickson, 1990; Gilman, 1990). There were understandable concerns that this could lead to forms of discrimination which would cause those infected or at risk to avoid any contact with prevention or care services. Discrimination and victimisation of people with AIDS has in fact occurred on a large scale. Many have been denied access to schooling or housing (Cape Times, 6/5/93; Krieger & Appleman, 1986; Patton, 1985). Immigration, travel and tourism have been restricted (Panos, 1988, 1991; Sabatier, 1988). Employment has been jeopardised, HIV+ workers dismissed and insurance cover refused (Panos, 1988; Weeks, 1988). And in prisons, those identified with the virus have been isolated and denied adequate health care (Earickson, 1990; Olivera, 1991).

However, this is not to argue that voluntary or informed consent testing is not an important aspect of AIDS control. Because of recent advances in treatment options there has been renewed focus on the advantages of early identification of infection (Bayer, 1992; Watney, 1990).

Opposition to the public health strategy has emphasised the importance of civil rights generally and the specific need for protection of people with AIDS. Although they were also slow to take up the issue of AIDS initially, it was gay activists who first responded to government initiatives, or the lack thereof (Plummer, 1988; Shilts, 1987; Wachter, 1992b; Weeks, 1988). There were a number of factors which contributed to this reluctance, as Wachter (1992a, p. 128) describes:

The reasons for this early resistance to more aggressive forms of political activism included denial, a fear of losing the hard-won sexual freedom gained during the 1970s, and concern that a vigorous gay response to the epidemic would unleash a surge of homophobia.

These gay AIDS activists have had an enormous impact on AIDS policy. They have been successful in increasing allocation of funds to AIDS work and access to drug trials, and in having the price of the antiretroviral drug AZT reduced (Wachter, 1992b), and have also lobbied strongly against mandatory testing (Patton, 1990a). These achievements can be understood against the background of the trend towards increased patient involvement in health matters generally in the USA since the 1970s, as well as the well organised and politically literate and experienced gay movement. The inclusion of people living with AIDS in the campaigns also strengthened their impact on AIDS researchers and clinicians (Patton, 1990a; Wachter, 1992a).

However, more recently there have also been criticisms of AIDS activism. One concern has been the relative emphasis placed on AIDS at the expense of other pressing health problems, especially as the expected surge of HIV infection among heterosexuals has not occurred in developed countries (Bayer, 1992; Wachter, 1992a). Secondly, it appears that the focus of much lobbying has been on treatment issues rather than education and that gay activists have failed to broaden their approach to include the plight of other minorities (Patton, 1990a; Wachter, 1992a).

In this regard, there has been particular concern about the extent of the problem in Africa and other developing countries (Bayer, 1992; Earickson, 1990; Wachter, 1992a; Weeks, 1988). Here it has been the WHO which has been most actively involved. Since the WHO Global Program on AIDS was established in 1987, 176 countries have started reporting AIDS cases and 151 have national AIDS structures in place. In Africa, although there initially were high levels of denial at government level, all but two countries are involved in these education, surveillance, research and care initiatives (Bowman, 1989; Goldsmith, 1988; Panos, 1988; Okware, 1987; Sabatier, 1988).

SOUTH AFRICA

Responses to the problem of AIDS in South Africa have been similar to those elsewhere, although coloured by the particular political complexities of the country currently. Initially there was considerable denial of the reality of the problem, with different groups alleging that others were at risk and not themselves (Sadie & van Aardt, 1992). It was gay organisations which first acknowledged that AIDS was an issue for their members and began prevention and counselling work (Perlman, 1988).

Although the spread of the epidemic was slower in South Africa than in most other African countries, predictions were that AIDS would assume the same critical dimensions here. However, despite this forewarning and precious time available to establish AIDS prevention programmes, official responses from the South African government were slow and limited (Cape Times, 3/12/92; Crewe, 1992; Head, 1992b; Holmshaw, 1992; Zwi & Bachmayer, 1990). Funds allocated for AIDS work were also grossly inadequate (Head, 1992b; Perlman, 1988; Sadie & van Aardt, 1992). Legislation was introduced in 1987 which allowed for the testing and repatriation of foreign mineworkers, as well as making mandatory testing and detention of HIV+ people possible (Critical Health, 1988; Sadie & van Aardt, 1992; Zwi & Bachmayer, 1990).

There have been many other criticisms directed at these early government efforts. Firstly, the structures which were set in place were considered inadequate and poorly managed, with internal conflicts, changes of staff and claims of financial irregularities

(Gevisser, 1992; Holmshaw, 1992; Sadie & van Aardt, 1992). Media awareness campaigns were seen as racist and moralistic (Crewe, 1992; Perlman, 1988; Toms, 1990). For example, safe sex messages were perceived by blacks to have associations with past population control programmes (Toms, 1990; Workplace Information Group, no date). No condom advertisements were permitted, sex education videos were banned for being too explicit and there was reticence to introduce AIDS education in schools (Crewe, 1992; Head, 1992b; Gevisser, 1993a). When a government-sponsored AIDS education package was eventually introduced into schools in 1992, it was withdrawn soon afterwards, after negative responses from many quarters (Sadie & van Aardt, 1992; Everett, personal communication, 10/6/93).

Criticisms have come from both sides of the political spectrum. Right-wing political groups claim that it is the government's policy of negotiation and political transformation which has been responsible for the spread of AIDS in South Africa (Crewe, 1992; Sadie & van Aardt, 1992). On the other hand, mass-based political and community organisations stress that it has been the racist and economic policies of apartheid which have exacerbated the problem in South Africa (Perkel, 1992; Sadie & van Aardt, 1992). As a result, the state is seen as lacking the political credibility to respond adequately to the problem (Crewe, 1992; Maputo Statement on HIV and AIDS in Southern Africa, 1990; Perlman, 1988; Sabatier, 1988; Toms, 1990). The African National Congress (ANC) spelt this out more fully at an AIDS seminar in Lusaka (ANC, 1990):

The regime has neither the will nor the capacity to deal with the AIDS problem in any meaningful way. Whatever attempts it makes lead to denial, increased anxiety and suspicion. AIDS is a political issue in our country and as such all programmes related to it must be encouraged, especially those managed and controlled by the democratic formations of our people.

Furthermore, government initiatives have failed to include community organisations or to consult with extra-parliamentary forces. They also are hamstrung by the fragmentary nature of apartheid health structures (Perlman, 1988; Sadie & van Aardt, 1992). Moreover, there were accusations that the government was responsible for an anti-ANC AIDS smear campaign, which maintained that ANC soldiers were spreading the virus (Jochelsen *et al.*, 1991; Workplace Information Group, no date).

Responses from opposition political organisations have involved challenges to state AIDS interventions, as described above. They have also recognised the seriousness of the problem, spelt out guidelines for a broad-based initiative which located AIDS within the struggle for socio-political change, and called for the establishment of a national AIDS task force (ANC, 1990; Maputo Statement, 1990). However, these early responses were not followed by much concrete action. This has been explained in the light of the escalating political crisis and violence which have relegated AIDS to an understandably lesser priority in the eyes of many (Crewe, 1992; Perlman, 1988; Sadie & van Aardt, 1992; Toms, 1990). In addition, although many community organisations have developed educational materials and policy documents, AIDS is also not seen as an issue high on the political agenda for many (Critical Health, 1988).

However, there are indications that the situation is improving. Restructuring of government bodies has led to the formation of a new AIDS Programme within the National Health Department, which seems to have taken cognisance of previous criticisms and has a stronger focus on community-based involvements (Gevisser, 1992; McGarry & Haddon, 1993; Steinberg, 1992). A National AIDS Convention of South Africa (NACOSA) was convened in October, 1992, which brought together government and other relevant organisations for the first time. Although this initial meeting was marked by considerable disagreement, it did resolve to draft a National AIDS Strategy and has strong representation of the ANC in its structures (Medical Research Council, 1993; Gevisser, 1992; Rudden, 1993). In addition, an AIDS Charter has been launched which has been widely supported, although not by government. As a result, many companies which previously screened potential employees have now dropped this practice (Crewe, 1992). While there has been at least some training of teachers and AIDS education in white and Coloured schools, a mandatory AIDS curriculum has only now been introduced into African schools (Everett, personal communication, 10/6/93; Gevisser, 1993b). There is guarded optimism that these positive steps will go some way toward tackling the considerable problem of AIDS in South Africa.

HEALTH EDUCATION RESPONSES

As no vaccine or cure is yet available, it is generally agreed that prevention is a central component of responses to AIDS. Although other strategies like the control of STDs and treatment of IVDUs are recognised as playing a role in such prevention, it is health education which is regarded as the essential means of slowing spread of the disease. As a result, most countries in the world have embarked upon national and community AIDS education programmes of differing scope, content and effectiveness, and there is a growing academic and popular literature in this field. Many of the projects have seemed to be rather hastily introduced, in response to the obvious urgency of the problem. Few are based on a clear theoretical conceptualisation of the problem and fewer still have been adequately evaluated (Aggleton, 1989; Leviton, 1989; Schopper, 1990).

In order to ensure that AIDS education initiatives are not merely well-intentioned but also appropriate and effective, rigorous research is needed. This is especially pertinent in South Africa at present, where the relatively early stage of the epidemic makes prevention especially important. This section, therefore, will give an overview of current findings in the realm of health education, by considering some of the major approaches to health education, reviewing the criticisms of these models, and highlighting the implications for future programmes.

HEALTH EDUCATION MODELS

While there are education initiatives which clearly are built upon or designed to test a particular theory, many draw on more implicit assumptions of how the process occurs. It is therefore quite difficult to get a comparative idea of the overall picture. Leviton (1989) has provided a useful classification of the various theories and applications into five categories:

- cognitive and decision-making theories, including the Health Belief Model and the Theory of Reasoned Action;

- learning theories, including operant conditioning, social learning and self-efficacy theories;
- theories of motivation and emotional arousal, including theories of fear arousal;
- theories of interpersonal relations, including group processes;
- theories of communication and persuasion.

It is particularly models which focus on individual behaviour, falling into the first three above categories, which have been applied to AIDS education. Some of those will now be reviewed briefly:

The Theory of Reasoned Action approach is based on the assumption that humans act rationally in making choices, so that changing behaviour requires shifts in related cognitive structures. It aims to explore the links between knowledge, attitudes and beliefs, intentions and behaviour (Ajzen, 1988; Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975; Fishbein & Middlestadt, 1989). It postulates that behaviour can be predicted from intentions, and that intentions in turn are influenced by attitudes to the behaviour, beliefs about the behaviour, perceptions of subjective norms (what significant others think about the behaviour) and the value the person places on approval of others (Leviton, 1989). The model has been used widely in other health contexts, with mixed results: links between knowledge, attitudes and behaviour have proved tenuous, but those between attitudes and subjective norm, and intentions have been stronger (Leviton, 1989; Pagel & Davidson, 1984; Salazar, 1991). In the field of AIDS education, dozens of knowledge, attitudes and practices studies have been undertaken. Although the association between these variables has proved consistently weak, there have been some encouraging findings, especially between attitudes and intentions to implement safe sex and between past behaviour, intentions and behaviour (Beaman & Strader, 1989; Gallois, Kashima, Hills & McCamish, 1990; Jemmott & Jemmott, 1991; Rosenthal, Moore & Boldero, 1991). However, many researchers of this model now recognise that behaviour is not only influenced by rational choices and that an effective approach needs to include a broader range of psychosocial and

interactional factors (Ajzen, 1988; Fishbein & Middlestadt 1989; Kashima, Gallois & McCamish, in press; Perkel, 1991; Rosenthal *et al.*, 1991).

A dominant approach among health workers has been the **Health Belief Model**, which developed within applied practice, although it was influenced by the work of Lewin (Kirscht & Joseph, 1989; Salazar, 1991). Four central components of the model are: perceived susceptibility to a negative health condition, perceived severity of the condition, perceived effectiveness of protective strategies and perceived barriers to effective action (Kirscht & Joseph, 1989; Leviton, 1989). In order to change behaviour then, the individual has to change her/his beliefs, and this is thought to happen as a result of providing relevant information (Simon & Das, 1984). The element of perceived susceptibility has received particular attention, with attempts to prove an association between perception of personal risk and safer sex yielding mixed results (Catania, Kegeles & Coates, 1990; Kirscht & Joseph, 1989; Valdiserri, 1989; Weinstein, 1989). However, overall this approach also has had limited success in bringing about appropriate safe sex behaviour. This has been attributed to the fact that it too focuses on individual rational choices and does not account for the varied range of factors associated with behaviour change (Freudenberg, 1984; Leviton, 1989; Perkel, 1991; Salazar, 1991).

The concept of **Self Efficacy**, which emerged as significant in the health belief model, developed within the social learning theory of Bandura. It claims that a person's perception of her/his ability to exert control over motivations, behaviour and the social environment is important in implementing behaviour change. Four major components are involved: information, development of skills, consolidation of skills and social support. Important in this process are the use of role models and the provision of practical skills (Bandura, 1989; Leviton, 1989). While self-efficacy is not considered to be sufficient to bring about safe sex practices, it is regarded as a significant variable (Kashima *et al.*, in press; Nyamathi, Schuler & Porche, 1990; Perkel, 1992; Salazar, 1991; Simon & Das, 1984).

Fear arousal has often been a central aspect of information-giving in health education. Again here results are ambiguous, with evidence for both functional and dysfunctional effects of fear in changing behaviour. Overall, however, it is considered a risky approach, as it increases anxiety and can produce anger, denial or helplessness (Hubley, 1988; Leviton, 1989; Perkel, 1992; Sherr, 1990).

As is evident from the above, health education has not delivered one single model to account for the multiplicity of variables involved in AIDS prevention behaviour. Many researchers have attempted instead to combine elements of different theories to produce a more nuanced, wide-ranging psychosocial approach (Allensworth & Symons, 1989; Basen-Engquist, 1992; Catania *et al.*, 1990; Perkel, 1991; Solomon & DeJong, 1989).

A number of strong criticisms have been directed more generally at these various approaches to health education. The fundamental issue has to do with their basic assumptions, which are thought to reflect a biomedical understanding of health as the result of individual actions. It is the individual who must make choices to avoid ill-health and it is the individual who is to blame for her/his inability to undertake this responsibility. Such an approach leaves the ideological status quo in tact. On the other hand, a transformatory model of health locates individual health or illness within broader societal and structural contexts. It recognises the multiple influences on health and requires responses at the structural, legislative, organisational, community as well as individual level (Aggleton, 1989; Becker, 1986; Brandt, 1988b; Freudenberg, 1984, 1990; Homans & Aggleton, 1988; Minkler, 1989; Valdiserri, 1989). Homans & Aggleton (1988) have provided a useful classification of health education strategies along such a continuum, by identifying four paradigms:

- **behaviour change** models reflect a biomedical understanding of health and rely on experts to provide information, which is usually not effective in changing behaviour;
- **self-empowerment** models focus on skills development, awareness-raising and participatory methods to enhance choices and action, but they often overlook systemic inequalities and structural barriers to personal power;

- **community-orientated** approaches recognise the need for collective action in tackling health problems, and while successful in bringing about behaviour change in some groups, often fail to problematise notions of community and fail to address policy and legislation issues;
- **social transformatory** approaches aim to bring about far-reaching social changes through challenges to power inequalities in society, and focus on four aspects: dominant ideas, social relations, political processes and allocation of resources.

LESSONS FOR AIDS EDUCATION

What are the lessons for AIDS prevention strategies which can be extracted from this extensive literature on health education? Firstly, as has been mentioned above, most researchers recommend a multi-faceted approach, in order to reach the wide variety of behaviours, thoughts and emotions involved in avoiding HIV infection. Many education projects have been implemented which draw on aspects of different models as part of comprehensive strategies with particular target groups (Jemmott, Jemmott & Fong, 1992; Kelly, St Lawrence, Hood & Brasfield, 1989; Magura, Shapiro, Grossman & Lipton, 1989; Mohanty, Bashier & Allen, 1988; Nyathi, Wilson, Lamson, Nharuwa & Weir, 1991; Solomon & DeJong, 1989; Williams, 1986). There is also consensus that it is essential to adopt a grassroots approach which involves the relevant community at all stages (Anderson *et al.*, 1990; Duke & Omi, 1991; Freudenberg, 1990; Profumo, 1991; Williams, 1986). Furthermore, AIDS education should not be tackled as an isolated issue, but linked to other health and community concerns (Cates & Bowen, 1989; Freudenberg, 1990). It has often been helpful to address AIDS issues in terms of social responsibility (Kelly *et al.*, 1989; Mays & Cochran, 1988a; Nyamathi *et al.*, 1990). Furthermore, it is suggested that interventions will be most effective if located within broader political struggles for social transformation (Freudenberg, 1990; Homans & Aggleton, 1988; Maputo Statement, 1990).

Together with this social contextualisation of AIDS, educators recognise the importance of presenting messages in credible and accessible ways. A nuanced understanding of the culture and language of the target group is crucial (Airhihenbuwa, di Clemente,

Wingood & Lowe, 1992; Cohen et al., 1989; Flaskerud & Nyamathi, 1990; Freudenberg, 1990; Hu, Keller & Fleming, 1989; Marin, 1989; Siegel & Gibson, 1988). Work has also been done on the role of lay health beliefs and the need to incorporate these into AIDS education efforts (Butchart, Terre Blanche & Mgoduso, 1991; Fitzpatrick, 1984; Flaskerud & Rush, 1989; Warwick, Aggleton & Homans, 1988). Moreover, the use of educators who are perceived by the target group to be credible is important. This might in some instances be those who are perceived to be influential or role models, or else insiders to their circumstances, as in women educators for women (Siegel & Gibson, 1988; Solomon & DeJong, 1986; Nyamathi *et al.*, 1990; Williams, 1986). Peer educators have often made valuable contributions, for example among gays and sex workers (Kelly *et al.*, 1989; McCombie, Bukombi & Rwakagiri, 1991; Tan, *et al.*, 1989; Valdiserri *et al.*, 1987). The need for appropriate training of educators to carry out the complex range of tasks involved in effective education is clear (Freudenberg, 1984; Minkler, 1989).

Another aspect of prevention work has been the challenge of reframing safe sex from unacceptable, unappealing and limiting behaviour into socially desirable, normative and sexually pleasurable options. Especially the image of condoms needs attention, with social marketing having a role to play (Ostfield, Fevier, Jagdeo, Cole & France, 1991; Solomon & DeJong, 1986; Valdiserri, 1989; Watney, 1990). In addition, condoms must be readily available and affordable if they are to be used with the necessary regularity (Ngugi *et al.*, 1988; Solomon & DeJong, 1989).

Many education programmes have made use of group settings, which are often more economical, allow for interactive learning and enhance the notion of safe sex as interpersonal behaviour (Anderson *et al.*, 1990; Herasme *et al.*, 1991; Konde-Lule, 1988; Magura *et al.*, 1989). Related to the idea of not working only with individuals has been the suggestion that perhaps the most important variable in adopting safe sexual behaviour is the ability to talk about sex comfortably to partners (Kashima *et al.*, in press; Siegel & Gibson, 1988; Watney, 1990).

Understandably, the need for rigorous evaluation of AIDS education is essential, although depicting the disease as epidemic and therefore a crisis has often resulted in over-hasty interventions (Aggleton, 1989; Schopper, 1990; Valdiserri, 1989).

Thus, much has been done in response to AIDS in the field of prevention. And, although no neat blue-print has been developed, much has clearly been learnt. However, despite recognition of the complexity of psychological, social and political factors which surround AIDS, most interventions still seem to rely rather heavily on information to change individual behaviour. Also, the evidence for the effectiveness of various strategies remains elusive. Finally, amidst the barrage of suggestions and recommendations for the 'how' of AIDS prevention, it seems timeous to return to Freudenberg's (1990, p. 597) conception of the problem as more than just the limiting of the exchange of bodily fluids, but as an opportunity to connect '*with a vision of a better world*'.

RESPONSES TO AIDS AS A PROBLEM FOR WOMEN

As was outlined in the previous chapter, there is a growing recognition of the ways in which AIDS raises particular issues and problems for women. While it is simplistic to assume that women share a common position or uniform set of experiences in society (McDonald, Kleppel & Jenssen, 1990), many writers feel that their concerns have been largely ignored in responses to the epidemic (ActUp, 1990). However, with the increasing incidence of HIV infection among women, this is changing. This section will look at organisational, service and research initiatives in the area of women and AIDS, in both developed and developing countries, with a particular focus on South Africa. It will include a detailed assessment of two projects on women and AIDS in South Africa.

Firstly, at the international level, a variety of women-related projects have been initiated and specialist working groups have met to tackle AIDS as it affects women, and which have identified priority areas in prevention, care and research for women. For example,

The International Conference on the Implications of AIDS for Mothers and Children, was convened in Paris in 1989; the United Nations co-ordinated an **Expert Group Meeting on women and HIV/AIDS and the role of national machinery for the advancement of women**, which was held in Vienna in September, 1990; and the WHO GPA also hosted a **Meeting on research priorities relating to women and HIV/AIDS** in Geneva in November, 1990; while the UK NGO AIDS Consortium organised a conference on **Women and AIDS in developing countries**, also in 1990. This was followed by the 1990 World AIDS Day focus on women, and the focus on women at the Eighth International AIDS Conference in Amsterdam in June, 1992 (CDC, 1991; van den Boom & Gostin, 1992). Other initiatives include the development of community-based organisations, like the Women's Caucus within the AIDS Coalition to Unleash Power (ActUp), which aims to identify the particular needs of women from a feminist perspective, and to promote grassroots activism around issues of diagnosis, treatment and research (ActUp, 1990; CDC, 1991). Books documenting women's experience of AIDS have also been published (AVERT, 1990; Kaleeba, Ray & Willmore, 1991; Rieder & Ruppelt, 1989), and the **International Community of Women Living with HIV/AIDS** was established in July, 1992.

In the USA and Europe, there has been growing acknowledgement of the need for a specific focus on women (ActUp, 1990; Duke & Omi, 1991; Fullilove, Fullilove, Haynes & Gross, 1990; McDonald *et al.*, 1990). Much of the work has focused on minority women, especially women of colour and IVDUs or their partners. It is especially the work with African American and latina women which seems relevant for South Africa. A number of studies have reviewed the knowledge, attitudes and practices of these women, while others have implemented and evaluated education programmes.

They stress that minority women's difficulty to adopt safe sex behaviour must not be seen as a lack of will or inability to make rational decisions, but needs to be understood against the complex backdrop of often contradictory positions and forces which shape their understanding and options (Kane, 1990; Worth, 1989). Socio-economic circumstances often result in poverty and unstable relationships for minority women, with many being the head of household and struggling to fill the provider role

(Amaro, 1988; Cochran, 1989; Fullilove *et al.*, 1990; Nyamathi & Vasquez, 1989; Worth, 1989). As a result, they often do not have accurate perceptions of their risk of HIV infection, especially in relation to the other problems which they must face (Carovano, 1991; Kane, 1990; Mays & Cochran, 1988a; Nyamathi & Vasquez, 1989). They are also then often difficult to reach through traditional health service provision (Amaro, 1988; Campbell, 1990; Flaskerud & Nyamathi, 1990), and sometimes show resistance to utilising such services because of feelings of alienation from mainstream approaches (Mays & Cochran, 1987). Moreover, they may lack the resources and context to generate collaborative and supportive networks (Wiener, 1991).

Together with these socio-economic factors, cultural and traditional practices often constrain women's preventative options, although they do not influence women uniformly (Airhihenbuwa *et al.*, 1992; Amaro, 1988; Flaskerud & Nyamathi, 1988; Flaskerud & Rush, 1989). As a result, women frequently lack the power to negotiate effective prevention, are unable to talk easily to partners about sexual matters and seldom use condoms regularly (Amaro, 1988; Ehrhardt, Yingling, Zawadzki, Martinez-Ramirez & Stein, 1991; Fullilove *et al.*, 1990; Mays & Cochran, 1988a; Worth, 1989).

In the light of these problems, educators advocate community-based programmes, which focus on the empowerment of women and collective action (Airhihenbuwa *et al.*, 1992; Amaro, 1988; Duke & Omi, 1991; Fullilove *et al.*, 1990; Shaw, 1988). Moreover, projects need to be culturally and linguistically appropriate, with women educators often preferable (Amaro, 1988; Cochran, 1989; Flaskerud & Nyamathi, 1988; Nyamathi *et al.*, 1990). Finally, some writers have recognised the need to involve men in the process as well (Airhihenbuwa *et al.*, 1992).

In the UK important ongoing research into young women's sexuality in order to develop more appropriate AIDS interventions is under way. This **Women, Risk and AIDS Project (WRAP)** is located within a feminist and social constructionist framework and has involved questionnaire and in-depth interview methods with large numbers of young women and more recently also young men. They have documented how, as a result of gendered power relations, women have difficulty negotiating safer sex. At the

same time they recognise that these women are not without power and actively participate in constructing their conditions. However, they are often confronted with a male-centred discourse of sexuality which requires women to get men to use condoms. The team of researchers advocate the role of empowerment, both at the personal level of condom use, but also at the structural level of altered gender relations (Holland, Ramazanoglu & Scott, 1990a; Holland et al., 1990a, 1991; Thomson & Scott, 1990, 1991). Prevention and care work is also undertaken by a variety of organisations (Berer & Ray, 1993).

In Africa and other developing regions, given the high rates of infection among women as described earlier, AIDS education and care have become an urgent priority. A central feature of responses to these needs has been the establishment of a range of community-based organisations. **The AIDS Support Organisation (TASO)** which was started in Uganda in 1987 aims to provide AIDS-related counselling, information, care and material assistance (Kaleeba, Ray & Willmore, 1991). In Zimbabwe, the **Women and AIDS Support Network (WASN)**, which started operating in 1989, strives to share AIDS information on women, to support women with HIV, and to encourage women in organised groups to support one another in protecting themselves against infection by active participation in wider AIDS initiatives (Kaleeba *et al.*, 1991; Ray, 1992; WASN, 1990). The **Society for Women and AIDS in Africa (SWAA)**, which is an international federation with 27 member countries, was established in 1988 and its goals are: to undertake AIDS prevention and control activities appropriate to African women; to increase AIDS awareness and action among African women; to understand how HIV infection affects the lives of women, children, families and communities and to explore ways of reducing the effects; and to cooperate with government and NGO agencies in controlling AIDS (Akinsete & Harris, 1992).

Clearly such organisations have an essential role to play in AIDS work in Africa. They have contributed to identifying the multiplicity of factors in women's lives which make the implementation of safe sex so difficult. Especially the use of condoms has remained low, despite increased knowledge and greater availability, although there is evidence of some changes (Goldberg *et al.*, 1989; McCombie *et al.*, 1991). For

example, it appears that in urban areas, condoms are increasingly being used in casual and extramarital rather than marital relationships (Schoepf, 1993; Hubley, 1988). In addition, an evaluation of the Ugandan national AIDS programme found that women consistently made less use of written materials than men did (Anderson *et al.*, 1990). These organisations have also provided valuable services in countries lacking resources and the infrastructure to undertake effective AIDS work, especially at the community counselling and care level. However, this approach which seems to be based on the assumption that all this is in fact '*women's work*', has also raised concerns that such an emphasis, drawing as it does on notions of '*the strong women of Africa*', motherism and the positive value of the family (Campbell, 1991; Gillespie, 1984; Wells, 1991), runs the risk of entrenching stereotypes and absolving men of any responsibility in AIDS prevention and care (Panos, 1990; Reid, 1992).

SOUTH AFRICAN RESPONSES

Closer to home here in South Africa, it is only recently that the rapid expansion of the epidemic among women has highlighted the need for a particular focus on the issues they face in dealing with the problem.

Early research showed that while many women were aware of AIDS, they often lacked detailed knowledge and had many misperceptions about the disease (Abdool Karim, Abdool Karim & Nkonakazi, 1991; Cooper, Pick, Myers, Hoffman, Sayed & Klopper, 1991; Strebel & Perkel, 1991a). However, they seldom used condoms (Preston-Whyte, Abdool Karim & Zondi, 1991; Smit & Venter, 1990). In fact, two studies found no condom use at all among urban black women (Abdool Karim *et al.*, 1991; Cooper *et al.*, 1991). Furthermore, many did not perceive themselves to be at risk of infection (Perkel, Strebel & Joubert, 1991; Vergnani, 1993), despite high rates of STD infection (O'Farrell *et al.*, 1989; Strebel & Perkel, 1991b).

Since these studies were conducted, a number of research projects have been completed or are underway, and researchers in the field of women and AIDS have met to share work, create a network and identify future policy and research needs (Miles

et al., 1992; Miles, Steinberg, Strebel & Cooper, 1993). There are also plans to establish a national women and AIDS research unit.

In the light of the limited information, and in order to obtain a better picture of what was happening in the country with regard to women and AIDS, two preliminary studies were carried out in the area of women and AIDS in South Africa. They were intended as a prelude to the main body of this research project, which will be described in more detail in the following two chapters.

STUDY ONE

The aim of this project was to obtain an overview of prevention and care facilities for women in South Africa at that time (See Strebel, 1993a). The intention was not to arrive at a comprehensive directory of all available services, but rather to provide an indication of the type of work being done then, the issues that this generated, as well the implications for future programmes. To assess the status of prevention and care services, semi-structured interviews were conducted in 1991 with people in relevant medical, research and organisational settings in three major centres in South Africa (See Appendix A for a list of those interviewed).

FINDINGS

Focus on Education for Women?

Many AIDS educators felt that there was a need for a specific focus on women, although the majority of education services did not provide this. In practice, a number of education programmes did have mostly women participants. However, some interviewees expressed strong feelings against this special emphasis on women, arguing that to focus on women only would marginalise the problem and stigmatise women, or that the problem was so vast that such a focus could not be justified.

Problems in Prevention Work with Women

According to those interviewed, much of the training in AIDS work has been with health workers, most of whom are women. Education has often focused on knowledge and information at the expense of meanings and personal reactions to the epidemic. While health workers were extremely anxious about risk of infection at work, they seemed to downplay their vulnerability in their private lives. These experiences of fear and denial could interfere with their ability or motivation to conduct effective education themselves. Also, health workers had to add the demanding task of AIDS education to their already substantial workload.

Interviewees claimed that experience in AIDS education with women had highlighted the obstacles to effective prevention which cultural practices and material realities raise. For example, if women were not supposed to see or touch male genitals, and if many sexual encounters occurred hastily in the absence of privacy and comfort, they felt it was inappropriate to talk about '*eroticising condom use*'. Moreover, if men still paid brideprice (lobola) for their wives, it was extremely difficult to shift this relationship of control and ownership to one of accepting equal, shared responsibility for sexual behaviour (Ramphela, 1989).

Furthermore, they thought that for many women AIDS was not yet seen as a priority: it was not yet visible in the community and many denied its seriousness. Talking about sex was difficult, so that education efforts had to deal with initial reluctance and discomfort. Also, many women were illiterate and so unable to benefit from existing educational material. On the other hand, during education sessions, women often expressed anger towards men at their unwillingness to tackle the problem, at their violent reactions to suggestions to change sexual behaviour and at their attitudes to the use of condoms. There was a danger that women could see themselves as victims only and not recognise their own risky practices: it seemed acceptable to talk about multiple sexual partners of men, but there was a silence about such behaviour among women themselves.

Strategies for Education

A variety of suggestions were made about improving effectiveness of education for women. Many AIDS workers stressed that education was best in small groups and that the approach would differ for different target populations: work with youth often needed to focus on sexuality, while for older women it might be more appropriate to make talking to their children about sex the priority. While some training dealt directly and solely with AIDS, other workers felt strongly that what was needed was to start with people's more immediate concerns like sexuality and STDs, and only to speak of AIDS within such a context.

Many educators had strong opinions about whether education groups should be single-sex or mixed. The advocates of groups for women only maintained that men tended to dominate mixed groups, that it was easier for women to express their feelings about sexual behaviour in the absence of men, and that it was culturally inappropriate for men and women to discuss such issues together. Also, women needed to be taught to be more assertive in an unthreatening environment. However, there were equally forceful arguments for education to take place with both sexes together. It was after all men who wear the condoms and so it was more effective to involve them directly than to teach women how to 'get' them to change their behaviour. Also, the sexes had much to learn from each other in such joint groups, through the use of role-play and the exchange of ideas. Some educators were trying to run groups for couples, but it was often difficult to involve men. One centre had also found that women responded very well to male trainers: their messages seemed to carry greater credibility, especially those which indicated that women were entitled to say no to unsafe sex.

Further valuable suggestions were made. Resistance to changing sexual behaviour on the basis of cultural tradition needed to be vigorously challenged with examples of ways in which such shifts had in fact occurred. Women were not only passive oppressed victims, but also had power in the family and marriage which could be harnessed to develop mutually acceptable safe practices. Furthermore, HIV+ women

and community women's organisations were valuable participants in AIDS work and, despite the invisibility of the epidemic and its absence from the 'agenda' of most grassroots organisations; at least one rural hospital had managed to achieve their involvement. Finally, AIDS trainers required on-going support and education.

Care

There were no special care facilities for women at the time (1991). Blood tests to identify those with HIV or AIDS were carried out at the request of clients, as part of research projects, or at the discretion of a medical officer. Pre- and post-test counselling was available from private organisations, City Health AIDS Centres and HIV clinics in hospitals. AIDS patients were treated in the appropriate medical wards and discharged as soon as possible. No hospitals had special AIDS wards, although there were suggestions that this might change as numbers grew. Community clinics were also beginning to provide counselling and follow-up care. The trend seemed to be towards community-based care with the establishment of hospices, as both the most appropriate and cost-effective approach. Medical staff, especially nurses and primary health care workers, were being trained to offer counselling and care, and psychiatric and psychologist personnel were being involved at some hospitals.

Thus far, the majority of those treated had been white gay males, but increasing numbers of black men, women and infants were beginning to require care. A particular research focus in some major hospitals was on women in antenatal care, where all patients were being tested and HIV+ women followed up with counselling and care. This testing of women at antenatal clinics without properly-informed consent had caused some controversy. While some felt that this was justified in the interests of research and because those testing HIV+ were then informed and given counselling, others felt that this could not be condoned on ethical grounds. Further ethical problems were caused by the fact that many HIV+ women found it difficult to inform partners or family about their infection and as a result did not manage to adopt safer sexual practices. Health workers felt this confronted them with difficult decisions about the role of confidentiality in such cases.

Other infected women claimed that they were scared of new relationships and so avoided any sexual contact. Although offered the option of termination of pregnancy, few, if any, had chosen to do this. Women were also advised to avoid future pregnancies, although HIV+ mothers were usually not advised to switch to bottle feeding. Some women did not return for follow-up once the HIV+ diagnosis has been made. There were suggestions that some of these women left the city to return to their place of origin and that some were making use of traditional medicine when told the disease had no cure.

Regarding the women being seen for care: those who voluntarily sought counselling and testing were often better-educated and -earning women. The numbers of infected women were still too few to make accurate generalisations. However, impressions were that they spanned the whole socio-economic spectrum and had not necessarily had multiple partners, although some were the partners of men who were mobile in their employment.

AIDS workers stressed that the majority of care-givers were also women; either in their professional roles or within the family and community. They would need support in this work, especially when infected women had the additional burden of caring for others who were ill.

DISCUSSION: WOMEN AND AIDS - WHERE ARE THE MEN?

Discussions with AIDS workers about women and HIV highlighted issues to consider when planning future initiatives. Firstly, it is clear that more was being done regarding prevention than care. This reflected the early stage of the AIDS epidemic in South Africa, with relatively small numbers of identified AIDS cases. However, this '*invisibility*' of the virus reinforces denial of the extent of the problem and the possibility of personal risk of infection, both of which do not facilitate effective preventative steps. It is interesting that, while countries in the rest of sub-Saharan Africa have much to teach us about dealing with advanced stages of the epidemic, most have perhaps less experience of persuading people of the seriousness of AIDS in these early days.

Secondly, the effective functioning of health workers, most of whom are women, is a priority. Theirs is a demanding and emotionally-fraught task (Kaleeba *et al.*, 1991). They are expected to bring about changes in people's behaviour in the inaccessible area of sexual practices, as well as provide counselling and care for the terminally ill. Training that does not provide enough space for them to come to terms with their own concerns about the virus will be ineffective. Expectations that the complex task of counselling, and in many cases therapy, can be learned in a few brief sessions are unrealistic. Ongoing education, supervision and support are essential (Amaro, 1993; Knox, 1989; Mathews & Linn, 1989; Richardson, 1987; Vergnani, 1993).

The ways in which cultural practices influence AIDS education also need careful consideration. Creative approaches to understanding the complexity of issues and interests involved are required; which on the one hand utilise cultural beliefs to make education messages more relevant, but, on the other, encourage exploration of ways in which they increase risk of infection and need to be challenged. This is especially important in the area of women's power and rights to ensure their safety from HIV infection (Campbell, 1991; Seeley, Wagner, Mulemwa, Kengeya-Kayondo & Mulder, 1991).

Ethical issues raise thorny considerations. The right of medical doctors to decide on uninformed testing, and their right to test patients in their own health interests, without consent from the patient, must be strongly questioned (Cape Times, 2/12/92; Ijsselmuiden & Faden, 1992; Knox, 1989; Panos, 1988). The extent of confidentiality regarding results on the one hand as opposed to the need to follow-up the partner/s on the other must be carefully considered (Allwood, Friedland, Karstaedt & McIntyre, 1992; Schaay, 1992; Karstaedt, 1991). Also, the quality and substance of counselling regarding reproductive rights for women must be monitored.

Most importantly, it became apparent during interviews that the practice of approaching women as a special category in South African AIDS work is not without its contradictions. It is undeniable that women are affected by AIDS differently to men,

with special problems and needs in prevention and care. However, what must be explored is how to respond to these concerns most effectively.

What emerged was that while a particular focus on women indicated a recognition of such needs, it could also carry other implications. This emphasis could suggest that AIDS was primarily a women's issue, that they were responsible for spreading the virus by infecting men and infants. Therefore, it was up to women to do something about stopping the further spread of HIV infection. In reality this requires women to bring about behaviour change in areas where they have notoriously little power. It seems counterproductive to focus on 'getting' women to persuade men to alter their behaviour in such a difficult area. It also enhances women's dependence on men for their safety against infection, and implicitly again places the burden of responsibility on women. Furthermore, if AIDS is perceived to be a women's issue, it then becomes a 'soft' issue, one not taken seriously in terms of legislation, resources and funding (Strebel, 1991b).

The approach to HIV+ women at antenatal clinics may further reinforce this view of women and their role in the AIDS epidemic. It is women who are being tested and counselled about not spreading the infection, although their unpregnant partners, who are unaware of their HIV status, are far more likely to be practising unsafe sex. It is women who are being judged for not telling their partners of their HIV status and for not using condoms; and who are labelled as non-compliant when they do not return for follow-up appointments. Similarly, women commercial sex workers are targeted as a high-risk group, needing screening, education and even control through legislation; with no parallel focus on their male clients and the health risks they generate for themselves and others (Campbell, 1990; Pauw, 1993).

Thus, much of the work done with women runs the risk of subtly enhancing the image of women as the problem, the responsible agents in dealing with AIDS. Unless heterosexual men are also targeted and actively involved in prevention and care, a focus on women could do more harm than good (Miles *et al.*, 1992; Panos, 1990; Reid, 1991; Strebel, 1991a).

In conclusion then, while there was an awareness among South African AIDS workers about the special needs and problems of women, it seems that at this stage of the epidemic, planning for effective prevention and care must be strategically approached. While it may be advantageous at times to work with women on their own, this must not happen at the expense of programmes which identify AIDS as a problem for all South Africans. It would be most unfortunate if a concern for the particular problems which women face would result in discrimination and blaming of women, or, equally, in the neglect of efforts to provide effective services for *'the other half'*.

STUDY TWO

While the above study focused on those involved in AIDS work, this project was concerned with the experiences of women living with AIDS (See Strebel, 1992, 1993b). It seemed important to obtain a clear understanding of how the disease manifests in South African women, as well as the interplay of factors which have an impact on its spread and management. It is not enough to know the rate at which women become infected. We need to know the context in which such infection occurs and the meaning of the disease for those living with it.

AIMS AND METHODS

A central aim of the study was to ensure that *'the subjugated knowledge'* (Stamp, 1989), the voices of women already living with AIDS would be heard (Viney & Bousfield, 1991). Although his conception of people with AIDS as victims is problematic, Fortin (1987, p. 918) highlights the problem of keeping invisible the experience of those with the disease:

Sacrificed in the African discourse on AIDS, for example, is the voice of the victim. There is no literature, no popular media, no major group articulating this voice. There is, in other words, no visible response from those who can most directly communicate the meaning of this pain.

It was hoped that this study would help to avoid inappropriate activities borrowed from other contexts and generalisations about 'women' which assume that they form a uniform group with identical interests. It could also serve to reduce the gap between the power of the decision-makers, researchers and health workers and the easily-disempowered 'victims', the recipients of services, the stigmatised 'others'.

Some of these are concerns raised by feminist research methodology. In line with challenges within social psychology and approaches to qualitative methods, feminist researchers have expressed reservations about many of the assumptions of mainstream traditional positivist research, at both the theoretical and methodological levels (Lather, 1988; Mies, 1983; Oakley, 1981; Wilkinson, 1986). In attempts to redress previous imbalances, they aim to make the subjective experience of women visible (du Bois, 1983; Klein, 1983; Oakley, 1981; Schoepf, 1992). They also reject the notion of the researcher as neutral and objective, and have explored the interactive nature of the relationship between researcher and subject, focusing especially on the need for reflexivity in understanding how knowledge and meaning are jointly constructed during research (Burman, 1992; Griffin, 1986; Marshall, 1986; Stanley, 1990; Stanley & Wise, 1983). They share the view of Danziger (1986) that it is not appropriate to separate theory from methodology, and stress the need for a conscious focus on the **how** and on bringing the process of research into analysis of results (du Bois, 1983; Klein, 1983; Stanley, 1990; Wilkinson, 1986). Furthermore, feminist research is concerned with social transformation and the generation of change-enhancing social theory (Lather, 1988; Mies, 1983; Stanley, 1990). As a result, researchers have to tackle issues of power in the research relationship and work toward enhancing resistances and empowerment of subjects (Burman, 1990; Stanley & Wise, 1990; Wilkinson, 1986). However, they emphasise that there is not one distinctive feminist method; but rather a '*plurality of standpoints*' (Stanley & Wise, 1990; Wilkinson, 1986).

Within such a feminist research framework, the objective was to talk with women diagnosed as HIV+, in order to better understand the issues involved in preventing the further spread of the virus. It was not intended to provide representative and generalisable information, but rather to capture some of the nuance and detail of

individual experience. In choosing an individual interview format, I was drawing on Mishler's (1986, p. 34) conception of *'the interview as a discourse between speakers ... [in which] the meanings of questions and responses are contextually grounded and jointly constructed by interviewer and respondents'*. This notion of the interview as dynamic, interactional and contextual, which challenges power relations in the research process, and which embraces the complexity and contradictions of the process clearly resonates with much of the feminist approach. In addition, it questions traditional criticisms of qualitative methods as being unable to provide reliable and valid data (Brenner, 1985; Brown & Canter, 1985; Griffin, 1986; Marshall, 1986; Mishler, 1986; Paget, 1983).

Women were approached during early 1991 via local health services in the Western Cape and participated in semi-structured, largely non-directive interviews (Brenner, 1985; Graham, 1984; Meulenbergh-Buskens, no date). Each of the five interviews lasted about 90 minutes and was tape-recorded (Brenner, 1985; Marshall, 1986). The session started with background family and personal information, and then covered the following areas:

- diagnosis: how they discovered they were infected and what they did about this;
- infection: how they became infected, what they knew about the virus then and what their risk factors were;
- reactions: how they dealt with/felt about the news, whether they informed anyone, how they are now coping, impact on practices and relationships;
- present concerns: reproductive issues, the future, their children, priorities, needs;
- prevention: ideas about avoiding infection for women;
- any other issues that the women raised or considered significant.

The recorded interviews were transcribed, translated where necessary and analysed. (Issues of transcription and translation will be discussed in the main study.) This involved locating the women within a broader socio-economic context, the identification of major themes in the experiences of the participants, as well as textual analysis to

explore the impact of the interview process on understanding the problem (Thomson & Scott, 1990). Decisions on what to include were guided largely by relevance to prevention issues.

THE ACCOUNTS OF HIV+ WOMEN

Being Black, Poor and HIV+

All the participants were black, although the research was not designed to exclude white women. This reflected national statistics at the time of eight white women out of a total of 722 identified AIDS cases (van Coeverden de Groot *et al.*, 1991), but also suggests that their economic status allows white women to be treated within the private practice system, rather than at state health clinics, through which these women were identified. Classification as 'non-white' will have had profound implications regarding access to resources generally, and especially education and health care (Miles *et al.*, 1993).

A striking feature of these black women living with AIDS was their lack of economic independence and security (See Appendix B for a brief description of subjects and coding conventions used in transcription). With an average age of 37 years, their options in the sphere of social relations and employment would be more limited than those of younger women. As it was, they were single and/or involved in informal relationships. Although some of these partnerships were of long-standing duration, none of the partners were employed and they were themselves either HIV-positive and/or had TB. Their children also offered little hope of financial support: of the total of four children still alive, two were under 12 and the other two were estranged from their mother. [The low number of children, amongst these mainly working-class women, as well as their relatively older ages were in fact noteworthy]. Furthermore, these women had limited education, without any additional training. They had been employed in the notoriously exploitative farming and domestic sectors but were all unemployed at the time of interview, with very little hope of re-employment (Marks, 1989).

As was argued in the previous chapter, these economic conditions play an important part in women's vulnerability to AIDS. Their lack of independence and power contributes to the difficulties of insisting on safer sexual practices with partners, increases the likelihood of multiple partners and limits access to effective prevention inputs. Once infected, they are also less likely to obtain adequate health care and support.

In sharp contrast to this was the one married woman, who had tertiary education and was still employed in a professional post. She had family also in professional jobs (one in the medical field) and was well-informed about AIDS. She was proud of her economic independence, attended clinics regularly and was about to start with AZT treatment. Although infected with the same virus as the other women, her middle class status seemed to alter substantially the meaning and experience of the AIDS diagnosis for her, as well as the quality of her remaining life. This difference of 'voice', of membership and dispossession in women of different social classes has also been described by Hutchinson and Kurth in their interviews with HIV+ women (Hutchinson & Kurth, 1991; Kurth & Hutchinson, 1990).

The Bad News: Finding Out About the HIV Diagnosis

These women were not the '*worried well*' who had requested testing, nor even among those identified by antenatal research projects. As a result of their partners being identified as HIV+ or dying of AIDS, they had been tested and found to be infected. Tuberculosis was a complicating factor in all cases, either in the partner or themselves. None had AIDS-related symptoms at the time of interview. For many at this relatively early stage of the epidemic, news of the diagnosis was likely to be unexpected. The initial contact with the medical world of AIDS is very important in establishing a context for future care and behaviour change. For these women it was not a positive experience. They claimed that they were not told what was wrong with them and only after testing learned of the AIDS threat:

They didn't tell me what kind of infection it was, they just drew my blood and the child's blood and his blood. (A)

I heard from the sister that doctor would come to tell me what other illness I had ... They told me nothing [about the illness], they said I must remember I have another illness. (B)

They didn't tell me. So I asked the doctor what was wrong. Then the doctor said: no it's nothing, there's nothing wrong with you. (D)

On the other hand, the woman with a professional background and family in the medical world had perceived her clinic visits as enormously supportive and she was well-informed about what to expect from the illness:

I've spent hours at the hospital talking to the doctors, talking to psychiatrists ... asking questions, and that has really put my mind at ease.

and:

I'm, I would say I'm very much interested in medicine ... when it came to my diagnosis I knew all about it. (C)

Even when information has been given, it is understandable that messages are not heard/comprehended: for women with limited education and infrequent contact with the medical profession, the process of pre- and post-test counselling is potentially foreign and alienating (Mays & Cochran, 1987). AIDS workers need to be aware of the expectations women have when they interact with the medical world, their existing framework for making sense of the specific diagnosis and the likely influence of perceived power differences between professionals and lay people.

'He infected me with the - thing': AIDS knowledge and beliefs

It is necessary for future AIDS education to examine what women know and believe about AIDS and its transmission, and how they relate this to their own situation. Among the women interviewed, knowledge seemed almost non-existent, very vague or a mixture of accurate and incorrect information. Little wonder then that infection was not avoided:

They say it's in the air. (E)

and:

I knew that this sickness is in the people who don't look after themselves properly, understand? that sleep with the men - somebody who had something, you don't know, you sleep with the man. (D)

and:

Q: What do you know about AIDS?

Nothing, I know nothing about the Ays (sic), I don't know if a person gets it that time when you were still a young girl in the rain and everywhere.

Q: What do you think, how does a person get it?

I moved around a lot at that time, slept with friends, sometimes we didn't even have a place to sleep, then we just slept in the bushes. I'm not hiding anything, what I did at that time, I think it all comes into it.

Q: And how do you think you then caught the illness?

[long pause] I don't know myself sister. (B)

As has been found in other studies, women are likely to have more than one set of beliefs regarding the disease. These may include a combination of popular, traditional and medical beliefs (Flaskerud & Rush, 1989). For one woman, there were her convictions about what the disease looked like, apparently gleaned from the media:

Before I came out with the stuff [the rash], the people in the house said that I was getting AIDS. Then I said it's not AIDS at all, it's a rash this, it's not AIDS. Then I asked them if they knew what AIDS looked like? Had they seen the people on TV, what AIDS looked like, that's what people with AIDS look like. AIDS means you come out in such pimples - totally neglected, that's AIDS, but this isn't AIDS ... they meant this was AIDS, but then I said I know it's not AIDS.

There was what she was told by medical staff:

Then the people at (Hospital) told me that he would infect me, it's an infection which he got but he will infect me, me and then I will infect the child.

as well as her beliefs about how it was transmitted:

There are some women who don't wash, and there are some women who use something [substance to increase sexual pleasure] for the men and that causes it.

and finally, popular knowledge:

Like, what do people say, he slept with a woman here and so, in other words, as they say, that's AIDS ... a dirty sickness, that's what they also call it sometimes. (A)

However, even accurate knowledge is not sufficient to prevent infection (Perkel *et al.*, 1991): This seems to be born out by the level of knowledge of one of the participants, also HIV+:

It could have been a lot of, look, look I'm, now you see that is where surmising is not for me. It could have been through sexual intercourse, right? He may have had a very healthy sex life, I wouldn't know. It could have been through blood, he had operations and so on, I wouldn't know. So the possibilities are there. But what I can say, I don't think it happened between our period of time, ever since we got married, because I would know for sure when my husband is having an affair. (C)

It seems that accurate information does not necessarily replace existing knowledge and beliefs. This is possibly why much AIDS education which relies primarily on conveying facts is ineffective. So it is not surprising that, regardless of how much the women knew about the spread of the virus, they were not clear about how to prevent it happening, and none of them had adopted safer sexual behaviour. This was true of even the best-informed woman who said:

I would've insisted on condoms.

but also:

I would've had a monthly check-up, blood tests, the lot. I would've seen to it that I had sterile baths, you know, that kind of thing, been very careful. (C)

Regarding risk factors: none had used condoms to avoid infection, they all seemed to have had/been treated for sexually transmitted diseases (although their information about them was vague), and while none of them talked of multiple partners themselves, they did not know whether this was true of their own partners.

Reactions to AIDS: Self and Others

Surely an HIV diagnosis is calamitous and requires a total re-orientation to what remains of one's life and relationships to the world (Carpenter *et al.*, 1991; Richardson,

1987)? Maybe, but we need to uncover more precisely what it means to 'have AIDS', how this meaning is constructed and what impact the knowledge actually has:

Women reacted to knowledge of their infection in different ways. For one with severe TB and epilepsy, it worsened her physical state:

The other sickness [AIDS], it feels sometimes that the day, when I don't feel [well], then it seems that I can go nowhere, not move, then I'm quite lame. (B)

For another it was a major emotional blow, made worse by what she expected would happen to her and how others would react:

Last year, when I heard I was sick, my head couldn't, I looked like someone who was going to die. I also didn't want to look at people, other people. I was scared of people. If the people knew I was sick, they're scared of you. I didn't want to go out, go around, I just stayed at home.

and:

My heart was sore, I wanted to kill myself, I would've, because I've seen the people who are sick, what they look like. So, I thought I would look just like that, because the people who have the sickness, they can't do anything for themselves, they just sleep, stay in bed, understand. Because I'm still young, I'm still young, I won't stand for it that I must lie in bed. I want to do everything for myself, understand. It's better if you can do everything for yourself. (D)

While for a third, it was important to cope and try to carry on as normal:

I don't know what I feel about it at the moment. You see it's something that after[wards] you can say, it was too [tearful] - things moved too fast. It was something we had to cope with immediately, to avoid any unnecessary questions being answered by relatives or friends. We had to learn to cope with it fairly quickly, there wasn't time to sit and mope around. Well sometimes, I feel a bit, a bit, I wouldn't say upset [tearful] - ja maybe, about it. It's something I just accepted ... look I can either sit around and mope or I can carry on with my life. That's the only two options that I've put to myself - and do whatever I can with the bit of time that I have left. (C)

What was striking was that, although the women thought they had all probably been infected by their partners, they denied any anger (Ford & Koetsawang, 1991). In contrast to this, a study of the narratives of HIV+ men found feelings of anger, depression and anxiety (Viney & Bousfield, 1991). Instead, these women expressed rather resignation:

I did feel a bit bad, but what could I do?

and:

Then you must just believe in God, because if it just came like that, then it just came, and there isn't a way to come right again. (A)

and in almost identical words:

It did make me feel a bit bad, but what can I do, I've got it now, you can't do anything about it, even doctor says there aren't any pills for it. (B)

and again:

I don't feel angry, what happened just happened. (E)

These were the women in the most economically deprived and dependent positions, and their feelings seem to highlight their powerlessness to influence any aspect of their lives. On the other hand, being able to acknowledge some anger and to explore areas of blame and guilt has implications for the relationship with their partner:

I think I have the anger, that's why you see the tears coming somehow.

and:

Sometimes it gets in my way, sometimes I feel like when we have arguments, I feel like just throwing it at him. But then you have to think twice before you say something, and luckily for him, and for me, we both have our own transport and I get into the car and go somewhere, cool off down and come back. We don't argue that much, see, and I don't know, maybe we feel guilty towards each other in a sense too. You don't know who, how to cope with it, in the sense that it gets to: it's through you that I contracted the disease. That is a very dangerous, you know. We don't discuss it any more ... the word AIDS is never mentioned ... we haven't talked about it at all.

and:

Where does one go to look to put the blame on whom now and how far do you go back? ... You don't want all - the dirty washing coming out just to put the blame on someone. (C)

So I came to tell him [that she was HIV+], then he said it's my own affair, then I said it can't be my own affair because who told you I slept here tonight, there tomorrow, or perhaps also in the day ... then he said it's not his fault, it's not him, everything comes from me ... he said it's not him, it's me who sleeps around ... but the thing is in him, but he argues himself out of it and says it's me. (A)

The threat or presence of HIV infection will inevitably raise such thorny issues between partners. For example, other studies have found that women often are blamed for infecting their men (Panos, 1990; Schoepf, 1992). Prevention and care work will need to tackle these problems with sensitivity and flexibility, recognising the specific dynamics of each situation. Moreover, in the absence of community care facilities and

reluctance to inform others of the diagnosis, partners are often thrown back on each other for support and care, which can increase stress, but also provide opportunities for caring and concern:

Now, since I've had the sickness he's changed a lot, he does lots of things for me. Some mornings I can't move my head this way, then he asks what sort of coffee he should make, [what] piece of food he should put on [the fire], so that I just have to watch it. (B)

As has been found in many other projects, HIV+ women do not easily tell others about their diagnosis for fear of rejection (Allwood *et al.*, 1992; Kaleeba *et al.*, 1991; Karstaedt, 1991; Panos, 1990; Schoepf, 1992). However, in some instances this fear has been unfounded (Chaava, 1990; McGrath, Ankrah, Schumann, Lubega & Nkumbi, 1991). In this study, only one woman had told a family member, while another had told family about her husband's diagnosis but not her own and still another had spoken to family about her TB but not AIDS. The dominant theme was that people would not understand:

Except for the people here [named hospital staff] the only other persons that do know [about husband, not self] is my family. Not even my inlaws know because I don't think they are adult enough to be able to grasp what actually is happening, because most probably of the negative side of what AIDS is all about. (C)

No, I won't tell other people ... our nation if you're sick, they're funny towards you, understand, they are scared of you, they don't want to talk to you, or they don't want to [care] for you, you don't have friends, your friends run away from you. (D)

Informing others or not could also be a point of conflict between partners and result in violence:

He also didn't want to tell the people what was wrong. When I was drunk the other day, then I told them, I accused him, so he hit me, so I scolded him in front of the people about it ... he was very cross so he hit me. (A)

Participants generally felt that there was not much awareness of AIDS in the community, a perception closely tied into the wider process of denial in South Africa about AIDS at present. If people who are infected feel unable to tell those closest to them, and if their expectation is that society at large will reject them, it will be extremely difficult for them to bring about any behaviour change. Also they might be reluctant to

seek out care and experience considerable isolation at a time when they desperately need support and caring. It has been suggested in fact that women get less support than men, that women have been abandoned by their partners once their HIV+ status is known and that the threat of isolation is very real (Campbell, 1990; Ford & Koetsawang, 1991; Hutchinson & Kurth, 1991; Panos, 1990). Moreover, the notion of family is often problematic for women, in that rather than offer support, it may instead function to oppress women (Campbell, 1991). On the other hand, in cultures where family cohesion is especially important, the threat of rejection will be more acutely felt (Mays & Cochran, 1987).

Condoms or Abstinence: Are There Choices?

Generally, the advice for HIV+ people is to practise safer sex in order not to infect others or worsen their own health. This usually translates into suggestions to use condoms or to abstain from sex altogether. For some women in this study, trying to get men to use condoms was a risky business, so that it was easier to avoid sexual contact altogether:

No, I'm not interested in that [sex] anymore, I'm not interested anymore because I'm scared of men. I don't know if the man is sick or not, understand ... that I'll get sick again. I would use the condom ... they [men] don't want to use the condoms: you bring the condoms, you give it to him, he doesn't want to use it ... they say they won't use the things ... they don't believe in them, even they get angry. (D)

For others, condoms were threatening and abstinence was no option:

We still sleep together - but now because the bed is small, now look it's a small bed, now the child and I lie underneath, he lies on top ... we use nothing ... I'm so scared of that thing [condom] ... I'm too scared ... perhaps sometimes it will stay behind inside you ... I won't come right with that thing ... I'm not interested in using it.

and:

I don't know about that [abstinence] (laughs), but they say if you have the urge [for sexual intercourse] then it must just come. If the urge is there and he wants you to be there, then you just must be there. Because, sometimes the men hit you also over that ... the man won't allow me to suggest that [abstinence] ... he will just assume that [the reason] why I don't want to sleep with him is that I'm flirting around or I've got another man.

and finally:

There's nothing that I can do, just believe in God's mercy. (A)

HIV+ women with only one partner also do not necessarily understand the reasons for using condoms anyway:

They advised us not to have sex at the time when they didn't know I contracted the disease. So, afterwards when I knew I was positive, I thought it was one and the same, isn't it? ... No, I don't see the sense in using condoms. (C)

Prevention of spread of AIDS is of particular urgency for those who know they are HIV+. Clearly, it is one thing to know what can be done to avoid further infection but quite another to overcome the fears, beliefs and powerlessness which impede such action (Holland *et al.*, 1990a; Kane, 1990). Negative attitudes and beliefs about condoms may make it unlikely that women use them. Others, who may wish to use them, lack the power to negotiate their acceptance by partners, while for many there are added threats of physical violence and suspicions of unfaithfulness. Studies have shown that HIV+ people do not easily adopt consistent condom use (Allwood *et al.*, 1992; Skurnick *et al.*, 1991). Counselling must take into account these varied and contradictory conditions which women face in trying to change behaviour. For to offer only suggestions which are impossible or difficult to implement (one thinks of the recommendation to '*eroticise condom use*') only increase women's guilt and anxiety (Carovano, 1991; Shaw, 1988).

Living with AIDS: Hopes and Fears

An HIV+ diagnosis generates a variety of additional problems for women to face. A dominant theme in this study was one of worry, about current concerns as well as the future. For those already debilitated by long standing TB and poor living conditions, their health was a major worry:

I am alone, I move when I can, make food and so on, because I need to sit often ... I get tired very quickly, doctor. (B)

Inability to work or find a job was also a concern:

Sister, I don't feel right to work. It won't help to look for work; today I feel good, tomorrow I must stay at home again, then I'm weak again. I still feel like working, but I can't. (E)

Understandably, the future looked bleak. As has been found elsewhere, women were afraid to get involved with men again (Panos, 1990; Richardson, 1987) or have more children:

Look, there won't be another life for me, look after (name) has died ... I'm scared of infecting another person. (C)

and:

No, I won't have more children ... I don't use anything [condoms] because I don't worry. That's why I don't use anything, I don't want to have a boyfriend, I don't want to have more children. It is too burdensome to raise a child, to buy the child clothes, food, all that, going to school. (D)

The reservations about having more children seemed to be related to financial constraints, rather than worry about passing on the virus to them. None of the women interviewed had HIV+ infants themselves. For such women, there are likely to be different issues and priorities.

One woman captured vividly the fears, as well as the hopes about her future:

I am so sad about the future, I am so sad about the future ... I feel that the sickness has gone ... if I look after myself well it will stay away, I believe so, I believe so, I believe so. I am better, much better ... I'm happy now, really I'm happy.

But then again:

If I could go to night-school and study, to get my thoughts to forget about it ... It stays here in my thoughts ... I just think that if I get ill from this illness, who will look after me, because the people are frightened when the illness comes to you ... Yes, I'm scared ... I don't want to give other people that sickness, because people die from the illness, many people. (D)

The theme of being abandoned was echoed by another woman:

I don't feel okay at all, not at all okay ... I'm going to die, it's unexpected, it's very difficult ... No, sister, I haven't told anyone yet ... it's too sore to talk ... I will write

a letter home to my mother and tell her, then I must just go home, because who's going to bury me here? (E)

For the woman with financial resources, the future held other possibilities:

Yes, if I should live another ten years I intend to retire and do my own thing, a little bit of touring, before it starts to get me down.

and with a certain degree of bravado:

I'm spending my money like crazy, doll (laughs), there's nothing left for nobody, doll, you follow me. I'm giving myself a good time ... I'm enjoying myself. I've got nobody to take care of. I told my husband: you take care of yourself, otherwise you're gonna die. I'm carrying on, and that's my attitude; carry on with your life, to hell with what other people think. (C)

Thus it seems that support, both emotional and economic, is central to coping strategies, and unlike gay men, women often lack such social support structures (Campbell, 1990). These were women who were at the time not nursing partners, children or other family members. When the epidemic reaches that stage in South Africa, much more will be needed in terms of resources.

'No-one will say no to sex': Can Further Spread be Prevented?

It seemed that although the women knew what to say to others about avoiding the virus, they didn't think it would help much:

No, I say to them: if you're a woman, you mustn't [sleep] with all the men, you must have one boyfriend ... or you must use the condom if you sleep with a man. (D)

People are most probably the species that do things first and feel sorry after ... it's only 1 in 10 that will listen ... I think the best method of getting this thing across is like me for instance, you know, having the personal experience, knowing what I'm talking about, that's the best ... they'll listen to whatever you say and tomorrow do the bloody same thing ... No-one will say no to sex, are you with me, nobody will say no to having a good time and that is what life is about for most of the people, having a good time ... People who are health conscious and are victims of what happened, they will listen. You have to educate society and how to educate society? You can't tell them when to have sex or not, you know, and it's going to be difficult. (C)

Further research would require a much more detailed look at what women regard as realistic options for preventing HIV infection. Perhaps these women had not fully accepted the implications of an HIV+ diagnosis, so that they regarded preventative measures as desirable but not essential. It is also possible that the nature of their circumstances was such that the prospect of possible AIDS-related death in the future was balanced against other more immediate priorities (Mays & Cochran, 1988a; Worth, 1989). However, prevention strategies need to be developed in the context of the diversity of factors which influence the ways in which women make their decisions.

BRINGING THE PROCESS INTO THE PICTURE

As outlined above, in order to know how to 'read' the experiences which these women shared, it is important to look more closely at the whole process of the interviews: to make heard the '*unspoken*' communications, to evoke the presence of the interviewer and to reflect on the dynamics of the interactions.

Firstly, the project was initially conceived of as a way of getting closer to the issues in prevention of HIV infection in women, which is the focus of the larger study. As such, it was intended to be somewhat of a pilot, together with the overview of what was being done in South Africa at that time in the areas of prevention and care for women. These two projects were carried out simultaneously, which highlighted some important issues. Firstly, the juxtaposition of voices demonstrated powerfully the gaps at times between the thinking of AIDS workers and the experiences of women living with AIDS. This has significant implications for the effectiveness of interventions. Also, it became clear that HIV+ women were not a separate group of people regarding AIDS intervention, but could be viewed on a continuum of awareness and risk. One university-educated AIDS educator, with an HIV+ husband was herself not always able to negotiate safer sexual behaviour, despite her knowledge and prevention messages to others. It seems therefore essential to incorporate the experience of people living with AIDS into attempts to understand the difficulties of changing behaviour.

Secondly, the interview process was necessarily influenced by my expectations of the encounters. As a result of both academic and community organisation work in the area of AIDS, I brought with me to the study a sense of urgency and recognition of the epidemic as crisis, both in South Africa and internationally. This view of the virus was amplified by the discussions with other AIDS workers throughout the country. These were also the first HIV+ people with whom I had worked individually. This 'crisis' mindset was both echoed, but also strongly challenged by the circumstances and experiences of participants. One woman I saw was bed-ridden in a cold, dirty room high on the mountain slope of a prosperous farm. She spent her days alone, worried that she would be evicted if her condition was made known to the farmer, a risk which was increased by my presence. She was a long standing epileptic whose grand mal fits sometimes resulted in her finding herself lying in the flames of the indoor fire which was her only source of heat and energy. Added to this was the debilitation brought about by years of TB. For her, the news of her diagnosis was an intensification of her plight, rather than a new crisis. With no hope of improving her living conditions or health prospects, there seemed very little place for 'AIDS talk', and much of my semi-structured interview had to be abandoned as we chatted about the 'old days', amidst the insistent farm flies, whose buzzing provided a telling background on the tape-recording.

Another important element of the research process was the dynamics of the interaction between researcher and those interviewed. It was an encounter between 'professional' and lay people, which was reinforced by the fact that meetings were arranged through local clinics and conducted in their offices (except for one woman too ill to leave her home). This role distinction was taken up by the women in their frequent references to me as 'doctor' or 'sister'. In addition, there was the impact of admonitions from nursing staff to the participants to be 'good subjects', as well as the expectations these staff had when they initially explained what the interviews would be about (possibly for some, the hope that I would repeat messages about safer sex, alcohol consumption, etc.). Also, the difference in race between interviewer and interviewees played a part in establishing a power dynamic which influenced the relationship (Bhavnani, 1990), and highlighted aspects of the 'insider/outsider' dilemma raised by Merton (1972).

However, while it was the researcher who had determined the parameters of the interaction, this was not an all-or-nothing power imbalance: participants were active in constructing the accounts which they related and in deciding how they would engage with the researcher. This was apparent from the nature and quality of rapport, which varied within and between sessions; and included deep sharing, bare-bones recounting of facts, giving what they thought was expected, attempts to 'seduce' the researcher to a particular viewpoint and inaccurate information. Although also being a woman improved communication at times, it was not enough to privilege information or understanding, nor to outweigh all other factors in the interaction, as has been found in other feminist research (Phoenix, 1990; Riessman, 1991). My training and work as a psychologist/psychotherapist also contributed to the way in which the interviews were conducted and the relationships interpreted. Awareness of this diversity of ingredients in the relationship recipe was central to an accurate and nuanced reading of data.

Language was another crucial dimension in understanding the meaning of what these women recounted. With the exception of one, the interviews were conducted in Afrikaans. Although this did not raise direct problems of communication, comprehension or translation for the interviewer, it did have implications. For one woman this was not her mother-tongue, so that care had to be taken to ensure accuracy of interpretation. Afrikaans is rich in idiomatic expression, some of which could not be adequately captured in translation, especially when referring to the texture of sexual interaction. The Afrikaans-of-the-streets is also at times far-removed from Afrikaans-proper, which further emphasised the gap between interviewer and the subjects. In addition to this, a close reading of the text revealed instances when communications between researcher and interviewee had been misunderstood.

CONCLUSIONS

The process of talking to HIV-infected women and trying to understand their communications as well as the context in which they occurred, has produced detailed and powerful material regarding AIDS-related issues for women. At this relatively early

stage of the problem, generalisations about women-at-large seem particularly inappropriate. Rather, it seems helpful in conceptualising both care and prevention strategies to start developing a comprehensive picture of what the disease means to specific groups of women, how these meanings are constructed and the impact they have on their lives.

As we would expect, the stories of women living with AIDS unfolded along numerous dimensions put together in a unique way for each person, and reflecting the specific world they inhabited. Thus the AIDS diagnosis was clearly not just a biomedical problem. Much of the meaning of the illness seemed linked to broader experiences of vulnerability in women, associated with the ongoing difficulties generated by their socio-economic and gender positions. Overall, there was a strong sense in which HIV infection became yet '*another nail in the coffin*', an extra burden added to the weight of their daily struggles.

However, they also responded to the specifics of what they believed AIDS was all about and what they thought it meant to others around them. The perception of an invisible yet stigmatising disease increases the likelihood of denial of the problem, difficulties in changing risky behaviour and isolation from the support of others.

There are some clear implications of these experiences for care of HIV+ women, but also important messages for those engaged in prevention. Much of what we know of AIDS education has been developed and implemented in contexts very different to those locally. Also, much of the education work is done by people who often are located in a different material position to those at the receiving end; having at least some education and employment, and been exposed to the biomedical discourse on AIDS as fatal epidemic. AIDS education must begin with a recognition of these possible differences. But as many AIDS workers are themselves women, they can at the same time make use of their shared experiences, by providing the space for such issues to be explored by participants. This needs to occur within a context which recognises the contradictory experiences of both '*expert*' and '*subject*' and in fact uses these as basis for negotiating appropriate prevention strategies. Unless this is done, messages will

continue to speak only to portions of people's experiences. Also, the opportunity to incorporate the insights and experiences of those targeted for education will be lost.

IMPLICATIONS

Thus it appears that initial responses to the disease were slow, both at government level and from the communities affected by AIDS. Regarding policy there has often been a tension between official concern to protect the '*public good*' of those not seen to be at high risk of infection; and the fear of discrimination of those affected by the disease, usually from minority groups. Health education responses have proliferated, although many have not had any sound theoretical base nor been sufficiently evaluated. Also, despite attempts to frame the problem within a broad socio-economic context, most interventions remain targeted somewhat narrowly on individual behaviour change.

Responses to the problem as it affects women too have been slow. Given the fact that it is predominantly minority women and those from developing countries who are infected, they have often lacked the power and resources to challenge the existing shortcomings or initiate alternatives. Preliminary work in South Africa suggests that the issue of AIDS for women is still largely a hidden and unrecognised one. It can also not be understood in isolation from socio-economic and political dimensions. In addition, the process of identifying AIDS as a particular problem for women generates contradictions about their responsibility for infection and protection.

It appears, therefore, that detailed research is necessary to explore aspects of this complex problem, in order to ensure that interventions, both strategic and long-term, are based on a thorough understanding of AIDS as it affects women. The study described in the following sections is one attempt towards this goal.

CHAPTER THREE

THE MAIN STUDY: SETTING THE SCENE

In this section, the central study will be introduced. It will start with methodological considerations, go on to outline in detail how the study was conducted and analysed, and some of the issues raised in the process; and then describe the sample of women who participated. It will end with an analysis of the group process.

METHODOLOGY

Within the realm of research on sexuality generally and AIDS specifically, there have been many calls for a careful focus on issues of methodology and the selection of suitable techniques (Thomson & Scott, 1990). This has been especially so in the field of social science research, which has seen considerably less investment than biomedical research (Coxon, 1988). There seems to be some consensus on the absence of any blueprints, and instead the need to develop a diversity or creative mix of techniques (Dalrymple, 1992; McQueen, 1992; Pickering, 1988; Reinisch, Sanders & Ziemba-Davis, 1988; Schopper, 1990; Standing & Kisekka, 1989). Others have stressed that it is not so much the specific methods which make a difference but the experience of the researcher with the particular techniques, together with considerable cultural sensitivity regarding the world of those targeted in interventions (Reinisch *et al*, 1988; Standing & Kisekka, 1989). Standing (1990, p. 481) has expressed this as follows:

The two basic requirements for any study of sexual behaviour are cultural knowledge to supply meaning, and social knowledge to supply context. Both of these need qualitative methods of research.

QUALITATIVE RESEARCH METHODS

While calling for an eclectic use of methods, there has been increasing attention paid to the use of such qualitative methods for research into sexuality in the context of AIDS. Firstly, researchers have found that more traditional quantitative methods, and especially the ubiquitous questionnaire, do not allow for the complexity of issues, depth of understanding and flexibility of exploration around 'touchy' subjects needed for research in this sphere (Griffin, 1986; Reinisch *et al*, 1988; Schoepf, 1991). Moreover, feminist researchers have found qualitative methods to be particularly suited to enhancing an understanding of gender relations; because of the flexibility, the detailed focus on meaning, the willingness to confront uncertainty and the person of the researcher in this approach (Griffin, 1986; Marshall, 1986). There is also growing recognition that the micro-level analysis of qualitative methods has the potential to make a valuable contribution to the development of macro social theory (Fielding, 1988; Fielding & Fielding, 1986). However, the duality between quantitative and qualitative methods is not always as distinctive as many would claim, and the two approaches can be fruitfully combined in triangulation approaches (Fielding & Fielding, 1986; Mostyn, 1985).

When talking about qualitative methods, most writers point to the assumptions underlying this approach to research: that data collecting is not an objective, neutral process of identifying the truth about subjects. Rather it values the subjective experience of participants, is concerned with meanings rather than frequencies of events, recognises the complexity and contextual basis of knowledge (Ferreira, Mouton, Puth, Schurink & Schurink, 1987; Glaser & Strauss, 1967; Mudaly, 1985; Standing & Kisekka, 1989; Strauss, 1987). Also, the role of the researcher is brought into focus, through her reflexivity and recognition of power dynamics in the research process (Bender, 1985; Fielding, 1988; Krueger, 1981).

Although qualitative researchers emphasise the need for a clear theoretical and conceptual framework when undertaking such work, with few exceptions there is very

little detail on the **how** of the approach (Kirk & Miller, 1986; Miles & Huberman, 1984; Mostyn, 1985; Strauss, 1987).

Tied to this concern about lack of systematic procedure are criticisms about reliability and validity of qualitative methods. This has been particularly relevant for data concerning sexual behaviour (Baum & Nesselhof, 1988). There have been differences of opinion regarding especially the reliability of self-reported sexual practices (McQueen, 1992). Some researchers have found that such data is in fact both reliable and valid (Darrow, 1990), while others claim that time is an important variable, with recent events being more accurately recalled (Coxon, 1988; Reinisch *et al*, 1988).

Proponents of more qualitatively-oriented research maintain that traditional approaches to issues of validity and reliability are not without their problems, and Mishler (1986) has proposed that what he calls the four R's of quantitative methods, namely Representativeness, Reactivity, Reliability and Replicability, need to be challenged. They would query the so-called scientific objectivity of these methods and argue that there are alternative ways of approaching the issues (Brenner, 1985; Miles & Huberman, 1984; Mishler, 1986). Generally this involves a focus on clarity and credibility of findings. Marshall (1986) has suggested that this occurs at three levels: by a focus on detailing how the research was conducted (through the use of systematic field notes/journals), in order to make the process open to the scrutiny of other researchers (Bender, 1985; Kirk & Miller, 1986; Mudaly, 1985; Paget, 1983); by explicating the relationship of findings to the data, to check theoretical assumptions (Layder, 1982; Strauss, 1987; Strauss & Corbin, 1990); and through the process of contextual validity, by linking findings to other work of a similar genre (Corradi, 1991). Furthermore, the use of triangulation also provides convergent validity (Fielding & Fielding, 1986; Miles & Huberman, 1984).

However, Kirk & Miller (1986, p. 73) have argued that with qualitative methods, while validity has often been achieved, this has happened at the expense of reliability. Nevertheless, they assert that '*qualitative research can be performed as social science and can be evaluated in terms of objectivity*' and suggest that '*the problem of validity*

is handled by field research and the problem of reliability is handled by documented ethnographic decision making.'

This shift to qualitative methods has been reflected in theoretical debates within the social sciences and taken up especially in social psychology. Contrary to the traditional view which saw subjective reality as a natural given, the '*new paradigm*' social constructionists have challenged this conventional understanding of knowledge with its objective basis, and claimed rather that knowledge is achieved through social interaction, that prevailing knowledge is not based on truth but on social processes, that the terms in which the world is understood are the product of historically situated exchanges (Gergen, 1985a, 1985b, 1987; Howard, 1991). Similarly, social representations also highlighted the social processes involved in giving meaning to experience and framing reality. According to Moscovici (1984) these social representations were seen as systems of values, ideas and practices which served to order and code social exchange, providing a shared social reality which influenced behaviour (Jaspars & Fraser, 1984).

The importance of conversation in constituting and restructuring social reality had also been emphasised in the writing of Berger & Luckmann (1971), who further saw power as an important means of determining legitimacy of experience. The study of narrative accounts expanded work on the significance of language. In this approach, narratives are seen as ways of organising and structuring experience around time and consequential events, which depict constructions, attempt to find meaning and function reflexively (Bruner, 1987; Corradi, 1991; Howard, 1991; Mishler, 1986; Riessman, 1990). Narrative analysis has been used in a variety of contexts, for example in feminist work (Graham, 1984), accounts of illness (Riessman, 1990), in psychotherapy (Epston, 1992; White, 1992), around racism and sexism (Etter-Lewis, 1991) and in the area of AIDS (Viney & Bousfield, 1991).

DISCOURSE ANALYSIS

In line with these '*new paradigm*' developments, there has also recently been an increasing amount of work in the field of discourse analysis. According to van Dijk (1985a), this approach has a long history, with its roots in classical rhetoric. In the sixties it re-emerged with the analysis of texts in the work of structural linguists and anthropologists, but it was only in the seventies that it developed as an independent research orientation across disciplines and included a widening of focus from written texts to spoken discourse in a social context, as in psycholinguistics and conversation analysis (Potter & Wetherell, 1987; van Dijk, 1985a). Within psychology, the influence of post-structuralism has also been strong (Burman, 1990; Gavey, 1989; Parker, 1990b; Weedon, 1987).

Presently there is no one approach to the study of discourse and the concept has come to be used in a variety of ways, which range from the more formal and detailed language analysis of linguistics, to an emphasis on communication and the relationship between language and human subjectivity, to a focus on ideology and the power dynamics of discourse (Stamp, 1989). However, these different tendencies share common concerns. With challenges to traditional notions of the natural unitary self as the centre of experience and separate from society, has come a move toward recognising subjectivity as socially constituted, culturally and historically contingent; producing a shifting, fluid, decentred and even splintered sense of self (Hollway, 1989; Levett, 1988; Lowe, 1991; Potter & Wetherell, 1987; Weedon, 1987). Further, in keeping with the constructionist perspective, there is agreement that language does not just convey meaning but in fact is used to construct versions of the social world, that it is through language that experience is interpreted and made understandable (Bowers, 1988; Burman, 1991; Potter & Wetherell, 1987; van Dijk, 1985b; Viney & Bousfield, 1991). This conception of knowledge production allows for different versions of experience and requires an understanding of the conditions which produce different accounts (Hollway, 1989; Levett, 1991). Discourses then are not static but inevitably multiple, fragmentary and contradictory (Foucault, 1979; Gavey, 1989), and always occur in relation to other discourses (Hollway, 1989; Macdonell, 1986). The positions

which the subject takes toward the available range of discourses are shaped by the context and the investments (rewards and satisfactions), which may be both conscious and unconscious, of particular positioning (Hollway, 1984b; Levett, 1988).

However, some writers maintain that a social constructionist approach does not necessarily account for the fact that discourse has a dual character, in that it is both the means through which the world emerges and action becomes possible, but it also constrains which meanings or knowledge are possible. In other words some versions of social reality are legitimate, given 'voice' and reside in the hands of 'experts'; while others are silenced, so that power relations are produced and reproduced through ideological systems (Fielding, 1988; Lowe, 1991; Parker, 1989; Stamp, 1989; White, 1992). As Young (1987, p. 114) claims '*it is this duality, through which action and understanding are simultaneously enabled and constrained, that links knowledge to power*'. So it is the gaps and silences, that which is not said which become as significant a focus in analysis (Bhavnani, 1990; Lowe, 1991; Parker, 1992). Nevertheless, power is not an all or nothing business, nor is it merely a question of power being oppressive. Rather power can also be both positive and productive, is manifest in multiple sites and is always accompanied by resistances (Foucault, 1979; Hollway, 1984a; Macdonell, 1986; White, 1992; Young, 1987).

Another relevant debate in discourse analysis has centred on the extent to which this approach promotes critical interventions and is socially transformatory. On the one hand, it is argued that the focus on variance and difference can favour relativism, while concerns with deconstruction and reflexivity can replace resistance and political action (Abrams & Hogg, 1990; Burman, 1990, 1991; Lowe, 1991; Parker, 1990b). Also, notions of power being suffused through all social practices suggest that power structures are not easily altered (Young, 1987). However, other work emphasises that the shifting, contradictory nature of discursive positioning ensures that resistances and transgressions are always possible (Foucault, 1979; Hollway, 1984b; Levett, 1988). Writers have also elaborated on the functions of discourse analysis in making apparent how power/status relationships are maintained (van Dijk, 1985c), and suggested how discourse analysis can be conceptualised as a variety of action research (Parker,

1990a). Burman (1991, p. 328) has recently argued that attention to discourse has mounted a '*critique of social science (including psychology) practice by challenging its function, truth claims and methodological adequacy, and by importing concerns of moral-political accountability*' so that it is '*possible to use the analytic framework to make interventions in practical dilemmas*'. Nevertheless, she claims that the approach is not necessarily inherently politically transformatory but suggests a number of ways in which political interventions are possible from this perspective:

Discourse analysis can (a) champion the cause of a particular discourse by elaborating the contrasting consequences of each discursive framework, can (b) promote an existing (perhaps subordinate) discourse (as the 'empowerment', 'giving people a voice' model of research), can (c) intervene directly in clarifying consequences of discursive frameworks with speakers (as in training or action research, for example), as well as (d) commenting on the discursive-political consequences of discursive clashes and frameworks (Burman, 1991, p.340).

Hollway (1984b, p. 260) on the other hand has drawn attention to the place of the unconscious in current investments, making them particularly inaccessible to alteration. However, while recognising the complexity of the process, she identifies how shifts may occur:

Changes don't automatically eradicate what went before - neither in structures nor in the way that practices, powers and meanings have been produced historically. Consciousness-changing is not accomplished by new discourses replacing old ones. It is accomplished as the result of the contradictions in our positionings, desires and practices - and thus in our subjectivities - which result from the coexistence of the old and the new. Every relation and every practice to some extent articulates such contradictions and therefore is a site of potential change as much as it is a site of reproduction.

From the growing literature on discourse analysis there have been a number of studies which have relevance for this project. Strongly influential in many of these writings has been the complex and wide-ranging contribution of Foucault (Parker, 1989; Stamp, 1989). Within psychology the challenge to traditional social psychology from Potter & Wetherell (1987) with their development of the notion of '*interpretative repertoires*' was central (Bowers, 1988). The work of Henriques, Hollway, Urwin, Venn & Walkerdine (1984) stimulated the process of decentring the self of mainstream humanist and other psychological theory. Post-structuralist feminists have also explored the place of discourse analysis in theorising gender and subjectivity (Gavey, 1989; Weedon, 1987).

Stamp (1989), in her work on gender and development in Africa, has highlighted the significance of a discourse analytical approach to the feminist political economy orientation which she favours. Hollway (1984a, 1984b, 1989) has used what she calls '*interpretative discourse analysis*' in her analysis of the construction of sexuality in heterosexual relationships. She has made an important contribution by incorporating a psychoanalytic framework to understand the role of the irrational, the unconscious and (Kleinian) interpsychic defences, in the uniqueness of each person's discursive positioning. Her work has also stimulated much other research in related areas of gendered subjectivity (Gavey, 1989; Levett, 1988; Miles, 1992).

And finally in the area of AIDS research, there has been growing recognition of the need to understand the range of discursive positions available and how these mediate responses to the problem. Schoepf (1993, p. 15) explains that '*because the terrain includes multiple, often competing discourses, including racism, moralism, male chauvinism and denial, the changing representations of AIDS are a necessary starting point for behavior change*'. And Seidel (1990) has suggested that the study of AIDS discourses, because they shape individual and social attitudes, has important implications for social policy, social action and the quality of life for people with AIDS. Other theoretical work in this area was discussed in Chapter One (for example, Plummer, 1988 and Treichler, 1987) and the issues will be taken up again in detail in the next chapter.

AIMS

This study then, aimed to both explore the range of discourses which women had available regarding AIDS, and the ways in which these discursive positions mediated possible prevention action. It was expected that hegemonic professional discourses would be reflected in the positioning of women in the study, but also that alternative, non-dominant, contradictory discourses would be evident. The research therefore intended to capture both range and interplay of discourses, in order to generate an understanding which would contribute to possible interventions.

MOTIVATION FOR METHODS USED

In order to achieve the above goals, I decided to draw on Potter & Wetherell's conception of **interpretative repertoires** which they defined as '*broadly discernible clusters of terms, descriptions, common-places and figures of speech often clustered around metaphors or vivid images and often using distinct grammatical constructions and styles*' (Potter, Wetherell, Gill & Edwards, 1990, p. 212). However, as I was also concerned to pursue how gendered subjectivity served to mediate women's positioning in AIDS-related discourses through the negotiating of power, I made use of Hollway's **interpretative discourse analysis** approach to some extent as well, in which she defines discourse as '*a set of assumptions which cohere around a common logic and which confer particular meanings on the experiences and practices of people in a particular sphere*' (Hollway, 1984a, p. 63).

THE SAMPLE

Ninety-five black subjects, eighty-five of whom were women, were involved in the study. Many researchers have commented on the dominance of a white middle-class perspective in understanding the experience of women, and the need to make the worlds of black women more normative (Cannon, Higginbotham & Leung, 1991; Dugger, 1991; Etter-Lewis, 1991). There is a particular absence of research information regarding the sexuality of black women (Fullilove *et al*, 1990; Wyatt & Lyons-Rowe, 1990). Because of their long history of oppression on many levels of society, this '*silencing*' is especially true of South African women, who have moreover had limited access to economic resources, education and health facilities generally, but also to AIDS education, counselling and care. In addition the large majority of women affected by AIDS in South Africa are black. Of the total of 1803 reported AIDS cases by February 1993, 655 of the 665 women with AIDS were black (DNHPD, 1993a). Furthermore, most research and models of prevention have originated from within a white, middle-class context.

Ten men were included in the study to begin exploring how best to understand and tackle gender issues in education and care. As was argued in the previous chapter, there are contradictions in working with women only and there has been debate among South African AIDS workers about the relative merits of tackling single-sex or mixed groups. Also, as Hollway (1984b) has argued, women and men are positioned differently regarding available discourses of sexuality, both as subjects and objects. Therefore it was intended to explore this proposition, as well as the impact of men on the generation of data for analysis and on the group process (Stewart & Shamdasani, 1990).

Potter & Wetherell (1987) have pointed out that there are no natural boundaries to sampling in this type of research. Subjects were recruited across multiple sites in order to enrich the quality of data collected (Miles & Huberman, 1984; Morgan, 1988). While the nature of the study was largely exploratory and intended to provide depth of focus and understanding rather than broadly representative data (Hollway, 1984b), the wide range of settings and number of groups allowed for a certain degree of generalisability of findings and development of theoretical saturation (Bender, 1985; Standing, 1992; Strauss, 1987). It also provided the opportunity for some triangulation of data across group settings, as well as with material from the initial two studies (Fielding & Fielding, 1986; Miles & Huberman, 1984). In addition, the diversity of settings was chosen to reflect experiences of women in contexts considered relevant/significant for AIDS interventions. In this regard Nyamathi *et al.* (1990) have stressed the importance of targeting high-risk groups at those community sites which yield the greatest number of such women. Subjects were therefore recruited from the following settings:

- STD clinics, because of possible high-risk behaviour and the demonstrated links between STDs and HIV infection, and because these women already have concerns about sexual behaviour (Nyamathi *et al.*, 1990; Schopper, 1990);
- antenatal clinics, where the risks of HIV infection have serious consequences for pregnant women and their families, and require urgent reproductive decisions (Standing & Kisekka, 1989);
- community nutrition centres, providing for unemployed women who have family health problems, but lack resources and access to formal health

- facilities; so that they might be at risk of infection, but lack necessary information and be less able to protect themselves;
- community political organisations for women and youth, where some level of AIDS awareness could be expected and which could serve as structures for future AIDS interventions;
- employment categories of domestic workers and teachers: the former because of limited educational background and high levels of exploitation and the latter because of their important role in educating youth (Marks, 1989; Vergnani, 1993);
- university students, because they are likely to have had some exposure to AIDS education, yet are often seen as engaging in high-risk behaviour (Strebel & Perkel, 1991a).

INSTRUMENTS

FOCUS GROUPS

Data for discourse analysis can be generated in a number of ways. Potter & Wetherell (1987, p. 7) have defined discourse broadly as '*all forms of spoken interaction, formal and informal, and written texts of all kinds*'. In this study I decided to utilise spoken interaction, in order not to exclude the experience of less-literate women, and so focus group discussions were held. This qualitative research method originated in market research but has been used increasingly in social research and health education, for example family planning (Basch, 1987; Ferreira *et al.*, 1987). More recently it has also been utilised in AIDS research generally, and specifically in research with women (Duke & Omi, 1991; Ehrhardt *et al.*, 1991; Flaskerud & Rush, 1989; Herasme *et al.*, 1991; Irwin *et al.*, 1991; Nyamathi *et al.*, 1990; Nyamathi & Vasquez, 1989). Data gathering involves a '*systematic process of observing, detailing, describing, documenting, and analysing the social and cultural worlds of a particular group of people*' (Nyamathi & Vasquez, 1989, p. 302). Focus group discussions are considered to have advantages over methods like informant interviews and participant observation in that they offer '*the chance to observe participants engaging in interaction that is concentrated on*

attitudes and experiences which are of interest to the researcher' (Morgan & Spanish, 1984, p. 259). Discussion, therefore, is reasonably flexible and allows the researcher access to natural ways in which subjects talk about the topic but also ensures that relevant issues are raised (Ferreira *et al.*, 1987; Stewart & Shamdasani, 1990). The group format allows for interaction between participants regarding the topic, provides a supportive environment for exploration of meanings and also reduces the possible influence of the researcher on the construction of accounts (Kitzinger, 1990; Magura *et al.*, 1987; Worth, 1989). It is especially useful for dealing with somewhat sensitive topics and for promoting empowerment among participants (Basch, 1987; Lather, 1988; Stewart & Shamdasani, 1990). Irwin *et al.*, (1991, p. 928) in fact claimed that the use of focus groups in AIDS research was especially '*effective when dealing with sensitive, intimate topics among Africans with a strong oral tradition*'. However, such a constructed group setting with its group norms is also likely to produce different levels of disclosure and talk to individual interviews or participant observation and not to allow the same degree of control over discussion as informant interviews (Ferreira *et al.*, 1987; Irwin *et al.*, 1991; Morgan & Spanish, 1984; Pickering, 1988). Calder (1977, cited in Basch, 1987, p. 419), describes three types of focus groups: exploratory, clinical and phenomenological, the latter being concerned with '*everyday knowledge from the shared perceptions of particular respondent subgroups*'. This last approach to data-gathering seemed most suited to the purpose of analysing discourses. (See especially Basch, 1987, Morgan, 1988 and Stewart & Shamdasani, 1990 for a detailed discussion of focus groups.)

VIGNETTES

Stewart & Shamdasani (1990) recommend the use of aids where appropriate to facilitate discussion in focus groups. In this study vignettes were used in each group (Levett, 1988). On the one hand, they served to concretise the problem of 'AIDS' for subjects. They also allowed participants to distance themselves somewhat from the potentially threatening issues of disease, death and sexuality. In other words, they could make use of defence mechanisms like projection to explore their own experience where necessary (Perkel, 1992), by attributing anxiety-provoking motives and feelings

to those of the characters in the vignette. Three vignettes were constructed, which were intended to be sufficiently broad to allow subjects to create their own meanings, but which also highlighted slightly different aspects of the topic. All three vignettes dealt with women confronted by AIDS-related situations which affected their lives. The first story covered issues from the perspective of a young unemployed girl, financially dependent on a partner (*Sophie & Jakes*). The second concerned the options of an older employed woman wanting to marry and start a family (*Maria & Sam*), while the third tackled the problems of a family with an HIV+ father (*Dawn & John*). Each vignette was followed by the question: *What do you think of (name)'s situation?*. They were available in English, Afrikaans or Xhosa. Copies of the English vignettes and questions are to be found in Appendix C.

SKETCHES

Each vignette was accompanied by a coloured sketch depicting the scene. Such visual aids are encouraged in order to provide the richest possible data (Reinisch *et al.*, 1988; Stewart & Shamdasani, 1990). The purpose of these sketches was to reinforce the communication of the story and provide an ongoing stimulus. This was considered especially useful for less-literate women.

BIOGRAPHICAL DATA FORM

The brief questionnaire was designed to provide basic demographic data, including age, marital status, number of children, level of education, employment status, as well as information on domestic arrangements, possible migrancy and sources of financial and emotional support. These variables were considered relevant for understanding AIDS-related experiences. This combination of qualitative method and questionnaire is recommended by Morgan (1988), especially if comparisons are to be made between groups and sub-categories of participants. The questionnaire was available in English, Afrikaans or Xhosa (See Appendix D for a copy of the English version).

AIDS EDUCATION RESOURCES

Information leaflets and pamphlets in three languages were obtained from non-governmental and para-statal organisations, as well as condoms.

JOURNAL

I also kept a personal journal during the time that I was setting up and conducting the groups. Unlike the more '*objective*' field notes often recommended for qualitative research, this involved rather a recording of my feelings and responses during the process. This was intended to capture some of my reflections on the process, in order to emphasise awareness of the interactional nature of the research method and to facilitate analysis and interpretation of the co-construction process (Bender, 1985; Kirk & Miller, 1986; Miles & Huberman, 1984; Plummer, 1983).

PROCEDURE

SETTING UP THE GROUPS

Contact was established with the different research settings outlined above through personal connections or official channels. For example, through links with an Adult Education Project, I was able to set up a group of domestic workers, while the clinics were reached through regional health authorities. This usually involved telephonic communication followed by a meeting, in order to obtain official permission/support for the project. Next a meeting was arranged with the staff at the clinic or a key person in the group, at which the purpose of the project was outlined; a letter of motivation given (to ensure accurate informing of prospective subjects); and recruitment of subjects, a venue and date arranged. A few days before the actual session, a follow-up telephone-call was made to confirm arrangements. Generally there was strong support and enthusiasm for the project, as many health and organisational staff expressed the urgent need for such a focus. However, the practical arrangements required for this

scale of project were extremely time-consuming and required considerable flexibility as a result of factors like staff changes and other contingencies.

RESEARCH ASSISTANCE

Research assistance was considered necessary to deal with language differences, for co-facilitation of groups and as a result of a commitment to the development of black researcher skills (Hansson, 1991). Selection of the most appropriate person/s was not self-evident and I considered a number of options. These included the use of staff in the different health settings, a person from the organisation approached to do translations, or post-graduate social science students. In the end, after interviews with perspective candidates and consultations with researchers experienced in similar methods, one assistant with post-graduate qualifications in psychology, experience in organisational human relations and whose mother-tongue was Xhosa was recruited. She did extensive reading in the area of women and AIDS and was trained in the relevant research methods. She also participated in the construction of the vignettes, questionnaire and sketches. The sequence of groups was planned to gradually move her from minimal participation (in Afrikaans-speaking groups) to taking charge of Xhosa-speaking groups. The nature of the research process required a high level of motivation and commitment from the assistant researcher (AR), who had to identify with and own a project created by someone else. This also necessitated that as principal researcher (PR) I was able to loosen control and share responsibilities, which after months of preparatory immersion in the project was not always easy. The possible impact of some of the differences between us, for example of style and emphasis, as well as of age and race would need to be explored in analysis of data.

THE GROUP PROCESS

Fourteen focus group discussions were held: four in STD clinics, two in antenatal clinics, two at community nutrition centres, two with university students, two with members of the women's league of a political organisation, one with domestic workers and one with members of the youth league of a political organisation. One of the

groups with the women's league members consisted of women who were all teachers. One student group and the youth group consisted of both men and women, while the rest were women-only groups. The size of the groups varied from five to ten participants. Although there is some disagreement about the extent of heterogeneity considered optimal for such focus groups (Ferreira *et al.*, 1987; Morgan, 1988; Stewart & Shamdasani, 1990), the particular group settings were selected to provide both depth and range of experience, as described above. Subjects were either recruited beforehand or on the day of the session. In some of the groups, members were known to each other, while in others they were strangers. Although it is sometimes recommended that focus group participants do not know each other, there are also advantages to using pre-existing groups (Basch, 1987; Kitzinger, 1990; Morgan, 1988). Differences between groups who were strangers and those who knew each other were investigated in the intergroup analysis. Groups took place either in a room at the institution or in a participant's house, depending on ease of access (Ferreira *et al.*, 1987). Every group was co-facilitated by both myself and the assistant. Choice of language was negotiated with participants: six were conducted in Xhosa, three in English, one in Afrikaans, three in a mixture of English and Afrikaans and one in a mixture of all three.

The central issue of language in a research project of this nature will be discussed in greater detail later. However, at this stage a few comments can be made regarding the implementation of the procedures. The choice of language during sessions appeared to occur in a reasonably spontaneous fashion, except for one session in which subjects strove, with some difficulty at times, to speak English. This appeared to be in order to engage me directly, as I knew some of them personally. During the predominantly Xhosa sessions, the AR would at times make English summaries of the discussion, which were intended to allow participants to verify their understanding of communications and to provide me with the gist of discussion. These were sufficient for me to identify main themes, although obviously not to convey nuance and detail, and did not seem to disrupt flow of expression. However, given the time taken to obtain verbatim translations, these were mostly not yet available after each group, so that I found it frustrating at times not to be able to pursue some unexplored issues

during subsequent sessions. It also appeared as if the AR used these translation opportunities at times to tide her over pauses in the discussion. Overall, while this modus operandi was clearly not an ideal arrangement, it did provide some creative spaces for experimenting with options in a multilingual context.

Subjects were welcomed and thanked for their willingness to participate. Sometimes they had not been adequately/correctly motivated about the purpose of the discussion. This seemed to be the result of misunderstandings in some instances, and possibly the presence of different priorities of staff at the institutions concerned in others. For example, some health workers seemed to regard the researchers as '*experts from outside*' who could perhaps help communicate some of their health messages more effectively. So time was spent initially explaining the purpose of the session and subjects were informed about the tape recorder (Bender, 1985; Ferreira *et al.*, 1987). The use of the apparatus did not seem to bother participants. After one or two sessions, sections were played back at the request of members of the group, who said that they had never heard their recorded voices before.

The biographical questionnaire was completed either at the beginning or end of the group discussion, with assistance where necessary. Then the sketch was attached to a wall and the vignette recounted. Except in one instance when two vignettes were used, all groups responded to only one vignette. Vignettes were selected to suit the age and other circumstances of the participants and seemed to be an effective stimulus to discussion. However careful attention would need to be paid in interpretation to the influence of story content on data obtained and to the role of these scenarios in the different levels of identification by women with particular discourses. In other words, what was the difference in meaning between statements about the people in the vignette and subject's own experience?

Subjects were then asked what they thought about the situation, and other open-ended questions were introduced where necessary (Mostyn, 1985). Sessions lasted from about 45 to 90 minutes, after which refreshments were served, and there were opportunities for questions and private discussion (Kitzinger, 1990). The use of

condoms was demonstrated and information leaflets and condoms made available. This conception of AIDS research as more than just a one-way flow of data to 'experts', but rather as an active process of exchange of information (Schoepf, 1993) will be pursued in greater depth later.

The condom demonstrations were well-received, and provided a cohesive, if at times somewhat raucous, opportunity for closure of sessions. While subjects sometimes role-played the educator, it was clear that many had never handled a condom before. Subjects were keen to take away both condoms and information leaflets. Schoepf (1993) has also described the value of condom demonstrations in her group-work with women in Zaire. While most questions for more AIDS-related information were dealt with during group discussions, many women enquired afterwards about ways in which they could become involved with AIDS work, where to find AIDS resources in the community, and whether such sessions could be organised for their partners/friends.

Finally, each participant received R25-00 remuneration (Bender, 1985; Magura *et al.*, 1989; Phoenix, 1990). Although I had not planned it that way, subjects were not informed beforehand by those who recruited them of the payment. This seemed to reflect a degree of discomfort among 'gate-keepers' of the different groups at the prospect of subjects being motivated to participate by financial gain. In some instances, it was decided to donate the money to the organisation of which the women were members.

Participants were assured of confidentiality: no names were obtained and all identifying data was altered in transcriptions, which were handled only by the two researchers and two employed transcriber/translators. Feminist writers have raised concerns about the ethics of researching women: given the ease with which they talk about themselves, there are issues relating to trust and the potential exploitation/betrayal of women subjects and the data they generate (Finch, 1984; Lorber & Farrell, 1991; Oakley, 1981). I was made aware of this dilemma occasionally during analysis of data when faced with material which did not necessarily conform to expectations or depict women in the most favourable light.

All in all the fourteen groups went off without major hitches. Only one envisaged group, with HIV+ women, did not eventually take place: it seemed that women's attendance at the clinic was not regular and they had not been informed beforehand of the session, so that it was abandoned. With the exception of two groups, discussions were generally flowing and enthusiastic, so that the co-facilitators did not have to do a lot of work to generate discussion.

For purposes of analysis, the groups were coded as in Table 1:

Table 1: Focus group codes

Group	Description
A	University students
B	Antenatal clinic attenders
C	Sexually transmitted disease clinic attenders
D	Domestic workers
E	Members of political organisation (women's league)
F	University students*
G	Antenatal clinic attenders
H	Sexually transmitted disease clinic attenders
J	Members of political organisation (youth league*)
K	Nutrition centre attenders
L	Sexually transmitted disease clinic attenders
M	Members of political organisation (women's league)
N	Sexually transmitted disease clinic attenders
P	Nutrition centre attenders

* group included some males

ANALYSIS

TRANSCRIPTION AND TRANSLATION

Although qualitative analysis does not always require this, the discussions were transcribed verbatim from the tape recordings onto computer (Bender, 1985; Ferreira *et al.*, 1987; Kirk & Miller, 1986). This was considered essential for the level of analysis to be used (Paget, 1983). New speakers, pauses, hesitations, overtalk, background noise, unclear speech and other sounds were indicated, as well as talk from the two facilitators. Male speakers and speech not in the predominant language of the session were identified where necessary. Transcriptions were done by the co-facilitators and some by two other workers. These were then checked by the two facilitators. Translations from Xhosa and Afrikaans into English were either done by the group facilitators or checked by them after translation. Raw data consisted thus of both tape recordings and computerised transcriptions or translations, although in analysis I used only the latter. Both transcription and translation proved to be extremely taxing and time-consuming, and levels of motivation of paid workers could understandably have fluctuated.

Moreover, the process of transcription was not without problems. Despite the good quality of the apparatus used, it was sometimes difficult to pick up what had been said, especially in a group with much talking at once. In addition, whether the transcriber had participated in the groups or not influenced transcription. Having been in the group made it easier to recognise what was being said at times. However this also raised the likelihood of projecting one's own understanding of what was being communicated. It is generally recognised that the process of transcription always involves some degree of transformation of data and requires multiple reworkings for maximum accuracy (Mishler, 1986; Potter & Wetherell, 1987). Transcription of talk also does not capture the many non-verbal communications of such a process (Stewart & Shamdasani, 1990).

Translation of the text raised further particularly tricky questions for a methodology like discourse analysis. Firstly, there was the issue of whether to aim for translation of meaning or content. Also, the process of translation inevitably involved interpretations of meaning and constructions on the part of the translator, so that the end product would be likely to be somewhat different from the original. Furthermore, there was the decision about whether to have translations done by a mother-tongue speaker or not, which would result in differences in the eventual text for analysis. In this instance it was decided to use a Xhosa-speaker and stick to her English, rather than '*translating*' again into English-English. Either way, some of the texture and nuance is invariably lost (Strebel, 1992).

Overall it needs to be recognised that transcription and translation are not simply mechanical acts resulting in replicas of '*live talk*'. The process of carrying out these activities necessarily creates new versions of the discourse which reflect the positioning of those involved. Despite these obstacles however, as the intention was not to carry out detailed language analysis, but rather to look at broad discourses and sketch the range of talk, it was felt that the method still had value. Some of the dilemmas would need to be investigated further during analysis of data. For example, it would be necessary to explore differences in discourse between groups facilitated in the different languages, and ideally even between different translators. In addition, there was the question of how non-English-speakers would have positioned themselves regarding the dominant discourses of medicine and gender as depicted mainly in English (Fortin, 1987). However it was beyond the scope of this project to explore some of these and other intriguing questions of discourse and translation raised by this choice of method.

DISCOURSE IDENTIFICATION

Given that one measure of the validity of qualitative methods is the possibility of scrutiny of the process by other like-minded researchers, the stages of analysis will be described in some detail (Levett, 1988). Focus group methods of analysis are not standard, although two main options have been identified: a qualitative or ethnographic summary and a systematic coding via content analysis (Morgan, 1988). Likewise, there

are no standard techniques of discourse analysis (van Dijk, 1985b). As mentioned above, the methods used here followed to some extent those of Hollway and of Potter and Wetherell. Analysis included two stages, described below.

Stage One Analysis

Potter & Wetherell (1987) have recommended that initial coding of data should be as wide and inclusive as possible. The initial phase involved an '*immersion in the data*' as Mostyn (1985) suggests, a careful sifting out of themes, a searching for patterns, both of consistency and variance (Fielding & Fielding, 1986; Potter & Wetherell, 1987). The first level of coding was the result of prior reading of related literature, of my earlier work in this field and of multiple readings of the transcriptions. This testing of categories against the data is described in the grounded theory work of Glaser & Strauss (1967) (Layder, 1982; Strauss, 1987). Eleven such themes were initially generated and coded: AIDS (AID), medicine (MED), gender (GEN), condoms (CON), politics (POL), education (EDU), being HIV+ (POS), media (TEV), reproduction (REP), safe sex (SAS), and culture/tradition (CUL). Transcriptions were then read again and talk which corresponded with these categories marked. There are no clear guidelines on how to identify units of discourse, or what constitutes the natural boundaries of selected units (Levett, 1988). The excerpts used were phrases, sentences, paragraphs or exchanges between group members. Some quotes fell into more than one category: in this way discourse analysis differs from content analysis which focuses rather on discrete frequencies (Levett, 1988; Mostyn, 1985). All the instances of each category were then collected together and totalled for each group. See Table 2 below for total number of quotes identified in each category and in each group:

Table 2: Number of quotes per group and category

	AID	MED	GEN	CON	POL	EDU	POS	TEV	REP	SAS	CUL	TOTAL
A	52	25	43	49	30	50	19	14	7	6	5	300
B	14	7	5	4	0	0	4	0	3	3	0	40
C	10	8	5	6	0	0	8	0	1	3	0	41
D	34	12	19	12	3	2	13	1	2	2	0	100
E	27	19	29	10	24	37	29	5	3	8	1	192
F	22	24	23	14	12	33	11	9	0	7	0	155
G	22	29	23	12	0	1	20	1	8	4	1	121
H	20	9	36	30	0	1	13	0	2	1	0	112
J	16	15	34	9	7	21	8	1	2	6	9	128
K	30	11	25	16	0	5	18	0	2	2	6	115
L	22	14	45	27	1	2	14	2	3	2	0	132
M	22	3	28	28	30	40	16	6	0	2	6	181
N	18	10	21	13	0	0	4	0	4	0	0	70
P	23	9	13	21	6	2	22	0	3	0	0	99
TOTAL	332	195	349	251	113	194	199	39	40	46	28	1786

The texts were then read through again to see if additional categories needed to be generated at this stage. The marked sections were photocopied, extracted from the text and grouped together in the categories. The original texts were checked again for possible omissions and reclassifications.

Stage Two Analysis

After several readings of the groups of coded text and experimenting with different combinations, two major discourse fields emerged, which seemed to best reflect and make sense of the material: one around AIDS and the other to do with gender. (The AIDS group subsumed the previous categories of AID, MED, EDU, POS, POL, TEV; while the gender group included those of GEN, CON, REP, SAS, CUL.) Dominant, minor and contradictory discourses and their possible connections were mapped and relevant quotes from the text grouped accordingly. Again, those parts of the text excluded through this process were checked for bias. After several reworkings, a final version was developed and quotes selected to illustrate the discourses. Given the wealth of data generated during field-work, it was obviously necessary to exclude many examples of the discourses identified. Selections were made to represent voices from different contexts (group settings) as well as in an attempt to accurately reflect the weight of particular positions. It would also have been possible to produce a range

of discourses not included in the present study, or to have grouped/emphasised positions differently. In this instance, selection was made according to considerations of theoretical appropriateness and possible practical application. Finally, I returned to the original texts to test the interpretations which I had generated within their context and to check for possible distortions and omissions.

Although I had been guided by the literature and my experience to expect the two broad categories of AIDS and gender discourses, too little work had been done in this specific field for guidelines on what to expect from the micro-analysis. So after completion of the above process, I '*emerged*' again and returned to the broader context. This involved an exploration of the significance of these discourses by comparing them with mainstream academic discourses, searching for unexpected emphases and silences, trying to understand seemingly problematic stances, and reflecting on the whole procedure (Parker, 1992).

The process of discourse identification highlighted complex aspects of the research. Firstly, those discourses associated with the notion of AIDS seemed a lot easier and '*cleaner*' to recognise than those of gender. They seemed more clear-cut, obvious and discrete. Those dealing with gender, on the other hand, seemed less accessible, requiring much more '*massaging*' and able to be constituted/interpreted in a variety of ways. It is interesting to speculate whether AIDS as an issue out there, with which people have as yet very little personal connection, is more likely to be reflected in clear positions as encountered in mainstream discourses. While gender is much more part of women's ongoing, often un-reflected upon, internalised experience; so that talk about it echoes to a greater extent the complexity and interwoven-ness of this lived world.

Furthermore, the process of crystallising discourses had an arbitrariness which was both disconcerting and anxiety-provoking at times. Firstly, there was the sense of imposing an idiosyncratic structure, and thereby maybe distorting associations and simplifying relationships. There were also questions about the representativeness of selected quotes: how does one weight the position expressed by only one group or

one person within a group, or the force/frequency with which a position is expressed? What about the process of extracting phrases, sentences, exchanges from their specific context within the sequence of a particular group (Silverman, 1985)? And finally, how does one deal with the different relationships speakers express towards a specific discourse: how to interpret the difference between *'other people do'*, *'people should'*, *'if I were her I would'* or *'I would/do'*?

GROUP PROCESS ANALYSIS

A further stage of analysis focused on the group process, to explore the role of contextual factors in the generation of discourses, and also to check the usefulness of such group processes for AIDS intervention (Irwin *et al.*, 1991; Schopper, 1990). Lather (1988, p. 574) has suggested that in AIDS work *'group interviews provide tremendous potential for deeper probing and reciprocally educative encounters'*. This stage of analysis also occurred in two phases. Firstly the groups were compared across a number of variables: language, age, race, mixed/single sex, education level, familiar/stranger groups, facilitator, total output in each category, vignette used, different group contexts and political awareness, for the different categories of analysis as initially identified (Morgan, 1988; Morgan & Spanish, 1984). Each group was then also analysed for quantity, nature, range and progression of content, for the spread of speakers, for flow of speech (overtalk, interruptions, agreement), the impact of the facilitator, evidence of group learning (which has implications for AIDS education) and group support (with its implications for care of people with AIDS).

DESCRIPTION OF SAMPLE

Before proceeding to describe the findings of the analyses as outlined above, I will sketch an overall picture of the subjects who participated in the focus group discussions and comment on some aspects of the sample. The age of subjects ranged from 15 to 47 years of age, with an average age of 26 years. Two-thirds had an African language as mother-tongue, while the rest were more or less equally divided between

English and Afrikaans speakers. Eighty percent were single, with about ten percent married and the rest divorced/separated or widowed (See Table 3). Of the single subjects, almost 80% claimed to have a regular partner. One-third had been together with this partner for up to one year, 23% for two to five years and another third for six to ten years. Almost half (44%) the participants did not have any children, while the same percentage had one to three children and the rest had four to six. Regarding level of schooling, the majority had at least some secondary level education, while only one woman had had no formal education (See Table 3 also).

Table 3: Demographic features

Variable		Number	%
Marital status	Single	75	79
	Married	10	11
	Divorced/separated	8	8
	Widowed	2	2
Home language	African	63	66
	English	17	18
	Afrikaans	15	16
Education level	None	1	1
	Primary	16	17
	Secondary	44	46
	Tertiary	34	36

Just over half the subjects had been born in Cape Town (56%), and a further quarter in the Transkei. Fourteen percent came from the Eastern Cape and the rest from the Transvaal (4%). They were all presently resident in the Western Cape. Equal numbers of participants were employed and unemployed. Three-quarters claimed that they received financial support from family when they were without work, 17% from a friend and ten percent from no-one. About two-thirds said they would turn to family with a problem, and a quarter to a friend.

There are a number of characteristics of this sample which need to be kept in mind when interpreting results. With an average age of 26 years, this was a young group

of women. The majority were also single, although in a stable relationship, and almost half did not have children. Most had at least some secondary level education, but only half were employed. Many had been born and were still living in Cape Town. Family was the chief source of financial and emotional support.

Some explanatory comments on level of education are necessary. While the number of women with some secondary schooling is not unusual, the percentage of those with some post-school education/training is unexpectedly high (Budlender, 1991). While this is partly explained by the sampling (of university students, teachers), it also reflects decisions by those recruiting subjects for participation in the study (clinic sisters, leaders in community organisations). On more than one occasion it seemed that they had intentionally selected better educated women '*who would be able to answer the questions*' as one antenatal clinic staff member put it.

Given the youth, single status and absence of children of most subjects, they would be likely at some stage to have to deal with AIDS-related decisions about numbers of sexual partners, safe sex options and reproductive choices. Being single raised particular issues of power in gender relations, as mentioned in an earlier chapter. On the one hand they might be more dependent on multiple partners both emotionally and financially, and so possibly increase risky behaviour. However, on the other, they might have opted for this status in order to give themselves more control over their lives, and thus be able to be more assertive in practising safe sex. Both in South Africa and the rest of Africa there is evidence that many women run such female-headed households (Budlender, 1992; Cooper *et al.*, 1991; Jaffee, 1991; Ramphele & Boonzaier, 1988; Standing, 1992; Ulin, 1992; van der Vliet, 1984). Having stable partners also does not necessarily reduce risk of infection, as many monogamous women have become HIV-infected (Berer & Ray, 1993; Carpenter *et al.*, 1991).

The fact that many participants were well-educated but unemployed would increase the likelihood of financial dependence. However, the fact that most had been born locally, with their families resident in a large urban centre, meant that they did not have to deal with issues of migrancy and remittances to the rural areas. However, with their

reliance on family for financial help and emotional support in dealing with problems, these women might have to contend with family members' possible denial, rejection and discrimination if they were to become infected.

ANALYSIS OF GROUP PROCESS

As described above, this phase of the study involved investigation of features both across and within groups. The scope of this process was limited to a number of issues which would help to contextualise the later analysis of discourses, as well as those with implications for AIDS interventions.

INTERGROUP FACTORS

In this stage, groups were compared across a number of variables regarding output in the initial categories as identified in Table 2, as well as an overall assessment of each group. I also drew on entries made in the personal journal regarding my experience of the sessions. A number of salient findings will be discussed below, and a summary of some of the factors considered is given in Table 4.

Familiar/Stranger

Although the literature on focus groups has suggested that it is preferable for group members not to know one another, Kitzinger (1990) found that there were advantages to using pre-existing groups. Findings from this study did not show marked differences. Groups of strangers tended to have lower overall output, while those who knew each other gave more gender (GEN) and condom (CON) responses, although one might have expected that discussion of gender and condom use would be issues which were difficult for women to explore with friends. Group members who knew each other were also more likely to discuss or disagree over issues among themselves. One group of friends (Group A) summed it up after their session by saying that they felt there were both advantages and disadvantages to knowing fellow group members.

Making use of both types of groups probably increases the range of possible responses.

Table 4: Factors in intergroup analysis

Group	Race	Language	Fam/Str	Vignette	Facilit
A	African	English	Familiar	2	PR
B	Coloured	Afrikaans	Stranger	2/3	PR
C	Coloured	Afrikaans	Stranger	2	PR
D	African	E/A/X	Familiar	3	PR/AR
E	Coloured	English	Familiar	2	PR
F	African	English	Familiar	2	PR
G	African	Xhosa	Stranger	2	AR
H	African	Xhosa	Stranger	1	AR
J	Coloured	E/A	Familiar	2	PR
K	African	Xhosa	Familiar	3	AR
L	African	Xhosa	S/F	1	AR
M	African	English	Familiar	3	PR
N	African	Xhosa	Stranger	2	AR
P	African	Xhosa	Familiar	3	AR

Age and Vignette

Younger women were given vignette 1, while older women were given vignette 3, and the rest vignette 2. The use of different vignettes did not seem to significantly affect output or content, although vignette 3 tended to have more responses about being HIV+ (which was the focus of the vignette) and older women tended to talk more about their children and safe sex (SAS).

Language and Race

Groups conducted in English yielded the highest number of responses, while those in Afrikaans produced the fewest, although the groups were facilitated by the same researcher. Those in Afrikaans generally had very little discussion between group members, with short responses and a sense of constriction about them. Together with this, Coloured groups produced significantly fewer responses about condoms although the most regarding safe sex, while African women had many CON responses and least SAS statements. African women also tended to speak more freely and in greater detail about sexual behaviour generally. It is interesting that Fullilove *et al.*, (1990) found that lower income African-American women talked easily about sexual experiences in AIDS-related group discussions.

Education and Politicisation

In groups of women with higher levels of education there were substantially more statements about education (EDU) for AIDS prevention and political issues (POL), especially related to racism and the origins of the disease. On the other hand, those with less education tended to have more AIDS and medical (MED) responses.

There are probably a complex set of factors playing a role in these differences of language, race and education. The two Afrikaans-language groups described above were Coloured women of lower education who apparently had little information about AIDS. The facilitator found these groups difficult to get off the ground and keep going, so that in one of them a second vignette was introduced (the only time that this happened), with minimal effect. On the other hand, groups held in English with well-educated, politicised Coloured women had none of this restricted content and range. However as mentioned above, discussion about condoms and the practicalities of sexual experience was limited here too. It seems possible that for these women there were constraints regarding engaging in public discourse about matters sexual. Although the role of this '*consensual silence*' (Bhavnani, 1990; Etter-Lewis, 1991) needs further exploration, when it is considered together with the seemingly limited

AIDS information among less educated Coloured women, it might suggest that group methods are perhaps not optimal for generating discourses of sexuality and exploring prevention options among such women. On the other hand, African women across the language and education spectrum seemed comfortable in the group situation and in making use of discourses of sexuality. However, such a notion of public discourse needs to be approached cautiously. Foucault (1971) has argued that the public discourse serves to regulate sexuality; while Fullilove *et al.* (1990) have suggested that the presence of a '*public dialogue*' does not necessarily translate into a similar discussion of matters sexual in '*private conversations*'.

Regarding educational level, it is understandable that those with more exposure to education were more likely to advocate this route for AIDS interventions, while less-educated women tended to be more concerned with the facts of infection and transmission and to have a more passive belief in the value of medical options. This issue of the impact of the dominant medical discourse will be discussed in Chapter Four, as will the role of an educational discourse among politicised minorities in South Africa. The fact that political issues were predominantly raised by these women of higher education rather than only by those with formal political affiliation needs to be examined. On the one hand it suggests that political awareness of AIDS issues is most easily engendered through formal channels of schooling and the written media, so that less-educated women would not readily have access to such accounts. However, I also felt that the specific context of sessions facilitated by a white professional contributed to the differential airing or silencing of political positions in different groups. Either way, the implications for empowering individuals and communities to respond effectively to the AIDS epidemic need to be considered.

Gender

Two of the groups included both men and women. These two groups had the highest output regarding cultural factors (CUL) and also many EDU responses. Gender and condom statements were more or less equally divided between men and women, while AID, POL and CUL statements came mostly from men, who also overall had more

responses than women, especially in the Coloured group. Men expressed sentiments that women too had problems with using condoms, a stance which women expressed in women-only groups but not in the presence of men. Men also rejected the notion of women having to get men to change their behaviour. Although gender differences were not the focus of the study, some interesting issues were raised for consideration in planning AIDS interventions. Firstly, given the differences in interaction style of women and men in mixed or single sex groups (Stewart & Shamdasani, 1990), variations in output and content can be expected. Also, we can expect that women and men will be positioned differently as subjects and objects of discourses of sexuality (Hollway, 1984b). Moreover, the use of notions of culture/tradition by men in connection with gender relations is echoed in other South African work. For example, Ramphela (1988) has argued that male hostel dwellers manipulate notions of '*tradition*' as a resource for the social control of women; while van der Vliet (1991), in her study of marriages in the Grahamstown area, described how men opted for '*traditional defences*', and women for '*modern attacks*' in their negotiation of marital relations. It seems thus that under certain circumstances (eg. with better educated and informed participants) such mixed groups might be productive and in fact necessary for challenging unnuanced positions and constructing alternative discursive positions. This view was supported by requests from groups for such discussions together with men. However in some circumstances, both men and women probably need opportunities to explore gender issues away from the '*other*'.

Specific Concerns

There were issues which understandably reflected the particular concerns of some groups. So for example, women in antenatal clinic groups had questions about AIDS and reproduction, and women from STD clinics raised concerns about symptoms which might suggest HIV infection. This again indicates the necessity for education programmes sensitive to the specific concerns of target groups.

INTRAGROUP FACTORS

Here each group was studied in detail to observe overall process, relationship between group members, and facilitator, levels and type of expression and other significant factors. Some of the significant issues arising from this analysis are discussed below (See Appendix E for coding conventions for quotations from the text).

Role of the Facilitator

In exploring the inputs of the facilitators, it was evident that we both drew on many recognised group therapy principles to promote group discussion. These included promoting open-ended discussion by as many participants as possible:

AR: How do other people feel about telling people if you have the sickness? (H)

frequently requesting clarification:

AR: I want to make sure we are on the same wavelength. Are you saying that because men tend, when in a group, to discuss sex in such a negative light, it would be difficult for them to discuss in a more decent way with their partner? Is that what you're saying? (J)

trying to include less-assertive subjects:

PR: Sorry, you wanted to say something just now?/okay (giggling) (D)

responding to non-verbal communications:

PR: (Name), you looked as if you have a different opinion? (M)

bringing the focus back to the topic:

PR: It sounds as if we have got into a bit about what is the right way to conduct a relationship ... and I pick up that is quite an important issue for many of you. But perhaps if we focus it back onto the question of AIDS? (F)

reflecting questions back to the group:

What are the symptoms for AIDS and how do you know that you have AIDS?

AR: Anna, do you want to tell them about the virus, the symptoms of AIDS?

PR: What do other people think about the question?

AR: Okay, what do you think?

Some say your body temperature rises, your body becomes itchy/mm. (N)

providing information when this was appropriate (eg. for inaccurate information in the group or clarifying confusion about facts):

When people gi-, give some (pause) blood, and maybe she gets AIDS in the blood, and they don't test the blood before, they don't test the blood and then give it to you, the, you get, er, er, AIDS/mm/mm.

PR: Is that what others of you also think happens?

Mm/ yes.

PR: I think we are quite fortunate in South Africa because all blood gets tested/ mm/mm. (D)

testing out further areas for discussion:

PR: Okay, you mentioned the business of trust. Are there other problems that might arise in talking about condoms? (J)

Overall, groups facilitated by the PR generally produced a greater number of responses. This was probably mediated by a variety of factors, including more extensive clinical experience of conducting therapeutic groups and greater familiarity with the detail and nuance of the project. Reinisch *et al.* (1988) have stressed the value of such clinical background in conducting research on sexual behaviour and AIDS.

Challenges to the facilitator, both direct and more covert, came from a few of groups; in the form of resistance to being engaged in discussion:

PR: Have you heard anything [about AIDS]?

Nothing.

PR: And among your friends at home, it isn't?/

I haven't any friends at home.

PR: And on TV and in magazines?

I don't actually like the TV (laughter) and I don't read library books or the newspaper. (C)

as well as seeming political statements from the groups of better educated and politicised subjects:

Is there a reason why you only, um, are you talking to women like this?

PR: Ja, starting off talking mainly to women. You know, a number of people have said it's often quite difficult, many women feel uncomfortable about things sexual in front of men, saying: It's not our tradition, or whatever, or the men dominate/ (laughter)

In this group it wouldn't be a problem. (laughter) (E)

Can I just ask something to some of you? I mean, we are sitting here debating about this thing. Can you explain the purpose of this whole thing? (*)

Yes, are you taking some hints, or what? (laughter) (*)

The problem is we must actually think if this is relevant or not relevant ... what are you doing after this whole thing, that is important to me. (*)

Ja, ja. (*)

PR: [Explains again about purpose of study] What I heard you to be saying was that we were a bit stuck on how to proceed?

No, no, I, I, I was caught up in not knowing are we saying the right thing, are we getting somewhere, you know, are you gaining anything from the discussion/mm you know? (*)

But I don't think there is a right thing. (F)

This raised the issue of the person of the facilitator. As was indicated earlier, much has been written in feminist research methodology which emphasises the importance of women conducting especially qualitative research on other women (Oakley, 1981). My impression of the groups was that the presence of women researchers did create a sense of shared experience (Finch, 1984), especially related to men's treatment of women and sexual matters, and through a construction of men as 'other'. However, it has also been pointed out that this commonality is not necessarily sufficient to ensure optimum data collection. Class and cultural factors also play an important role (Riessman, 1991). In this study, while we facilitators were both women, we were also both middle-class and as principal researcher I was white. Although challenges were not directed specifically to one or other of us, my impression was that they seemed to have to do with both racial and class issues, as well as gender. It was interesting that when challenged by a male subject, I was immediately 'rescued' by one of the women in the group. It was also significant that although both researchers were introduced to subjects as psychology graduates, we were frequently referred to as doctor or nurse (the white PR as doctor, and the black AR as nurse).

There has been considerable debate about the feasibility and appropriateness of whites, and especially white women doing research with black women, both in South Africa and elsewhere (Funani, 1992; Gender Research Group, 1991; Hannon, 1991; Hassim & Walker, 1992; Thompson, 1992). On the one hand, there are obvious constraints of, for example, access and credibility; as well as important political questions regarding the legitimacy of knowledge and power being reproduced by especially white academics (Evans, 1990; Muller & Cloete, 1987). While these are crucial considerations, I nevertheless felt that there were strong arguments to undertake the present research: concern about the urgency of responding to the important issue of AIDS; an interest to explore issues affecting fellow women; considerable exposure to both African and Coloured world-views within an academic,

psychotherapeutic and personal context; the importance of collaborative work with a black co-researcher. Another consideration in this debate had to do with insider and outsider perspectives. There is sometimes an assumption of privileged access to knowledge for *'those to the manner born'* (Merton, 1972); as opposed to the argument that the outsider stance might both allow and constrain certain positions and interpretations (Hassim & Walker, 1992; Hollway, 1989; Lorber & Farrell, 1991; Merton, 1972). With these various arguments in mind, a central concern of the study was in fact to explore the impact of such variables on the process.

In practice, I did not feel that my presence inhibited the research process significantly. I was also aware of the value of my psychotherapeutic experience (for example, in handling challenges) in facilitating the process. Initial impressions from the data were that there were not significant differences between the repertoires generated nor the discursive positions adopted in groups led by myself or the assistant researcher.

However, I was interested in the impact of my presence on the kind of discourses which were voiced and those which might have been silenced. One impression recorded in my diary was of the sense of being let in on a different world at times, of subjects responding to me as *'the white uninformed'*. This was possibly partly in response to questions like *'What do you think that women like you could do to prevent the spread of AIDS?'*, but also seemed to include an element of a *'you'* and *'us'* positioning. Together with this was the tendency to draw on notions of *'we blacks'* and *'our menfolk'*.

I am talking from a black perspective. In the first place, there's a lot of people who actually feel it's a white thing, okay? (F*)

Because most of us blacks, we do not believe that AIDS is really there. (P)

Also, I'm very very, very concerned about our menfolk. I think they are the stumbling block, you know/ja. (A)

You must know that an African man will not be at a loss for words in his own home. (K)

This probably reflected their experience of me as being different, a stranger to some experiences and practices, as well as that of the distance between researcher and

subjects, the gap between insiders and outsiders referred to above. It also seemed to suggest a discourse of social position, in this case of minority status coupled with a positive identification of difference. The relative silence in their accounts about, for example, culture, traditional medicine and healing, all aspects of insider experience, also need to be considered in this analysis.

Language Use

The nature of the **talk** which groups utilised was particularly interesting. This should to be seen against the background of claims in the literature that the language of AIDS is predominantly a language of the developed world mediated by western media (Earickson, 1990; Fortin, 1987; Sabatier, 1988) and that in South Africa the discourses of AIDS have been overwhelmingly conducted in English. There has already been mention of the variation in flow of speech: from lively debate and free-flowing, animated exchanges with much overtalk in most groups and related to some topics, and with minimal direction required from the facilitator;

It's a cap [the female condom]/ no, it's like a flat thing, it's round and you insert it/you insert it?/is it a cap?/ja/l haven't seen it around/its been there for a long time/diaphragm?/no, not a diaphragm, it's a cap, you put it in and then/after sexual intercourse you pull it out/you pull it out and wash it and/you wash it?/can you use it again?/use it again?/ja/yes/my goodness!/phew!/(unclear) rather the male contraceptive, it's much safer, it just complicates everything/ja it does/because if the cap doesn't fit properly/ja/how do you, how do you/just like/just like the condom, you can use anything and any size (laughter)/it can adjust to any size and/it's not as safe as the man's condom. (A)

to groups which required considerably more effort to generate discussion and were characterised by short responses to questions, little debate among participants, and at times possibly resistance to contribute:

She could in fact pick up the virus/mm.
 PR: What would happen to her then?
 She dies. (pause)
 PR: Do you know how it happens? (pause)
 She gets thin and sick. (pause)
 PR: Is it a problem that is talked about much? (pause) (B)

Also striking was the difficulty which many subjects had in talking directly about sex or about AIDS, the euphemisms and hesitations employed around these terms

(although as was mentioned earlier, African women more readily raised issues of sexuality):

You know, some affairs are new, some affairs are/old/old, you know/mm/but even, I mean, I can't, I can't, you know, I can't, um, um, um, understand, I mean, to, to, to, it would take a long time for me to adjust myself to, to the question of my boyfriend coming with a pack of condoms all of a sudden. (M)

I mean, take it for myself, my partner don't want (laughter), to use, none of my partners don't want to use (laughter), he refuse to. (E)

Can someone correct me, um, there is (pause) a possibility that if you have, if you have, if you are HIV+, and you go for a test sooner, you stand a better chance of living longer? (A)

This absence of specific terminology for talking about sex has been found in other research among young women as well as recognised as a problem by some feminists (English, Hollibauch & Rubin, 1987; Thomson & Scott, 1990). Patton (1985, p. 104) elaborates:

There is scant language for discussing sexual experience that is not laden with the seedy if compelling language of the Gothic novel or the distastefully pristine terms of sexology. Ironically, the unorthodox bid for a language of sexuality that is closer to the physicality of desire takes an excruciatingly intellectual route.

Moreover, this has been found to be a problem in sub-Saharan Africa where taboos exist between generations and people of unequal status (de Zalduondo *et al.*, 1989; Standing & Kisekka, 1989). Such constraints pose problems for AIDS education which requires the detailed discussion of sexuality and sexual behaviour, especially if this reserve is also characteristic of private discussion between partners.

* Another noticeable feature of subjects' talk was the different levels of identification which they employed with regard to issues. This was clearly linked to the use of the vignettes as starting point of discussion, which allowed them to select their level of engagement. There seemed to be two main positions of a 'them' and an 'us' adopted. The 'them' stance involved discussion of the protagonists depicted in the vignettes, and revolved mainly around suggestions about how they could/should respond to the AIDS issue:

Okay, we know our men like to have lots of girlfriends. Because Sophie loves him, she won't leave him because of that, nor can she ask him to leave other girls. (L)

But this man, once he has heard that he has AIDS, he could listen if his wife advises him to use a condom. (K)

Another use of *'them'* language seemed to distinguish between subjects and others: people generally, the uninformed, the average citizen. This allowed subjects to actively distance themselves from particular positions and express their superior insight or knowledge regarding the issue under discussion:

It's true because I can see a lot of people going off and finding out they have AIDS and committing suicide or something like that. (E)

You know, that's actually quite a serious problem, that people know the AIDS exists, but it doesn't affect them directly, so they're not really, I mean, they're not worried about the issue. (J)

This strategy has associations with discursive positioning relative to *'the other'* discussed in the next chapter. Then there was the *'us'* position and its nuances. Much discussion involved expressions of what *'one'* or *'you'* **would** or **should** do in various circumstances:

Sometimes you think about leaving him and enjoy your life without him/give him up/yes, there's nothing you can do/yes. (L)

Okay, even if you produce a condom, your boyfriend changes and turns against you. (D)

This seemed to allow subjects some distance from their own beliefs and practices. However, there was also much *'I'* talk, reflected in accounts of personal experiences:

Even myself, I was worried, I thought I've got AIDS, I thought these pimples are AIDS symptoms/mm/because I was also worried that I might have AIDS. (N)

I chased my boyfriend away because I am frightened for the AIDS (laughter) or he'll bring AIDS from the outside. (D)

I would tell people about it [being HIV+] because I did not deliberately get infected, I don't know how I got infected. (H)

Many subjects shifted between *'them'* and *'us'* talk, although some spoke more easily about others than themselves:

I take it now if I must hear anybody in our flats that's got AIDS, I can see how people will react, they won't go there ... they definitely will stay away/mm. (E)

You find women very aggressive when you mention this [condoms] because most men, I am not talking about myself. (laughter) (F*)

This distinction had echoes of the distance created between researcher and subject discussed earlier. It also raises for educational initiatives the important question of the need for people to recognise their personal vulnerability to HIV infection in order to bring about behaviour change. This could be linked to the significance in psychotherapeutic work of using 'I' to own experiences (Nelson-Jones, 1982).

Groups as Education and Support

The other important feature of the group process was the role of these sessions in providing support and education on AIDS. There has been considerable discussion among AIDS researchers and service providers of the distinctions between the two functions, with varying opinions on whether research and intervention are and should be separate and different enterprises or whether the urgency and ethics of AIDS work requires a combination of the two processes (Miles *et al.*, 1992). As my initial involvement in AIDS research was strongly influenced by an interest in interventions, one objective of this study was to test the feasibility of this latter position.

Firstly, there was evidence that the groups were experienced as safe and supportive, as the majority of groups included divulgence of personal experiences, often in the private area of sexual behaviour:

I will never sit with my daughter and talk about boyfriends and condoms, because your child will take this to mean you are actually telling her to start now and she will be very cheeky with you ...

I once had a discussion with my daughter about family planning. She also told me that at school they do receive lessons about how to use condoms. (K)

I mean, I went for an AIDS test and nobody sent me on counselling before I got my results. (J)

Really, I've got them in my room, I got them from the clinic ... my boyfriend just took the condom, looked at it and filled it with water (laughter). He said: Sorry I can't use this thing (laughter) because it does not feel nice, you see. (D)

Many groups also involved examples of members resolving differences of opinion constructively. A number of participants directly stated the positive value they experienced in the group process (even if they hadn't been active participants):

Because these group discussions are important because it actually makes you interested in the whole thing/ya/in trying to combat/ya, ja/the whole question of AIDS and/even/those, if you come up with something, programmes and stuff like that, you probably would assist them, want to get involved with it.

And even if you don't participate, you can at least come and listen/mm/and go back knowing that you know a bit more. (E [a subject whose only contribution this was])

Like actually having discussions like we're having now, that type of thing, in the different areas. I mean, what wouldn't we accomplish if each one of us should go into a different area and do what we're doing now/mm/we'd accomplish a helluva lot/mm. (J)

There were also many requests for repeats with friends and partners, or on a much larger scale.

The group discussion was coupled with a more explicit educational component in the form of condom demonstrations and distribution, and the availability of AIDS literature. The response to these aspects was also positive. However, the most encouraging sign of the educative aspect of the groups was the presence throughout the groups of the negotiation of meanings and understanding jointly, and learning through peer discussion. Time and again there were detailed interchanges on differences of interpretation and belief, or the exchange of information and the recognition that subjects had gained new insight:

I would like to know if AIDS can be cured or prevented?

AIDS can't be cured, tablets and injections won't even help/but you can't tell your boyfriend that you have AIDS/but you must be honest with your boyfriend, tell him that you have AIDS. (unclear)

No, he will run away from you. (laughter)

So to me AIDS, the testing is a real problem/and because it cannot be seen now, you won't know that you have AIDS, it only shows after some years. (G)

A lady who has a man with 5 girlfriends must go and get condoms from the local health clinic, so that whenever you sleep with him you use a condom.

What if the man refuses?

No, he can't refuse, otherwise you need to discuss the issue with him, because it's your life, you need to tell him about AIDS and that it cannot be cured. Remember when you first met him, he agreed to most of the things, why not now? If he refuses and he knows that AIDS cannot be cured, what does he want you to do?

If you allow him to use condoms all the time, would you be encouraging him to be promiscuous?

If you didn't bring the condom, do you think it will stop his promiscuity?/to me it seems as if you are encouraging him/what can I say? You don't encourage him by using a condom. You have to talk to your man. (L)

Now this is the way I saw AIDS: if the father has got it, he sleeps with the mother, the children are there already, the father is using the same washing rags as the children, so then they can get TB/AIDS/yes, I mean to say AIDS.

Listen here/oh, is it contagious?/you don't get infected from kissing, you don't get AIDS by sharing washing rags/by sharing washing rags/you don't get AIDS by using the same toilet/AIDS/you get infected through sexual intercourse. (D)

There was also very seldom need for the facilitator to correct misinformation, as direct questions reflected back to group members usually provided answers:

What about the woman, er, the woman who perhaps, who likes sex and she can't do without it, what is she going to use?

PR: What do you think?

(unclear) (laughter) they say that if the woman is infected and the man uses the condom, then he won't get infected. (C)

Because I mean, if you're married I'm sure you'd never use a condom?

PR: Well, what do other people think of that?

Married people use it (laughter) of course.

No, I'm sorry, I didn't know that. (laughter) (J)

While the advantages of group counselling have not yet been systematically established (Schopper, 1990), a number of researchers have highlighted the value of group approaches (Kitzinger, 1991; Magura *et al.*, 1989; Worth, 1989). Irwin *et al.* (1991) have stressed the role of focus groups in education. Seeley *et al.* (1991) and Schoepf (1993) have raised the ethical consideration of providing a service in exchange for data-gathering, and the designing of research programmes as interventions. Valdiserri (1989) outlined the importance of the group workshop format in prevention initiatives with gays, as a means of transmitting new ideas and changing group norms. Leviton (1989) sees group approaches as enhancing community involvement and empowering subjects to implement their own prevention programmes. Moreover, such collaborative work obviously provides strong pointers for AIDS interventions which move away from depictions of AIDS as an individual problem and responsibility, to models for contextual analysis and joint action.

Although this focus on the group process has necessarily been somewhat cursory, it has brought to the fore the diversity of influences on the process of '*reading text*' and thereby created a context for interpreting the further analysis which follows. It has also paved the way for considering the place of group strategies in AIDS interventions.

CHAPTER FOUR

THE MAIN STUDY: RESULTS AND DISCUSSION

A critical study of AIDS discourse with its intertextual awareness is not only a legitimate concern, but needs to be seen as an essential dimension of AIDS research. It contributes towards a more caring and informed society, deepening the democratic project and the struggle to achieve greater sexual 'equality', to uphold human rights and human dignity (Seidel, 1990, p. 79).

This section will explore the repertoires women utilised in discussing AIDS and will investigate the range of different positions women adopted in relation to these discourses, as well as the implications of such positioning for AIDS interventions. While subjects drew on dominant professional representations of the problem, they also gave and moved between alternative and sometimes contradictory accounts. As mentioned earlier, the two main discourse themes centred around AIDS and gender. These will now be discussed in some detail.

AIDS DISCOURSES

The extensive representations of AIDS clustered around two main themes: a medicalisation and a stigmatisation discourse. Although these categories reflected much of the academic writing about social constructions of AIDS, as outlined in Chapter One (Plummer, 1988; Sontag, 1988; Treichler, 1987), women in this study revealed a complex set of relations toward these dominant discourses. The following section will outline the major stances, as well as some consequences for women of these positions.

THE MEDICAL DISCOURSE

Central in most conceptions of AIDS was the medical discourse. This incorporated a wide range of biomedical and disease-related notions, perceptions of what being infected meant, as well as clinical interventions like testing. It also included considerations on the place of education in dealing with the crisis. These positions were recognised and accepted with conviction by the majority of women.

AIDS as Epidemic

Firstly, AIDS was seen as an epidemic, with a concern for symptoms, how the virus was spread and comparisons with other serious diseases. In line with depictions of the syndrome in academic journals, conference proceedings and media reports (Baum & Neselhof, 1988; Cape Times, 18/2/91, 6/6/92; Chin, 1992; The Guardian Weekly, 18-24 June 1993), women spoke about AIDS as a new, serious, infectious, incurable and fatal disease:

No, because AIDS is a new disease here and people are not used to it. (G)

AIDS is an actual epidemic (background noise) I mean the statis-, the statistics around alone can tell you that. (J)

The disease is here now, this, um, is killing everyone. (M)

AIDS is really a problem/you don't even know it enters your body/other diseases are cured but AIDS cannot be cured. (L)

But, but I think AIDS is a killer. (J*)

They will both die (unclear) and other people will get infected. (H)

However, there were also conflicting opinions that the disease could be treated and/or cured (See The value of testing below). Participants drew comparisons with other diseases like TB, cancer and leprosy, especially regarding associations with stigma and denial:

I take this, the AIDS, like leprosy, I take it to leprosy, because if a person, if a person has leprosy they are kept far from the others. (M)

My point is we, it's actually, first because it's like an epidemic, it's worse, at least it's as bad as smallpox was. (J)

I think it's almost like cancer was before, people weren't keen to talk about it and I don't think it will be easy for them to talk about it. (B)

The same with women who suspect they have got cancer, they don't want to go, they just suspect they got it, they know there's a cure for it, but they won't go; the same with AIDS, you always think: Not me man. (E)

I think with AIDS, just like TB, in the old days you know TB was taboo and it was never associated with the higher classes, you know it was a poor man's disease. (M)

However they saw AIDS as worse than any of these:

While on the other hand, there's a lot of people suffering from cancer, so cancer can't shock you, it can be treated unlike AIDS, and cancer cannot affect others like AIDS/mm. (G)

Like there are certain diseases that can be seen at it's early stages, like syphilis, there are signs, your urine burn, but AIDS cannot be seen until after some years. (L)

You cannot tell people about AIDS, it scare them. We know that people are scared of TB, AIDS will scare them worse. (K)

They described a long incubation period with an eventual range of symptoms which inevitably lead to death, as well as conceptions of the virus as affecting the immune system and or blood:

I think it just depends on some individuals, with some people it takes longer before you actually become, before you actually have AIDS/mm/some people could be HIV+ for years before it actually/reaches the AIDS/develops into AIDS or whatever, some people I think it never develops into AIDS, I don't know. (A)

He could sit for years with the infection before anything happens. (B)

She will start getting thin and sweat and won't have an appetite. (C)

Okay, sometimes a person loses appetite and looks tired because he has got AIDS, and he gets a runny tummy/mm and it can be seen that he has a certain illness. (P)

Like AIDS is now all over. For instance we went to (place) to visit an AIDS victim ... the person is thin, she eats light food like fluids, she doesn't eat bread, she can't leave her bed, she use a tube for urine. (L)

The beginning of AIDS is (unclear) you get all the sicknesses because your blood can't stand it, all the cells are dead, and now you get AIDS, all the sicknesses. (D)

It's the lymphatic system/what happens to it?/I mean the cells that are protecting your body from being infected from the viruses, they start dying off/because of the AIDS/so your immune system now/is sort of like weak ... so if you get a 'flu, bang you can die/everything can affect you/because you don't have anything to protect you ... so your immune system is sort of affected, so you don't have those cells protecting your body. (A)

And another thing, the reason John got ill from TB is because his soldiers are weak, when you have AIDS you get sick from all diseases because you are weak, because AIDS is all sicknesses.

Yes it destroys your soldiers, it is not one illness, when it has killed all your soldiers, it becomes AIDS/mm. (P)

I don't know if I am wrong, but what I've heard is that if I don't have AIDS and I know that you have got it, er, it has got something to do with blood, if perhaps (unclear) I don't know but there is something to do with blood. (K)

What can I say, people's blood are not the same and they do not always match, you understand (pause) or maybe you slept with a man who's blood is wrong. (L)

Although the majority recognised that the virus was transmitted sexually, and identified other possible routes of transmission, they also expressed confusion about modes of infection and echoed many popular misperceptions about the role of injections, toilet seats, eating utensils, etc., as well as the fear that the disease could come from nowhere:

We get AIDS by sleeping with a certain person, by having sexual intercourse with that person who has AIDS/mm. (G)

If I have AIDS/mm/and you have a wound, if I bleed, if I get a cut and bleed and my blood gets into your wound, that is how you will get infected with AIDS. (D)

I think this way when you kiss your man you exchange each other's saliva, through that process you can be infected/mm.

I didn't know that just by kissing another person you can be infected/me too (laughter)/I thought it's only through sexual intercourse. (L)

You can get it from the needles that were used by people who use drugs/mm. (G)

She may also want a child but she is not sure if the child may also get affected. (N)

One other thing is that when our people get sick with something they like to go to the witchdoctors. We know the healers always open cuts all over our body (laughter)/mm/by allowing that you can get AIDS although you still use a condom. (K)

But you see in some cases, it's not necessarily from actually just sexual relationships, drugs and all that, dentists for example are not the safest people to go to anymore. (A)

Like I say you visit your nearest hospital or clinic for family planning late in the afternoon. At that time the nursing sisters are about to close for the day. You come in, they call you and inject you without changing the needle. Maybe they used it for a prostitute or AIDS victim, you don't know, that way you can be infected. (L)

Because now they think if they're gonna donate blood they gonna get AIDS/ja. (E)

You also get infected through blood transfusion if that blood is not checked/I agree with you. (G)

You can also get it from the spoon used by an infected person, you can also get it from the toilet and from the toothbrush used by a person infected by AIDS, if you stay with an infected person and you share toothbrushes. (N)

For example like toilets at the station and things like that where everybody sits and one doesn't know what sort of person sits there and then you go to the toilet and then you can also pick it up there/that's the truth. (C)

Other people could also get infected by Dawn because when she gets her periods, she uses the same washbasin/mm/we use that washbasin for everything ... so it can get transmitted because we will all use the same basin. (K)

But, um/it looks like if I touch you and you've got AIDS, I'll get AIDS. (J)

You sometimes get HIV out of nowhere, that's how, I mean that's how I conceive the whole thing/yes you could/nowhere. (A)

At the same time, there was awareness of the inaccuracy of some of these perceptions:

You know with AIDS, you know, just communicating and sitting near a person with AIDS, you will not contract AIDS. And you know that drinking from the same glass and such things, I think we need to understand that. (M)

Because people don't know, people don't know that if you go into their house you won't get it, if you drink out of the same cup, or you don't have to send your children in there, um, be scared if they give your child a lollipop, a sweet, the child will be infected with AIDS, people don't know that. (E)

You don't get infected with AIDS from kissing, you don't get AIDS by sharing washing rags/by sharing washing rags/you don't get AIDS by using the same toilet/AIDS/you get infected through sexual intercourse. (D)

This perspective also included the belief that the disease was easily caught and that if one partner was infected, the other(s) and children would inevitably also become infected. Any new symptom they experienced nowadays could also be AIDS:

Yes, she should be worried because AIDS is now everywhere, you can get AIDS everywhere. (C)

Can it happen that while we are sitting talking, that one of us get infected?

No, it cannot, one cannot get infected like that (laughter)

If one of us here has AIDS, by the time we leave we will all be infected with AIDS/no/no. (H)

That means, which also boils down to the fact that if Lindi has AIDS, her boyfriend is also, does also have AIDS, if she is positive, you see, er/(unclear)/if she is positive then he is positive. (F)

Then what will happen if he gives me a baby?/Yho, a baby!/What, a condom baby with AIDS, people what is this? (unclear, laughter) ... the AIDS show from two, the baby cannot last longer, it will die. (L)

They have got it already/the kids have got it/they have got it because it starts in the womb of the mother. If I have AIDS, my child will also get AIDS. (P)

No, we are scared of it (pause) because in reality there is no-one who survives with AIDS (unclear) even myself, I was worried, I thought I've got AIDS, I thought these pimples are AIDS symptoms. (N)

It seems, thus, that the medical paradigm was a powerful and convincing one, which people from a wide variety of positions in society readily recognised and accepted (McDonald, *et al.*, 1990; Plummer, 1988; Schoepf, 1992; Treichler, 1987; Warwick, Aggleton & Homans, 1988). It appeared in this instance to be accompanied by strong images of disease which drew on comparisons with other epidemics and illnesses (Alcorn, 1988; Brandt, 1988; Sontag, 1988). It also generated considerable confusion, with a welter of information, both accurate and inaccurate. However, it did not seem to allow for nuance and specificity. Once the language of disease and epidemic had been mobilised, subjects made use of an extensive range of associated meanings and beliefs to fill out their understanding, which probably reflects the interweaving of lay and popular beliefs with professional ones (Fitzpatrick, 1984; Schoepf, 1991; Treichler, 1987; Warwick *et al.*, 1988). It is likely therefore, that in tackling AIDS prevention efforts, broad information campaigns would be insufficient to replace the '*epidemic package*' with precise detail of what fits and what doesn't for this specific disease.

Such a medical discourse also serves to sustain the image of the medical professionals as experts, with the knowledge to understand the complexity of the problem and to determine solutions. Moreover, the dominance of this set of assumptions provides a justification for and obscuring of existing structures of social control (Berger & Luckmann, 1971; Gilman, 1988; Krieger & Appleman, 1986; Patton, 1990; Sontag, 1988). Levett (1988, p. 186) has described how:

'The significance of professional discourse is that it is self-perpetuating, ideologically dominant, and that it is filtered through the media, through formal education and by word of mouth, to shape the discourses of the lay public where it is echoed, verbally and in performance in particular ways.'

The ordinary person is thus disempowered, lacking in such expert knowledge and unable to take action without access to this medical world and its professional

language. So paradoxically, while the medical paradigm is one which implies individual responsibility for illness, it also communicates the need for outside 'expert' intervention to deal with the problems. This is then compounded by the rapidly changing medical knowledge about AIDS which is being amassed in the research and clinical sphere: any information acquired is soon outdated or contradicted by more recent findings, which perpetuates dependence on the 'experts'.

The media has played a central role in constructing representations of the disease. While it is recognised that the media, and especially television, has increased awareness of AIDS substantially, this has not lead to changes in behaviour (Valdiserri, 1989). In addition, the impact of media messages is not straightforward, but mediated by the social context (Kitzinger, 1989). Nevertheless, the media has been powerful and authoritative in the replication of existing social relations (Levett, 1988; Patton, 1985). This has been evident in a number of fields: by racist misrepresentations of Africa, especially regarding sexuality (Chirimuuta & Chirimuuta, 1987; Kitzinger & Miller, 1991; Sabatier, 1988); by serving to control women's sexuality through depictions of women as '*the contained threat*' (Juhasz, 1990); and by reinforcing the weight of the medical science perspective through the translation of academic findings into everyday knowledge (Becker, 1986; Wellings, 1988). A substantial industry has developed around AIDS: international conferences yearly draw thousands of delegates; specialist journals have sprung up in the last few years; large sums of money are being made available for research; and many academics and clinicians have made careers in AIDS work (Cape Times, 4/12/92). It is important that, especially from the ranks of the gay community, AIDS activists have challenged this biomedical hegemony and demanded a say for those affected by the disease in decision-making (Wachter, 1992a).

Significant in these medical depictions of AIDS was the absence of a discourse on traditional African medicine, as found in other AIDS work (Ingstad, 1990; Konotey-Ahulu, 1989; Staugaard, 1991). There was minimal use of traditional conceptions of health and illness to understand the problem, or to try to treat it. It is possible that the biomedical perspective silences such everyday knowledge, thereby distancing AIDS from the realm of common experience, which further emphasises people's

helplessness regarding the problem. Seeing AIDS as an alien disease then would increase denial (as discussed later in this chapter). It is also possible, as mentioned earlier, that the person of the researcher contributed to this void.

The Trauma of Being HIV+

Conceptions of the disease were given substance in images of the infected person. '*Having AIDS*' introduced one to a Pandora's Box of overwhelmingly negative consequences. Firstly, being HIV+ meant your whole world crumbled, with suicide a likely outcome:

We see their life as very sad because even if John works, can still work, even if he has AIDS, their future is very sad, because their future is leading to the grave. (P)

Because I think that's what scares you, because automatically you find out you've got AIDS then bang my life's ended. (A)

I think, I think to some extent it is correct that that person's world would to some extent crumble. (J*)

And the boyfriends say that if they go to the doctor (unclear) they will ask the doctor just to shoot them dead, so they can just go (laughter) ... yes, yes ask to be shot because he knows he is going to die. (D)

And if you heard that you have AIDS, you've got it, maybe it would be better just to kill yourself (unclear) there is no cure for it ... my advice is that you should just kill yourself, to take a quick way out. (H)

Furthermore, if you were known to be infected, others would avoid you and you should be isolated for fear of contamination:

Because people don't want anything to do with this sickness. (K)

It reminds me of a question that was asked by (name) this afternoon. She asked if, if I have, if I have contracted this er disease er/will you still be my friend?/and I said.no (laughter). (M)

I mean we live in a flat. Imagine I must hear our neighbour's got, um, AIDS. You'll say to your children: Don't go in there, don't go in the house, don't play with their kids, don't take anything from them ... Imagine now parents hear teachers' got AIDS. Can you imagine how they would react? ... I mean, I can only see the big explosion! (E)

She will be isolated, no-one will want to have anything to do with her because people know that this sickness doesn't, doesn't, it is infectious and it is incurable. (H)

I think if a person has AIDS there must be a hospital, they must not come to our homes. (G)

They should be made to live separately, they should not mix with other people, because they will pass it to other people. (P)

Also, your partner could justifiably desert you, especially if you were a woman:

And maybe her boyfriend could leave her if she told him that she has AIDS/he would leave her/He would see it better to go to other women/she might then see it better to hide it. (H)

AR: Didn't she have a boyfriend?

Yes, she had a boyfriend.

AR: Where is he right now?

He ran away when he found out that she had AIDS. (K)

If he's in the relationship for sex, then he's definitely gonna say: No, I think we better break off now. (J*)

However, some women also felt they were entitled to leave a partner:

If I was Dawn, I would divorce my husband. (M)

There isn't much you can do here, you will hear that he has it already and leave him. (D)

On the other hand, women would be more likely to stay with their partners:

Let me say, you cannot leave him with AIDS/it's up to him/I will stay with him. (L)

Because even if he, he, he should, er, er, that one has got AIDS, you are going to look after him and say: No, it's my husband, I made a vow that through thick and thin I'd be with him (overtalk, unclear) But when, when it's your turn, say if you got the virus, then the whole family, the whole family will be against you, I mean, there won't be any, you know/support/no, no, there will be no support for you because it's a disgrace, you shouldn't have done that ... but if it's a man, I mean, they, they make all kinds of excuses. (M)

If you were HIV-infected medical professionals would not want to treat you:

Usually, sometimes doctors, I don't know, I'm not sure, but maybe they won't get the type of, er, help that a social worker might give them or the counselling that they, that they needed, I don't know if hospitals provide that to patients that is HIV+. (E)

And then, what about the attitudes of doctors and nurses about the person who's got AIDS, especially the person who's going to be op-, going to have an operation, they usually don't want to be involved in that kind of, you know. (A)

That's why some doctors strictly just say they will not operate anyone with AIDS. (A)

It was your responsibility to inform others of your status to avoid them being infected:

She must tell them/she must tell them, why should she hide it?/she must tell them because you cannot totally conceal a thing because ultimately it will expose itself. (N)

Ja, if she hides the virus, she'll affect others. (G)

And if she perhaps finds out if she's got it, she can also tell the friends that she's already had, and they can find out if they maybe also have it, and in that way she can also help them before the sickness maybe goes further. (C)

And then it spreads because she did not talk about it. (D)

However, you might in fact intentionally try to infect others:

But other victims won't talk about it, they keep it to themselves because they want to infect other people. (G)

There are people who know that they have got AIDS, but what they do is they say: I want to put more people into that/mm/ja. (F)

If you don't talk about it, well it's you who's going to suffer, and it, to me it seems you want to spread it, you want to infect others ... AIDS victims always want to die with a number of people. (L)

What I think is that some of the AIDS victims will get pregnant intentionally so that she doesn't die alone, but with someone. (G)

If you appeared in public, you would need to disguise yourself, as in the many media representations of AIDS carriers with their identity masked:

Do you know that people with AIDS hide themselves? (L)

Because you find that people don't want to show themselves as having AIDS, like if they do have an interview on TV they like to censor out the face. (F)

The media who bring the stories forward, they should not reinforce the whole idea of AIDS being something really terrible to the people, the viewers, that's what I'm trying to say/ja, ja, I get you/to bring people forward and say: Okay, we'll hide your face and then we'll talk about AIDS. (A)

So the sensible thing to do was not to let others know if you were infected:

Those who suffer from AIDS must keep to themselves/mm/and to their families, they mustn't tell people about their problem, or else they'll threaten them, you understand/mm ... you don't have to tell people about your problem, instead attend your daily treatment. (K)

I don't think Sophie would tell anybody about it/she would keep it to herself/she will keep it to herself, and only herself and her boyfriend will know about it. (H)

Because if I have AIDS I don't think I'm gonna tell my mother and father, I'll be too shy or too embarrassed/mm. (E)

An alternative depiction was of the AIDS 'victim' who needed acceptance, support and care from others, should not be stigmatised or hidden away, and had a valuable role to play in education:

They must be with us, they mustn't feel that they have AIDS, that will make them feel sick, even worse, as if we want to get rid of them/yes, it's like that ... since you've got AIDS, so at least if we support you as a human being, you can be more relieved from worries. (G)

Yes, to me it would be better if they did tell us so that we know that they have AIDS, so that we can show them affection, so that a person does not feel shunned by other people/mm because we will love him for the fact that he has AIDS (pause) he should be accepted so that he does not suffer. (K)

Also, it is said it is not a shame to have AIDS. (N)

The, the other thing is that people that has AIDS, they're normal people .. so you mustn't isolate people like that, also you must involve the families (background talk, laughter) in the problems and try and organise people's families that's, that's affected by it. (E)

I don't see it as a disgrace/no, no/it is not a disgrace, it is just like TB, we don't laugh at people because they have TB/mm/it is a sickness ... so the way that I see it is that AIDS should be published, it must be said that such and such a person is found with AIDS, this should not be hidden. (D)

This thing of people that, that, that have AIDS being involved in, in the, in the whole campaign of AIDS prevention, etc. I think is also important, you know. (J)

I was once listening to, um, watching a video cassette of a lady who had AIDS, and you know, when she was explaining how did she get AIDS. So I could feel it that um that lady is, she was very, very, very heartsore because of, because of that having AIDS, and so much so that I've called on a friend of mine to come and watch the TV with me so that we can get the video tapes and, um, so that people can see it from the video ... but it's better if someone who has got AIDS can come and educate people about AIDS. (M)

Another striking aspect of the medical discourse was this traumatic and fatalistic representation of being HIV+, a depiction which people living with AIDS are likely to internalise (Gilman, 1988). Expectations were that it was a terrible and hopeless condition giving rise to desertion by partners, rejection from family and ostracism in the community, as well as neglect by the medical care system (Knox, 1989). Especially for women, who are often construed as '*reservoirs of infection*', this fear of abandonment is not unrealistic (Ankrah, 1991; dos Santos & Arthur, 1991; Irwin *et al.*, 1991; Schoepf, 1992; SWAA, 1991); and belies an image of strong extended family and community support for infected women (Campbell, 1990; Hutchinson & Kurth, 1991; Schoepf, 1991). Together with this was an emphasis on the need for secrecy, and the likelihood

of suicide or wilful spreading of the virus on the part of those infected (McGrath *et al.*, 1991; Okware, 1987; Schoepf, 1991; Warwick *et al.*, 1988).

Again, the professional version of the problem renders those affected by the disease relatively powerless to influence their fate, to avert such ostracism, desertion and neglect. Keeping HIV infection hidden would only further remove those requiring care and support from the route of taking control of their health.

Seeing people with AIDS as victims, although framed in more humane terms, was also not likely to enhance effective management of the illness. By couching transmission of the virus in individual lifestyle terms, the victims are also to blame for their infection (Alcorn, 1988; Plummer, 1988; Young, 1987). Given these dire expectations, it is important then to examine how such images arise. Also, we need to understand what the obstacles are to people taking the necessary preventative steps to avoid infection with its grim consequences.

The Value of Testing

In keeping with the above medical perspective, many women suggested medical-type responses to the problem. The most important of these was testing, which would allow them to know whether they were HIV+ or not, or whether a partner was infected or not:

If you are tested on a regular basis or, or tested once in your life, at least you can be assured and I think testing is the most important part of everything, because that's the only way you're gonna find out if you've got it or not. (E)

Also in a more medical way, man, that people must start taking, having AIDS tests ... so I think, if you're saying that AIDS is such, is such a big problem, then I think we also need to look at it medically, you know, that in some way we can, need to, going to have to force people to take AIDS tests. (J)

The boyfriend must also go and check if he has not got AIDS. (N)

They'll have to go together/ja/ja/go together/we were told at work about this and I really think we must both/go for a test. (A)

This would achieve a number of objectives. Firstly, it would reduce unnecessary worrying:

I think the test is a good idea since Maria is worried about her situation, at least she'll know that there is nothing wrong with her. (G)

I think there is also this big fear that when you have, you are HIV+, you have AIDS/ja/there's that confusion as well/and therefore you might be dying in a year's time or two years time or very soon, you know, and if they, if that can be clarified, I suppose a lot of people can go for AIDS/AIDS test/ja/mm. (A)

Also, if you had been tested, you could ensure that you didn't spread the disease further:

Let's say maybe she went for a check-up and they discovered that she had the virus, she cannot go out with another boyfriend because many people can become infected/mm/Okay/so I mean that can help her from spreading the disease/from spreading. (G)

But there is an advantage to a certain extent, in a sense that, a very small advantage, in a sense that you immediately practice safe sex, if you do care about your other fellow human beings. (F)

I think it actually helps you to be (pause) not to go around spreading, if you are a person who's not having a stable relationship. (A)

Furthermore, knowing your HIV status could assist in making informed decisions about marriage and children:

But if you are asking, I think if you want to make a baby, go for a test, quickly make the baby and go back to condoms/phew! (laughter) (A)

The boyfriend must also go and check if he has not got AIDS. If the results are negative then they can marry and have children. (N)

So the advice for them would be that both of them should actually go for, er, AIDS test to see that they are cleared before going into a relationship, especially if he is serious about her,/mm/the relationship, of getting married, get married or gonna have children. (E)

In addition, the person who had tested HIV+ could be treated:

Er, I would advise her to go to the doctor, tell the, er, (pause)/AR: talk mama/the doctor the problem, who will then get a blood sample from her. She will be given results and then she will be called for treatment. She can recover, then she will be able to bear a healthy child. (N)

The person I knew had AIDS was always getting injections, he was getting treatment. (K)

Some also recognised that the earlier the virus was detected the better:

Can someone correct me, um there is (pause) a possibility that if you have, if you have, if you are HIV+ and you go for a test sooner, you stand a better chance of living longer than if you go later. Is that correct? (A)

They say you can't cure AIDS.
It can be cured if discovered on time. (K)

and that counselling was needed before testing:

And you know he must be counselled around it before he goes to an AIDS test. (F*)

The crucial step is that both of them have to first go to counselling/ja/both of them. And I, er, suppose from those, er, counselling sessions they are to be made aware of the significance of the outcome of the test, no? And they must be aware of the significance of, of a positive test, what would happen to both of them before they actually go to do the tests/mm/mm. (F)

Other medical responses were that people should go to the clinic or to a doctor, for help, advice, a check-up, treatment:

She must not drop him, they must talk until they reach some agreement and decide to go to the nurses and get advice at the clinic. (H)

Then suggest to her boyfriend that they together go to see a doctor, before anything happens, so that they can get help. (N)

I suggest that she go for a check-up. Although at the clinic they won't see it now, but she must keep on attending, even if they say she is wasting her time. Another option is she can visit a gynaecologist for a papsmear and ask the doctor to clean you inside, something like that, I don't know. (L)

If she went, if she went to the doctor with him, then I think they will give her, like if there is something that she can take that can stop it from, like you know, spreading the disease. (B)

To me it seems if you get more injections, the AIDS will get out of your system quicker than the other one, you know. (L)

I think before, er, the two of them plan, they must first get to the clinic, then it isn't necessary, then she can get treatment for it, it isn't necessary that the children also. (unclear)

PR: So she must go to the clinic for treatment?

There isn't actually treatment, but one must know what is actually going on in your body. (C)

The set of beliefs in the value of testing and other medical strategies highlighted some of the implications of working from within a medical framework. Medicine as '*objective science*' with its process of symptom identification, diagnosis and treatment raises expectations of action and control. Although the emergence of AIDS as an as yet

incurable and probably fatal disease confounds this image, many people still believe that the medical profession can and must be able to provide solutions. This hope is perhaps strengthened paradoxically by the above-mentioned hidden, invisible, secret aspects of the virus: in the face of such opaqueness, technical knowledge and expertise offer some tangible response.

Furthermore, because of the lack of observable symptoms initially, the individual is unable to identify for her/himself whether they are infected: specialist tests are needed before they can 'know' about their health status, only an 'expert' can confer the HIV+ label. Again everyday knowledge is not sufficient, again the power of the medical profession is asserted.

Testing is Pointless

At the same time women were aware of a contradictory set of possibilities. This was evident in an alternative discourse of resistance to testing. Women gave a number of reasons why they felt that there was no point in going for testing. To start with, a person who was infected could still test negative:

So to me AIDS, the testing is a real problem/and because it cannot be seen now, you won't know you have AIDS, it only shows after some years. (G)

From the little I understand about AIDS is that by, if Dawn could go for tests and then he, she was found that, er, she, she is negative, it does not mean that she has not contrac-, contracted this disease./mm/It could be that she, she is still, um, in that period called the window period, where it cannot be detected as yet. (M)

The test is, is, it relies on detection, not directly of the virus, but on these factors that are produced by the body, you know to fight the virus, so there might be a timelag before the, these factors are produced inside the body, and you go there to do the test and they cannot, er, detect these factors and the test comes negative, yet the virus is still inside/mm. (F*)

Moreover, there was nothing that could be done anyway:

Ja, if you go for tests and you've got it, then you've got it/mm. (E)

But then what, what is going to be the use of testing them (laughter) I mean, you'll be knowing the stat-, stat-, statistics (laughter), you know how many people have got AIDS and how many don't (pause) then what will you do after that? (F)

But, but, er, even if you go for testing, what are they going to do because if you are HIV+, there is nothing that can be done/mm/mm.

But it just makes your life a misery/mm/mm/you know. (F)

Also, it would be really scary to know that you were HIV+:

I'm sure most people are scared to actually go/ja/it is, it is/yes/to go and have a test, but I think it should really, I mean, I, for myself, I wouldn't want to go for a test if I suspected that I'm HIV+. Then if I know I'm not, you easily go for a test. (A)

I was just thinking that people in such situation, they don't always want to go to doctors, because they're afraid of what the outcome might be, because if they have AIDS, what do they face then? (E)

Finding out about it, it doesn't mean that it changes the fears that, um, Maria has about, about AIDS itself. That fear might even continue. (J*)

Then too, it was difficult to go for testing yourself or to persuade others actually to go for testing:

But it is not that easy to go for the test.

I know it is not easy/because I always like to go for a test but I/ja, I know/but I'm always reluctant/Okay/then to know. (A)

I think that although testing may be an important part of the whole thing, before you can go for the test, it takes a lot of effort for one to actually have the guts to go for that test. (F)

But I mean, it's not easy, you cannot, it's not easy to tell your partner to go for the test/mm/it's quite a difficult situation. (B)

But then for uneducated people it's even more difficult/mm/to get a man to understand he must go for an AIDS test/ja. (A)

Furthermore, there were inadequate facilities for testing, and no proper counselling available:

The government could also help us, we don't know where we could go for tests, so that I know, so that I know if I have AIDS or not. Because there isn't a place for AIDS testing/yes. (P)

And also I think that like, er, with this AIDS, with the testing, everything is so (coughing) restricted, like you have to go to a special place to be tested. I don't see why they can't have, like, um, clinics, like they have with the blood transfusion coming round to peoples' work. (E)

I mean, I went for an AIDS test and nobody sent me on counselling before I got my results. (J*)

And, er, I, I feel, I am right when I say that a lot of people are aware that there is AIDS around, and as (name) said, people are afraid of, for the test, because there are no counselling services where we stay. You see, there are a lot of people who

might like to go and take, and do the test/ya/ but the (unclear) counselling services (pause) are so, I don't know. (F)

Finally, it was impractical to think of testing the whole population:

Do you think it is realistic to test 18 million people of AIDS? (F)

But can you imagine what dilemma the health department of this country will be in if the whole population must be tested, and here comes a boom of a few thousand (pause) er, positive/what do you/will they be able to cope? (E)

The opposition to testing which these women expressed echoed concerns elsewhere in the world (Kriegler & Appleman, 1986). As outlined in Chapter Two, early depictions of AIDS as a disease of certain high risk groups fuelled attempts to identify these 'others'. Implicit in this approach was the belief that those identified could then be isolated in order to protect the majority of the population (i.e. those not gay, black, drug-injecting, etc). This stigmatisation of HIV+ people was accompanied by a range of discriminations and, for example, led to the moving of the 1992 Eighth World Conference on AIDS from Boston to Amsterdam because the United States government refused to alter legislation prohibiting the entry of HIV+ people into the country (WorldAIDS, 1991). Testing became increasingly controversial, and a strong argument was made by activists within so-called high risk groups to do away with any form of mandatory testing (Patton, 1985). This more humanistic position argued that testing was unnecessary as there was no cure and anyone could be at risk of infection and so knowledge of infection was not the issue: safe sex had to be practised by everyone at all times. It also raised concerns about the rights of the individual to make choices about her/his life against those of society to protection (Bayer, 1989).

Challenges by the women in this study to the necessity for testing could then be construed as resistance to the medical discourse: attempts to remove the problem somewhat from the medical realm, to gain more control over its management. However, it also seemed to reflect a measure of helplessness and fatalism in the face of the epidemic, so that this stance could potentially be both enabling and constraining.

More recently there has been a renewed focus on the value of testing (Bayer, 1992; Kanki & Coutinho, 1992; Panos, 1988). This was probably associated with the advent of AZT and other drugs which offered the hope of prolonging life and delaying the onset of AIDS-related diseases, as well as the claims that lifestyle changes (less stress, better diet, more exercise, etc.) improve the quality of life for HIV+ persons (Bayer, 1992; Graham *et al.*, 1992). Thus the sooner one was aware of one's HIV status, the sooner such preventative measures could be implemented. However, such a holistic healing perspective was not reflected in the accounts of these women. Given the stressful socio-political and economic circumstances of working class blacks in South Africa, it is perhaps not surprising that a measure which involves both considerable personal expense and personal lifestyle choices does not have much place within people's response repertoires. Moreover, the limited access of especially black women to adequate health care facilities, makes this an unlikely source of hope (Marks, 1989; Siqwana-Ndulo, 1992; Zuma, 1989).

Education is the Answer

A complementary aspect of the biomedical approach to AIDS has been the conviction that in the absence of a vaccine against or cure for the virus, prevention strategies provide the major route to avoiding further spread of the epidemic. This has resulted in a recognition of behavioural factors and the role of social science in coping with the disease. Health education is therefore urgently required to bring about the necessary behaviour change.

While this discourse of prevention and education is endorsed by medicine, the relationship between the two modes is also not without its tensions. This meeting of the '*hard*' science of medicine with the '*soft*' social sciences raises disturbing clashes of interests (Packard & Epstein, 1991). While clinical research remains in the hands of biomedical experts, *nl.* doctors, the task of education, which is often depicted as merely a temporary measure until a cure is discovered (Patton, 1990b), is usually left to those of lower status: nurses, primary health workers, volunteers, the majority of whom are usually women (Squire, 1993). Professional medical journals and

conferences overwhelmingly are dominated by clinical research findings, while those concerning social and behavioural aspects are relegated to minor positions or alternative occasions. It would seem thus, that while the crucial role of education is acknowledged, this has not been allowed to dislodge the status and resources of biomedicine. This needs perhaps to be viewed against the background of the threat which AIDS has posed to the image of biomedicine as successfully controlling modern health and illness (Patton, 1985; Sontag, 1988).

The women in this study reflected prevailing beliefs in the importance of behaviour change to avoid HIV infection. In contrast to the relative silence discussed above on the role of lifestyle factors, accounts of the need for education and possible strategies to follow were detailed, wide-ranging and enthusiastic:

But the important thing is education, education is going to be important at all levels, at every level: at school level and community level ... the important thing is continuous education. It may take, it take years to, to do that but finally you will somehow reach a goal where we have basically educated, um, the majority of the people about AIDS, and it must be a topic daily on the lips of the people, because it's very serious. (J*)

But I think this whole thing, since that, this is a cycle from school to, to, from primary school, secondary school up to the community, if we do, if, if we, if sex education is done at home, it becomes more understandable at school, it will be more honest in the community, and as a result, the whole village will understand. Just like AIDS, if AIDS is talked about at home by father and mother, and then people come to school at a specific time, they explain AIDS, they talk, each, the necessity of, of, of sticking to one partner because, of course AIDS now is within the adults, I think so. But I feel once the AIDS has been diagnosed within, um, the adolescent stage (unclear) so I think education should be done, of course at home, because really at home, but mostly at schools and at community centres for the adults. (M)

Can I just say something? I think the best way, not necessarily the best, to actually get this thing into our communities or whichever communities. People organise in structures in our communities, in organisations and all that. Would it be possible for, maybe for AIDS activists to introduce these things through the organisations, the structures which exist in the communities?/ja/mm/People are organised into these structures. And another important thing, whatever, besides that, there is what you have just mentioned, the, the, the bias against the rural areas. That I think has to be looked at very serious. So, I am just making two points here: the bias against the rural areas and the use of our democratic structures, if they are democratic, and penetrate people through these structures. (F*)

But that's why we have organisations, that's why we have ANC Women's League, ANC this and this and these other organisations. They, they, they accommodate everyone, whether you are a township wife, whether you are this and this and this/

mm/and that's where you can get them educated, get them standing up, put AIDS on the agenda, just like any other issue. (A)

Many arguments were raised in favour of education. Education would help people, especially the youth, become aware of the reality of the threat:

And like, also, I think the whole issue of education plays a very major role, because um, if people can really understand, as she was stating before, that's it. (A)

Like what everybody needs to do is to demystify AIDS. Like we have to make it real, and people must understand it, and the counsellors should do work at that. (F)

There should be more AIDS programmes in the form of role plays or anything using the youth. Of course, you know, because they will be the people who will be the victims in the near future. (M)

But really, we need to have sex and AIDS education at schools, even from primary level, because our peo-, our children make sex without knowing what they are doing, they just enjoy the pleasure of making sex, without knowing what the difficulties will be, and the problems that they've got to encounter in the future. (M)

Education would stop further spread of the disease:

Yes, they should not hide it, they should educate those who have not got it yet, so that it does not spread/in an attempt to stop it, in an attempt to stop it/yes/if they hide it, it will spread and everybody will get AIDS. (P)

But what I am saying is, when you engage in the first step of educating, you get everyone to educate and then when people go and test, and all of them discover they have AIDS, at least they won't transfer it to everybody, because also the other half are aware of AIDS and will be using safe sex/ja. (F)

Definitely, that's why if everybody is literate about it, everybody will protect themselves. (E)

Education would motivate people to go for testing, although on the other hand it would remove the need for testing, as everyone would practise safe sex:

In fact, you educate first and then you test all the people. (F)

What you have to do if you really care about this problem, what you have to do is to educate them about the danger of having one or more, or whatever, to educate them. Okay, that is the best way, then it is up to that person to go to the clinic or wherever and to test. Don't actually, if you impose, you are fighting a losing battle about this thing. (F)

No, what I am saying, (name), is when you engaged in, in, in, in a campaign educating everyone/ja/then, then everyone knows about AIDS and there is no, it

is no advantage to go for a test, because whether you are positive or negative, it makes no difference. (F)

Education was also important for people to understand the origins of the illness and for helping HIV+ people:

So we really need that education/ja/to know where it originated. (M)

So, it's, it's like education has a big part in it, to get people to actually understand exactly where it comes from. (A)

We should educate people on, on, on, the whole thing of AIDS is we must educate the AIDS victims on coping and families and so on, and coping with AIDS/mm/ja/I mean, how do you cope (background talking) with someone that's gonna have it, and the victim himself or herself will also/(E)

But they recognised that education was not always easy to implement:

But I think also man, if you talk about education and that, we are basically talking about changing the way people relate to each other, and that is a lo-o-ong term thing. (J)

It will take a matter of time, because even amongst us people who should be educating the people about these things/mm/certain things are still not acceptable to us/mm/we view them with critical eyes. So there is still a lot to be done with us, the people who should be educating the people who are not educated, before we can just go down to the masses. (M)

It will be quite a long process, because you will have to build the trust first, before you can start to educate the people about AIDS. (M)

I think we live in a, er essentially um, as (name) mentioned, (name) talked about religion and so forth. I think it is a very important aspect, because the one thing is what, what comes with, with, um, those religious beliefs is, say for example Muslims and for some Christians, that priests they won't talk about it really. (J*)

I think also on the issue of AIDS education, it is important in addressing the issue in rural areas, that for example in rural areas they don't, the people are old-fashioned, even sex is like, er/taboo/yes, it's taboo to talk about it, see. So while now you are trying to get through to them, you see it is important that you don't just, er, before you actually talk about AIDS ... it has to be very plain to people. (F)

Because, ja if you look at the majority of the people in South Africa, people is illiterate as, as well, so even if there's pamphlets and things, our people can't read. (E)

People's not only negative to being, people having AIDS. Also, information: if you tell somebody in your community now that you're going to a workshop, or you're going somewhere, they tell you: What, what are you going to do? Is it necessary for you to go there?, things like that/ja, ja/they have the opportunity to get information, but people is not prepared to go out. (E)

But the (unclear) counselling services and these organisations who are actually trying to prepare us for AIDS are so, I don't know.
 Ja, they don't quite go down/they don't go to grass, they don't benefit the people down there/mm/they are just elitist, something elitist about them, that's what I hate about them/ja. (F*)

The strong emphasis on education amongst these women represents a possible sense of this being a path of access to taking control of the issue, reframing it in terms which connect with other everyday phenomena. It thus links in to a broader political discourse about the significance of education. In South Africa, racial discrimination has had far-reaching implications for the lives of blacks, and has resulted in limited educational opportunities with all the concomitant disadvantages this produces. Education is therefore perceived as an essential route to greater opportunities and has been at the centre of political struggles in the country, particularly since the 1970s (Khotseng, Matlou & Mahlomaholo, 1987; Mkhatswa, 1985). The salience of educational rhetoric needs to be seen within this context. Future AIDS prevention activities would also need to consider how best to mobilise this particularly potent force amidst the current talk of educational and national restructuring in South Africa.

AIDS AS STIGMA

The other major AIDS discourse theme was centred around notions of stigma, which included views on sexuality as well as a variety of conceptions of AIDS and '*the other*'. These will both be discussed below.

'You get it from sleeping around': AIDS as Sexual Stigma

A set of beliefs which was central to much talk about AIDS was its associations with sexual promiscuity. This stance was expressed in a number of ways. Firstly and most emphatically, people became infected with HIV from sleeping around, and if you were HIV+ that meant you had been promiscuous:

And it is said that AIDS is spread by promiscuity. (K)

Friends explained about this sickness, sleeping around, and that er you get AIDS from it, er/get AIDS from sleeping around. (C)

I mean so many people have AIDS from sleeping around, like statistics, ne, say 90% of people get AIDS from sleeping around, 1% gets AIDS from needle pricks and all that. (E)

AR: You are talking about prostitutes, what makes you think that they have AIDS? Because they sleep around with sorts of men from different countries. (L)

Another thing that becomes obvious is that John has been found to have AIDS, that means that he was sleeping around/mm/that is why he got infected/mm. (P)

If she was informed about AIDS, um, and, um, what the causes of AIDS were, then I'm sure if she was worried that she, um, might well have AIDS, then, um, she also did the things that cause AIDS. (B)

Then, anyone with multiple partners ought to be worried about becoming infected, and so limiting the number of partners would reduce risk:

She must consult a doctor.

AR: Why, mama?

She is worried because she was busy sleeping around with different guys. (G)

If she had many partners in the, in the past, is it likely that she'll have, um, that kind of sickness?

I think if she did not do, or didn't have intercourse with other men before, then I'm sure that she wouldn't have a problem now. (B)

Just like today in the (name) magazine, and all the TV stars were, were advertised there and they were shown with their pictures, that so and so has got AIDS and he has died. One of my friends said: Oh, I'm so worried, and do you know what I said to her, I said: Oh, why did you have sex too much? (M)

They will not wake up, they will want to sleep around, and yet if they tell them, they will wake up and realise that it was through sleeping around that John got the sickness, and stop sleeping around. (P)

That guy must cool down because Sophie didn't get AIDS from heaven. (L)

Furthermore, anyone who became infected as a result of sexual transmission was stigmatised and to blame for their condition. In addition, if a partner got infected in this way, you were entitled to leave him/her:

For all sexually transmitted disease/there is, there is/a social stigma. (F)

I mean, I don't think AIDS is accepted as cancer has been already, you see/mm/there's still a major stigma. I mean with getting cancer, it's not like as much as your fault ... but it's a major stigma with actually having contracted AIDS with many partners and all that. (A)

I mean I may be having safe sex in my own, er, kind, I mean, of definition, whatever, having a boyfriend, breaking up with him, having another one, not actually having many boyfriends at the same time. You can also contract AIDS in that way, and as the stigma is also, I mean, you might have contributed to it, but

you might not (pause)/(unclear) not because you're a, er/a bitch (laughter)/ sleeping around or anything like that/promiscuous (laughter). (A)

But I think personally, if the man was never honest, he did all the sorts of things, went from one lady, trying affairs, I think he deserves to get AIDS, and even deserving the disease, the fact that Dawn should tell him that these are the results of what you have been doing, so you have got to pay for what you have been doing, I can't go on with you like this. (M)

At the same time, they used the notion of innocent victims: those who were infected by non-sexual means deserved more sympathy:

What I was thinking was, if the man really, in the sense that he was an honest man, good guy, and really through blood transfusion then he got the disease, then it would be unfair for the man that Dawn would harass him and try to divorce him or be funny to him, or neglect him, right? (M)

And I think there is a lot of people, not a lot really, but I think there are cases of people who've got AIDS, who have only had one sex partner in their life. Mm, but is that fair? (M)

It is pathetic when you see a child of seven years having AIDS, because in today's (magazine name) there is a child of seven years who has contracted AIDS and an 18 year-old boy. So, those haven't had any affair, they didn't have any affair. (M)

Like because so many people are illiterate, um, as far as AIDS are concerned, they think, you know, you can only get it if you do this/mm/or you do that, um, they don't realise how, um, innocent people can get it. (E)

However, for some women this was a problematic position: they recognised that HIV+ people would be rejected because of this sexual stigma and identified parallels with other diseases in the past. They warned against moralising and thought that by publicising other modes of transmission the sexual stigma would be reduced:

At the moment the whole thing, I mean, I think that's why people don't even want to go to doctors, because having AIDS can be an embarrassment/mm/ja/because you think you only get it from sleeping around/ja/so very, in very conservative communities people will say : Just stay away from me. (E)

But let's look at how you actually contract AIDS. Whenever you hear someone has AIDS, the first thing you think is sexual ... I think the first thing that, that people have a stigma of is the sexual thing and also the drugs part, and I think with that, that's the main stigma, why it's not actually going to be as easy as cancer, because you don't get, I mean with getting cancer it's not like as much as your fault. You might have contributed in various ways, but it's a major stigma with actually having contracted it with many partners. (A)

You know, the mode of spread and such things, I don't think we should moralise about the issue, you know, pinpointing you had many partners and such things, I mean that will not help us, I don't think that will help us. (M)

And also, another thing that I've noticed, that, um, many people associate AIDS with, um, sexual activities, and I think the community must be made aware that AIDS can't only be contracted in that manner ... I think that's why some people distance themselves from the AIDS topic as well, because, um, they're not, um, sexually active themselves ... but the fact remains you can get AIDS without sex, that's the most important thing to concentrate on in terms of religion. What's important is other ways AIDS can be contracted, for instance blood transfusions.
(J*)

Many writers have explored ways in which sexual transmission of the virus has been linked to notions of stigma (Weeks, 1988). Early identification of the virus in the homosexual community and other '*high risk*' groups like sex workers contributed to this process, as did the parallels with responses to syphilis (Brandt, 1985) and in western society has seen the emergence of a '*moral panic*' as described in Chapter One. This has given rise to calls for a return to traditional values of the nuclear family, monogamy and heterosexuality. In this study, while women made use of discourses around sexual stigma and promiscuity, they did not extend this readily to notions of homophobia or a return to the '*good old days*'. One statement for this position was immediately rejected as unfeasible:

It's a pity that, you know, having religion really, the whole aspect of religion deteriorating, because you see previously you get, like it was strict, it was an accepted thing that you don't have sex before you get married (unclear)/no ways (laughter) I don't accept that/... I mean if we hadn't had such a free liberal society as we're having now, where you do what you want, you don't necessarily wait till you married and/ja/er, you live together for as long as you want, without actually thinking about marriage, I mean, er, okay, it's liberal, you see, okay, we're not really emphasising on no sex before marriage ... I mean, there isn't that whole force anymore on having people believing in like, I have to be clean on my wedding day, I have to be a virgin and you know, (laughter) the whole works ... It's just so because you can't turn the clock back, there's no ways you're gonna go back to those values and standards. (A)

This absence of a '*call to moral arms*' response is interesting. It is possible that, in a society where homosexuality is generally considered to be unacceptable and therefore largely invisible, these concerns might not be aired too publicly (de Jager, 1990; Maluleke, 1990; Nkoli, 1991; Standing, 1992). Also in South Africa, the AIDS problem for blacks is located largely among heterosexuals rather than homosexuals (Cape Times, 1/3/93). Furthermore, it might be that for blacks in South Africa, political struggle is centred more around basic democratic rights rather than Right- and Left-wing

nuances as reflected in the moral panic concerns of the UK and USA. However, this focus on so-called more basic political rights has also had problematic implications for attempts to counter sexism in South Africa, where attempts by women to focus on gender discrimination have sometimes been interpreted as divisive of the primary struggle against apartheid (See later in this chapter under Gender Discourses).

The sexual stigma of AIDS discourse, with its echoes in the literature on STDs, produces some very thorny obstacles for AIDS prevention and care. Sexuality is associated with much that is unconscious and not readily accessible to people's awareness (Hollway, 1989). Socialisation has also not made for easy communication about matters sexual. Disease that is in any way linked to this set of sensitive experiences is not going to be approached with ease. Yet AIDS prevention requires exactly such openness and willingness to talk about and alter sexual practices. Moreover, a focus on sexuality, '*as an especially dense transfer point for relations of power*' (Foucault, 1979, p. 103), clearly provides multiple opportunities for the emergence of contesting sets of values, so that those engaged in education and care endeavours need to confront such issues in their own practice. What is at stake then is the privileging of a particular world-view, which upholds certain practices as normal, while others are regarded as deviant, so that AIDS education becomes an opportunity to entrench such values. Watney (1987, p. 124) has described a '*discourse of punitive fidelity (which) has been imposed in the name of monogamy on those whose sexuality eludes the restrictive model of marriage as a sacrament, binding on individuals regardless of all ethical, psychic, social or sexual factors*'. (The implications of this for women's sexuality particularly were described in Chapter One). There is clearly much scope for AIDS work to be contaminated by such moral and other agendas of planners and implementers, as Seidel (1990) has documented in Uganda. In South Africa as we have seen, this has already occurred both in government responses and among some opposition political movements.

On another level, sexual stigma further hampers AIDS prevention work: because of the implications of sexual promiscuity, it is possible for partners also to use the threat of AIDS to try to impose sexual codes like fidelity or monogamy onto each other

(Schoepf, 1992). Finally, the notion of sexual stigma, with its associations of guilt and blame, contributes to a culture of silence around AIDS, as was evident in media reports on the recent death of ballet dancer Nureyev (Malherbe, 1993). As a result, infected people are less likely to come forward for testing or possible care, thus reducing the possibility of much-needed support and management of symptoms.

AIDS and the Other: Discourses of Denial

Women in this study made use of a variety of conceptions of AIDS which suggested that it was not an issue of immediate concern for them. This process of locating the problem at a distance from themselves would imply that they were not personally at risk of infection.

'It only happens to others'

Subjects identified themselves with aspects of the '*it won't happen to me*' position:

Because for me it's something that's very far removed. (E)

The same with AIDS, you always think: Not me, man, I, you know I've seen to everything. (E)

And they said South Africans are suffering from, um, phobia effect: It can never happen to me/mm/and so it happens to other people but never to me (chuckles) you know, so I hear it around me but never personally to me. And that's related to accidents, right? I'm just thinking it can also happen with AIDS, it happens around, you know, there, there, there, but never to me, until it strikes (smacks hands together). (J)

They also asserted their separateness from it by relating that many/other people saw AIDS in that way (and by implication then, that they understood the problem differently):

But it's denial, the whole denial story. (A)

Ja the other thing is that people are distancing themselves from, from AIDS/mm/(F)

Even if they can give us the number of the people with AIDS here in (place), that won't make any difference, because they will never identify themselves with it/yes/ (L)

PR: People think it won't happen to them?

I think they're very nonchalant about the whole thing/mm/ja. (B)

You know that's actually quite a serious problem that people know that AIDS exists, but it doesn't affect them directly so they're not really, I mean, they're not worried about the issue. Like we had a discussion on AIDS now here the other day and it just doesn't affect them. They know it exists, they know it happens to whoever, but like it won't happen to them, type of thing, not in their society, not in the way they live, type of thing/mm which is actually quite sick. (J)

This denial was manifested in a variety of ways. They said that people (and especially men) did not take the problem seriously and that there were other more/equally serious diseases needing attention:

That is why then people don't believe that AIDS is a reality ... that is why then men don't believe that there is such a disease called AIDS. (K)

They [boyfriends] say they do not believe you know, they say they do not believe about this AIDS thing, you know. (D)

Mm, the other thing is, is this, you know in terms of tuberculosis, in terms of kwasi-, kwashiorkor, how high is AIDS also on the agenda? Because there are also people dying of hunger, right? I'm not one to, to, but I just want to, to, how can we put AIDS in the priority list, 'cause some people would say (unclear) AIDS, and all our minds are just, just AIDS, AIDS, AIDS (unclear) (pause) er (pause) and although it's, it's a killer disease, there, there are other things that, I don't know. (J*)

It was very much a silent disease which wasn't spoken about in the community:

I still feel that the issue's not widely discussed you know even amongst peers, I mean that issue hardly rises up you know/ja/it's never discussed, seldomly discussed ... I mean, if it can be a subject that is discussed more often, probably people, I mean, with time may change their ideas, but for now it's still taboo and it's really causing a lot of problems. (A)

PR: Have you heard anything about it?

No, nothing.

PR: People don't really talk about it?

No, not really. (C)

It was also an invisible epidemic for blacks: people were not aware of it (although they also recognised that people did know about it); people could be infected without it showing on a test or without any symptoms for a long time; if you could not see it, it did not exist; people did not know anyone personally who was infected; the media often hid the identity of HIV+ people:

We feel so very far removed from everything because it's been kept away from us. Now, if the figures were open up to people, if you knew who, who's got AIDS in your community, if you knew the figures, say in (place), for instance how many

people in this area has AIDS, then you feel it, because you think: Who are these people? It can be your next door neighbour. (E)

The problem with AIDS, you can't see it now and you can say it is here. Like there are certain diseases that can be seen at its early stages, like syphilis, there are signs, your urine burns, but AIDS cannot be seen until after some time. (L)

There are some guys here at (name of university) who will tell you that AIDS doesn't exist, because if there were AIDS, I'll have AIDS, because they claim that: I've had so many sexual relationships, and I haven't infected, affected AIDS, therefore there is no AIDS. (A)

Because I mean, I came here this evening and I was like thinking, I mean like, I've never needed to, to think about it really, I mean, as a person with (unclear, laughter) I don't know nothing about AIDS you know, absolutely nothing about it, but I mean, like, um, and that's the reality, I mean, okay it's not close to you, you don't see it, you don't. (J)

This I'm saying because I once attended an AIDS (pause) um (pause) course, and you know, when I was looking at that guy and hear it from him, you know, speaking about AIDS, then it set me thinking. You know, some things you don't believe because we don't see them and we cannot imagine them, and when somebody you know, say a black person can stand up and talk to the black people, perhaps they can understand. (M)

And they will also wake up and realise that this thing does really kill (pause) because most of us blacks, we do not believe that AIDS is really there, since we have not seen it. (P)

And I think also you must make people see or realise that there's people quite close to them that have AIDS, because for me it's something that's very far removed. I don't know of anybody that has AIDS, so I don't think. Like the other day I was speaking to somebody about it and they said: Do you think that AIDS is rife in the Coloured community? Now, er, that just shows that we know nothing about it. I mean of course Coloureds have AIDS, but we don't know, or maybe if we know, I mean, I'm sorry to be making it a Coloured thing, ne?/ja/ but that was just, it dingus, er, it was an eye-opener for me ... Yes, yes, there's no-one that I know of who has AIDS you know. (E)

There was an article in the, in the paper earlier this year where a teacher was, er, they actually mention her name, she died, um/25 year old/that was the first time I knew there was somebody really close, I mean that's (place)/mm. (E)

You will get more reaction from people where there are groups, families who have that problem. (B)

I still feel that point still stands, I still say people, maybe the reason why people distance themselves from AIDS is because they never saw anybody they know who has got AIDS. (F)

Ja, and the way they put it on TV, I think if they could start treating AIDS like any other disease and stop treating it the way they are/mm/ja/you see they, they put people, when they're talking about AIDS, they have AIDS and then they cover their faces, they don't show the people's faces, and then it really makes the whole thing look terrible, really you wouldn't have anything to do with it. (A)

Together with this was a belief that the virus affected others, those in groups which would reinforce the perception that it would not affect them personally. They identified homosexuals, bisexuals, whites, Americans, drug-takers, prostitutes, the youth and the upper classes as being at risk:

It was felt that they're gays, they bring it, every gay has got AIDS (laughter). (F*)

I mean we were warned that there is this disease coming on but it was isolated at first to the homos/homosexuals. (M)

If it is a homosexual, he tells them: This is how I got AIDS, by sleeping with another man/yes/being a man. If it is a woman, maybe she was a, she was a homo, or she was a mix, there are those who are homos and mix, they sleep with both men and women. (D)

I am talking from a black perspective. In the first place there are a lot of people who actually feel it's a white thing, okay, and a gay thing, these two things are combined. (F*)

Well they seem to think it is the white man's disease. (M)

Ja, we don't drug ourselves as blacks, I've never heard of black people here in South Africa that have killed themselves by using syringe and sharing, er, and that's also on the AIDS transmission/they do. (F*)

One Wednesday I listened to them talking about a man who got AIDS from a prostitute. She didn't want to use a condom and she used to ask her clients if they have a condom with them, and if they do, she will tell them she doesn't use it. (L)

Yes, they say AIDS is American (pause) Idea to Destroy Sex (laughter). (A)

It was said once in the conversation which I felt quite bad about, it, it happens to this upper-class people, you know, because they have exhaust, they've got enough money, they exhaust life and they want to, (coughs) to, it's like homosexual activities, and it's drugs and it's not in the working-class/mm mm. (E)

This tendency to deny personal risk has been prominent in AIDS literature, especially because of its links with practising safe sex (Bassen-Engquist, 1992; Snyder & Rouse, 1992). We can perhaps understand this process of distancing in relation to dominant perceptions of the disease as serious epidemic and as stigmatising and fearsome. As was mentioned previously, early work depicted AIDS as a problem of high-risk groups, which often coincided with minority status. This seems to have served to reassure the population at large that they were not at risk and to entrench prejudice and discrimination against the 'others' (Earickson, 1990).

The dilemma of conceptualising the problem in terms of the 'other' is especially stark for black South African women. Here the disease has been characterised as one

affecting particularly blacks, in other words, the black 'other' in the white minority culture's terms. Also for women, the process of drawing on the discourse of 'other' echoes the disempowering positioning of women in patriarchal frameworks in this way, and reinforces the polarisation of men and women into static and opposing gender categories. This would, therefore, pose the contradiction that they as women were also regarded as belonging to this category of 'other', and so particularly vulnerable to the disease.

Arguments that the disease was new, invisible and unknown, both underscore the range of confirmatory stances for denial and generate a particularly powerful double-bind for educators: on the one hand the illness is not apparent within the community, so people don't believe that it exists; while on the other hand, the stigma of being HIV+ forces people not to reveal their HIV status and thus make the problem more 'known'. Some health educators claim that it is only when the disease in fact becomes visible, when people have manifest symptoms of AIDS (and therefore too late), that health education messages begin to have an impact (Bayer, 1989).

The origins of AIDS

Much has been made in the literature of the origins debate, with a wide range of theories being offered. What they have in common is a process of identifying the problem as rooted elsewhere and ascribing blame to others: the American imperialists, promiscuous Africans, etc. (Panos, 1988; Sabatier, 1988). In this study too, there was a strong concern with opinions about where the disease was thought to have originated:

And some will say it's American Intelligence (unclear) ... Ja, and also another important thing is where did AIDS originate from. (A)

It's very important to know where AIDS comes from, because, really, I am serious to know about the AIDS, where it's coming from/mm. (D)

Because my major concern in mind is the nature of the whole disease, this terrible disease, and taking an origin of theories which were, which were a number of theories that, which we were told about this AIDS that started in America, when they were trying to reduce the population in the laboratories, and they mix some stuff, you know, one tend to question these things ... but one still gets interested to know where does this whole thing come from. (M)

It does matter where it came from, because I read yesterday in the newspaper, they say cats/mm/also have a virus which is very much, er, similar/similar to AIDS/my goodness/so it's very important to know the source. (A)

They spoke of AIDS as a recent phenomenon, which had suddenly emerged, had not been there before, and had come from far away:

Where does the AIDS illness come from in the first place, because I am at a loss now. I am lost, because I want to know first of all, where does the AIDS come from? Because the time when I was born, I grew up and grew and grew, until 16, 18 years, I don't know about the AIDS, there was no word like AIDS/yes/I only hear of AIDS just now when I am 29, 30 years old/mm/mm/no, so the best thing that I would like to know is where does the AIDS come from. (D)

They [boyfriends] say they don't know this illness. Where does the sickness come from? They say they first want to know where this sickness come from. Because they say they grew up without this sickness. They heard about TB ... they know about pneumonia, they know about such illnesses, they say they only heard about the AIDS illness just now, but where does the illness come from? (D)

But it, it, I find it difficult, I can't understand why we can't be told what the origin of AIDS is, other than, er, being involved in sex. I mean, people have been sick for a long time, they have been having diseases that were not diagnosed yet, could not be diagnosed with tests. Now all of a sudden, all of a sudden this AIDS, all of a sudden, all of a sudden, where does it come from? ... All of a sudden we are told in America, in England, all of a sudden there's AIDS, AIDS, AIDS, AIDS, AIDS. You see, that is what I can't understand, where does it come from?/ja/(M)

Although not explicitly stated, these debates about the origins of the virus seemed to help position women at a distance from the epidemic and to imply that it was therefore not a problem that they needed to take seriously; again it was a foreign issue that 'others' needed to address, that required 'expert' interventions to trace and manage. There also seemed to be a suggestion of blame for those involved. Claims that the virus originated in Africa have led to charges of racism on the part of Western scientists and a possible reluctance in some African countries to deal openly with the epidemic (Chirimuuta & Chirimuuta, 1987; Kitzinger & Miller, 1991; Schoepf, 1992; Sontag, 1988). Locally, such suspicions of state motives in raising and dealing with the AIDS issue are understandable and again have obvious implications for AIDS work, as will be discussed below.

AIDS and racism

Many women expressed strong feelings about the way in which blacks were portrayed and approached in AIDS work in South Africa. To start with, and in keeping with concerns mentioned above about origins of the epidemic, theories of the African origins of the disease stigmatised blacks and were racist:

Because they claim it's from mid- central Africa, that's where, you know, the baboons, you know, or the barbarians, which is supposedly, people, that's where it all started from, and you see, automatically by saying it's from mid-central Africa, it's politicising it automatically, like/mm/you blacks are the one that started it/and a lot of people having AIDS/and now you are infecting the rest of the other people. (A)

But I, I, I didn't want to say it's, it's, it's within blacks or within whites. If it's with blacks, it's because of other education that our, our parents never, never gave us, sex education, that thing they never gave us. (M)

Together with this was a strong set of beliefs about the role of whites and/or the South African government. On one level, the government was using AIDS as a ploy to reduce the size of the black population, as they had done with earlier population control programmes:

And they think it is one of the government's, er, plans of eliminating the black, er, nation, because, I mean, sex is as old as I don't know and blacks have been engaging in sex for many years with no AIDS. (M)

You know now some people would tell you that: No, it's another strategy which is used by the government to eliminate voters for a new government, but we don't know.

The same as family planning, when it was introduced, you know, people are still reluctant to use it because they say that the government is eliminating the black soldiers, you know/ja. (M)

And another argument they use is that they say, um, that blacks have, um, are not concerned about over-population, so AIDS is another means of trying to, um, another means of/reduce the population/yes. (A)

They also used the AIDS threat to undermine the traditional lifestyle of blacks and as a way of trying to limit the one pleasure left to the poor and unemployed:

Another reason for people wanting, not wanting to go for an AIDS test is because they claim that, you know, um, they don't want us to have polygamy, you know, stuff like that. (A)

Just like some ideas about Christianity, you know ... people say it's just the white man's way of taming the black man, so it is some form of, people just regard it as some form of indoctrination. (F*)

So now all of a sudden there is this AIDS thing and it is connected with sex, so I think, er, I mean that is the only thing blacks can do freely (laughter) There are no restrictions (laughter) you know (unclear) I mean you will find a man who is not, er, er, an unemployed man, the only thing that he can do is to prove his manhood, is just through sex, producing more children, that is all, that is the only thing that he can do, you know. He can't do anything, he can't prove his manhood, because he has got nothing to do, he just sleeps the whole day and the whole night because they are not bothered. (M)

At another level, they saw the government as blaming blacks for the epidemic by depicting AIDS as exclusively a black problem, highlighting race in statistics and via their media campaigns:

You know I was just so angry when listening to the man who was, I don't want, I don't want to sound racist, but to the WHITE man who was talking on the radio. He said, er, blacks are more prone to AIDS presently because they spend most of their time living in rural areas with the kind of traditional life. But all of a sudden now their lifestyles have changed, even being involved, more involved, to have more partners, to get involved in more sexual intercourse, it is like a new experience, a new challenge to them ... you know, I find this nonsense. When it comes, when one talks about, er, sexual intercourse you cannot say blacks are more involved than the so-called Coloureds, or more than the whites. (M)

I think also the politicisation of AIDS, it's also a very, I mean, it makes people not want to go for an AIDS test, because they believe they are going to increase the statistics, you know/ja/so many black people having AIDS. And also, I also have a big problem against that, because I saw an article in (name of magazine) about maids having AIDS. No, I was just going to buy that article, I just told myself I'm not going to buy it because it gives the implication that it's only blacks who have AIDS/ja but/whites do not have AIDS. (A)

Now what they said now that the black people are prone to AIDS, and they shouldn't have used that, say the blacks. They should have said many people will suffer in the near future from AIDS. They needn't specify that the black people will suffer, knowing the situation in this country, you see. So I mean, I, I, I, in most cases the approach is what, um, complicates most things ... they shouldn't specify that blacks, they should just say, they should just generalise that there will be many people. (M)

On the other hand, I think one thing, you hear people saying that, maybe in the newspapers they see articles saying that like most people who have AIDS are black, saying so much blacks in SA have AIDS and so much whites have AIDS, and you know what, that tends to politicise the whole idea of AIDS/mm/definitely/ and then it sounds like something really terrible to everyone, and then, you know, blacks are bad. (A)

At the same time the government had kept the problem hidden from the public and could have done a lot more to address the issue. Their responses to the AIDS crisis

demonstrated their lack of concern for blacks. All in all, the South African state lacked credibility, and any messages from them about the disease could not be trusted:

We feel so very far removed from everything because it's being kept away from us. Now if the figures were open up to people, if you knew who's, who's got AIDS in your community, if you knew the figures say in (place) for instance how many people in this area has AIDS, then you feel it ... I mean they must open up the figures to the community. (E)

Ja that is why the government is to blame, is to blame for this because when they did this diagnosis, I mean when was the diagnosis done? When was it conducted, you know/mm.

Well they do tests/and then they keep them secret now ... until late, you know. If the disease was broadcasted when it just arrived and they said there's this thing, this thing about AIDS, then I'm sure people would be pleased, even if they blamed the government at the back of their mind, they knew that they were warned. (M)

So it's not, um, the government itself doing something about it, as far as I'm concerned they're getting lax about it (coughs), they're not doing anything about it. All they can give you, it's in the newspaper, they just throw out statistics all the time, and I'm sure that's not even true. (E)

In fact it is a political issue, it contributes a lot, it's a social political issue, when you come to think of it, where we are concerned, because there are things which can be prevented but they are not, and then at the end when things are out of control then the community is blamed for that thing, but the root cause is being ignored/mm. (M)

And now I understand there is one tablet, what is the tablet that costs about R1,000/AZT/AZT. There's that tablet and now even that tablet is out of reach for us and they tell us that we are the people who are prone to this AIDS, but still the only thing that can, um, er, at least give us some temporary relief is out of reach for the very people who are prone to this disease. Why can't they make it available for us? They keep it to the people who can afford and the people who are not at, at, at risk of, er, contracting AIDS. (M)

I don't know about other places, under the South African context, whatever the government says you tend to be suspicious, because I mean, you've been living under stressful situations, or you've never trusted the government anyway at any time, any time, so why should you trust them now when they say that AIDS is, I mean we, AIDS now is more, er, um, I mean, we are more prone to AIDS. (M)

There was also some awareness of the role of socio-economic factors and the state's responsibility in this regard:

Even amongst women there are those who stand on the road, a girl stands by the road because she needs money, because of this deprivation the person needs money, a person ends up selling herself in any way. (D)

I think it has a great deal to do with the social conditions that most people live under/ja/mm/because, if for example, I live in a shack in (name of township), I won't really bother about educating my kids, you know, sex education. All I bother about is what are they going to eat before they go, they go to bed/go to bed/So

if there could be improvements in the social conditions, probably they will pay more attention to sex education and, um,/ja/ja. (A)

On the other hand, we would like to ask them, the whites to, to increase jobs, because with some jobs, one woman, a man is taken to (city) and the woman remains in the rural areas/mm/sometimes the woman is working in the rural areas and the type of job she does is not available here/yes/I would request that the government increase the opportunities for us/mm. (P)

At the same time there were some women who recognised these arguments but acknowledged that they did not nullify the practical realities of the epidemic for them:

I don't think it's wise to start saying it came from there, because it's whites, that is part of the whole stigmatising thing/mm. (A)

And one other thing, if AIDS is a plot from the government, I mean we are not sure. What if it is not? I think we should also address that question, you know, and, um, as (name) has said, you know, we should try to create an awareness (unclear) and prevent the spread of the disease, in case it is not a government plot. Because if in the long run we discover it's not a government plot, then we will most certainly have an enormous problem, I think. (M)

Of course we know it's not a government plot ... it's not that we, um, er, I am not aware, but we must also think for people who are of the grass roots level. I, I, I, are, are they also going to be thinking in the same way that we are. (M)

Because it doesn't really matter where it came from because it is here. (A)

It is clear that racism and the government's discrimination against blacks in South Africa featured prominently in depictions of the problem. Again this needs to be located within broader political discourses of oppression and victims. For example, given previous government strategy regarding population control amongst blacks (Siqwana-Ndulo, 1992), it was not surprising that many were suspicious of campaigns to promote condoms. Also, the history of legislation regarding black lives in South Africa feeds doubts about state motives in targeting blacks in AIDS campaigns (Jochelson *et al.*, 1991). While this particular stance understandably provides a powerful set of ideas with which to identify, it is also problematic. What these positions on the discrimination and racism of the South African state could mean was that AIDS did not need to be taken seriously, that blacks did not need to own the problem or concern themselves with taking action (Allwood *et al.*, 1992). In other words, they could deflect attention away from the seriousness of the problem and the need for urgent action. However, on the other hand, there are also advantages to this stance. By

depicting the problem in these broad social terms which highlight power dynamics and exploitation, the emphasis is also shifted away from individual responsibility and blame toward possibilities for collective, structural responses.

At the same time, a wide range of academics and organisations have repeatedly accused the present government of racial discrimination in its health policies and especially with regard to its inadequate response to AIDS (Cape Times, 3/12/92; Head, 1992b; Perlman, 1988; Sadie & van Aardt, 1992). Such highlighting of ways in which the South African government has misrepresented and discriminated in its response to AIDS is an important political task. However, this needs to be supplemented by strategies which help people identify realistic assessments of risk to themselves and their communities. The challenge for a new government is great. In the process of transition to a transformed political dispensation many of the inequalities in health services will hopefully be addressed and give rise to alternative models of conceptualising health priorities (South African Health Workers Congress, 1991). In addition they will need to carefully consider the most appropriate ways to locate the AIDS problem within broader health issues (Head, 1992b). This work is starting to happen within the newly-established NACOSA structure (Gevisser, 1992).

It was interesting to note a relative silence on broader socio-economic factors in the AIDS epidemic, as depicted in much AIDS literature on Africa and other developing regions (Seidel, 1990). While the reasons for this are not clear, it is possible that for blacks it is racial inequality which most conspicuously seems to influence their daily lives. Maybe too, AIDS has not yet featured high enough on the agendas of the major political movements, so that it remains depicted still largely as a medical and not a political issue (Critical Health, 1988; Gevisser, 1992). These implications clearly need careful consideration in future policy planning around AIDS management.

CONSEQUENCES

How did women respond to these daunting repertoires of making sense of AIDS? Clearly the biomedical version of the story was dominant: it draws on apparently

objective, scientific data for its claims to knowledge and determines access to prevention and care options. However, the inability of this powerful sector to produce 'solutions' to the problem understandably confounds responses and options. At the same time there are societal perspectives which have to do with protecting particular social values and morals, and with defining the problem in ways which absolve some portions of society from involvement. Particularly for those identified as outside this reassuring laager, the options are limited and distressing. As outlined above, one common response from women was attempts to distance themselves from the immediacy of the problem by denying personal risk of infection. Another response seemed to be one of fatalism, with subjects feeling that there was nothing that they could do to avoid the disease, or once they were infected:

The reaction I heard was: If I must die of AIDS, then I must die of AIDS. (E)

There is no way that she can protect herself because there is no cure for AIDS, there is no way out/yes. (P)

And if you heard that you have AIDS, you've got it, maybe it would be better just to kill yourself (unclear) there is no cure for it ... my advice is that you should just kill yourself, to take a quick way out. (H)

Others were confused and uncertain about the information they had received: they struggled to sort out how the virus was transmitted, and grappled with the relationship between HIV and AIDS:

But still, I know that sounds like a reasonable explanation, but still it doesn't, if you're confused it doesn't explain anything. (A)

You can't say it can be cured or not, we can't tell. (K)

No, but I want to know, we cannot know when we've got it? It is our wish to know where we stand, how we can protect ourselves. (D)

That means, therefore, there is a stage where, I mean, we haven't got an answer yet, that it can be possible that she can be negative and he could be positive. (F)

The AIDS carrier is the person who is likely to pass the virus to another person but can not die from AIDS/from AIDS/I'm not sure about this, and then the person who is HIV+, at a later stage she or he might develop AIDS/so there is confusion/ja, I mean, if those, if those things can be clarified/clarified, ja, you see. (A)

They also expected that to be infected was to feel ashamed and guilty, that the person with the disease was somehow to blame for their condition:

When you walk on the street and you see people looking at you, you feel guilty/mm/you feel guilty that you've got this thing (pause) it's an ugly thing. (G)

Then she stays with the guilt that she has, that she's HIV+. (A)

And another thing is the way you get AIDS, that really worries a person, that if you have AIDS people might think that you were sleeping around, so that's why a person becomes ashamed/mm/yes. (G)

But I say, because now people are blaming each other now, nobody wants to take the blame for whatever is happening ... we are pointing fingers at one another. (M)

And most strikingly, women were fearful of this disease: they described it as scary, difficult, terrible, sad and worrying. They felt that people were becoming scared of any contact with others, and that youth especially were afraid of sex and new relationships:

It's a big problem, it's scary and worrying, because if you look at the statistics, if you just look how it can spread. (A)

You see people become scared, I mean, you can talk about AIDS/ja/people become scared easily, I just, we had, two months ago, they gave out pamphlets at work on AIDS and you just saw each one grabbing the pamphlets and going and sitting by his desk and started reading this pamphlet, you know. Everybody, when you look in everybody's faces and you can see everyone thinks, you know: Oh God! Oh God! Oh God! (laughter) you know, like, their eyes got bigger and bigger all the time because it can so easily be you or me, or your neighbour. (E)

Most men are really scared of AIDS, when you hear them talk about AIDS you can hear they are scared because AIDS is incurable, even healthy-looking men are prone to AIDS. (N)

Yo! no this is difficult/it is difficult. (H)

But their future is very sad, because their future is leading to the grave, because he will not get cured ... but it is sad because the end is death. (P)

When we chat at parties, you can see some people are really worried, they are scared, you hear some people saying they will change their lifestyle, you understand. (N)

And the scary part is that people will be scared to have sex. (J)

We had an AIDS program also at our school ... and we introduced some questionnaires or questions into the, into the biology in terms of AIDS, and some of the questions, er, some of the answers that I got was they were afraid now of sex/mm, and that is the disturbance of the whole pattern of normalising sex. (J*)

And when it comes to the issue of having boyfriends, she's 12 years old, she says: I wouldn't like to have a boyfriend because I understand that people who've got boyfriends, they've got AIDS, you know. (A)

Thus women make use of a range of responses to the AIDS threat, which have implications for AIDS initiatives. By denying their own risk of infection, they reduce the

likelihood of their readily identifying with AIDS prevention messages. They also expressed considerable confusion about the disease. The proliferation of technical jargon and changing medical evidence is indeed obfuscating, disempowering and detrimental to encouraging behaviour change. There was as well a tendency to experience guilt or blame, responses which are likely to perpetuate the silence and invisibility of the problem. Moreover, fatalism as response, while perhaps indicative of the present political crisis in South Africa, would need to be challenged in AIDS programmes.

In addition, the high levels of fear are certainly understandable in the light of what is known and not known about the virus at present. Whether it is the most desirable response for bringing about realistic behaviour change is another question. It is likely that high levels of fear result rather in increased denial and fatalism (Leviton, 1989), as seems the case in this study. Another interesting aspect of this reaction is its presence within the South African context. Much has been written about the current brutality of everyday life in this country for many blacks: violence is pervasive and unpredictable, so that very few families are untouched by its threat. Other social and economic problems like poverty and unemployment are endemic. People fear death from murder, starvation, gang warfare, political retribution, drug abuse, rape (Cape Times, 9/6/93). From this perspective, we might have expected more indifference to the problem (Worth, 1989), which after all is still largely unseen in communities. We need to understand the particular fears which AIDS invokes. It is possible to speculate that the very uncertainty and newness of the disease, its unknown nature is threatening. Also, the associations with epidemic as depicted in the medical discourse invest it with further weight. What is perhaps more important is to consider how such reactions stand in the way of effective education and care, and therefore how they can best be dealt with in AIDS work.

Finally, it is apparent that while discourses of medicalisation and stigmatisation of AIDS delineate and circumscribe how the disease is understood and the options for acting (Plummer, 1988), they do not provide seamless constructions of the problem. As Seidel (1990) has outlined, they represent different modes of conceptualising,

explaining and managing the problem, which are conflictual in many respects. In addition, it was clear that women assumed a variety of positions in relation to these dominant repertoires: they distanced themselves from stances, posed alternative options, recognised the limits of particular assumptions. These examples of variation highlight the contradictory and shifting nature of even these seemingly hegemonic discourses and need to be captured in AIDS prevention initiatives, if they are to have meaningful impact.

GENDER DISCOURSES

The second major grouping of AIDS-related discourses had to do with gender relations and their implications for women in response to the problem. Generally, these positions were less directly expressed, more oblique and difficult to recognise, and also more contradictory. They centred chiefly around concerns with power and responsibility.

WHO HAS THE POWER?

A central theme to much of the discussion around AIDS for women was the role of gendered power relations. What was striking was the complex range of positions and responses produced with regard to gender and sexuality in prevention and care. This was partly a result of the diversity of women participating in the groups, but also reflected shifts in positioning of women with regard to the multiplicity of discourses.

'Our menfolk have many partners'

A pervasive assumption was that men had the power to determine what happened in relationships. Significant then for transmission of the AIDS virus was the fact that men had multiple sexual partners and were often not honest or could not be trusted about this behaviour. At the same time women had very little power, so that even if wives/girlfriends suspected or were aware of infidelity on the part of their partner, they were not entitled to confront them or demand changes:

I think, like, the one very important aspect is the attitude of, of, of males towards sex. (J*)

The power a man has over a woman, um, um, the total dominance, which fits in with all this kinds of, um, things, like swearing, etc. It's, it's a very, um, real kind of dominance that, that, that men, especially in areas like (place) has over, over women ... you know I mean like things, like girlfriend battering, it's all reality. (J*)

Me, it's just that there has never been anything about me having an affair with somebody else, so he's the one, I have heard that he has affairs with other people. (D)

He could be having other affairs/mm/you can stay with him but he could go out and bring back AIDS/mm/he then sleeps with you and you get AIDS/mm. (P)

And the problem is that, from my personal point of view, is that you can be very straight but you never know what your partner is doing/ja/exactly/exactly/that's another point.

He can sleep at home every night, but you don't know/but what about lunchtime/during the day/what about lunchtime (laughter)/exactly. (A)

While you have only him, you'll find that he is having many girlfriends. You sometimes think he belongs to you only to find out he is still interested in other women. You as his girlfriend respect him while he doesn't. (G)

She can get it because you cannot fully trust a person. Whilst you are faithful it can happen that he is cheating. (N)

You'll find that your man sleeps around during the day, when he come to his wife he'll want to have sex with her too. (K)

Okay, we know our men like to have lots of girlfriends ... nor can she ask him to leave other girls, in fact he'll refuse ... during the day this man is all over the place, he drives to (place, place, place) and all the time he is with a woman. (L)

And from rape, possibly.

Sexual abuse maybe, which is a prime here at (place) at the present. (M)

He won't tell you about his girlfriends and about his disease. (G)

Some, some don't want you to know that he sleeps around (unclear) why does he have other affairs/why does he?/that is, he does not want it, he does not want you to know/mm. (H)

They explained this situation in a number of ways. On one level they saw it as something over which men (and women) had no control, they were just that way:

He, he can, you can control yourself, he cannot control himself. (D)

Just, I don't know how, how, that is how we are made.

I think that is true. (M)

It's just that women tend to be submissive, they accept things that don't normally suit them, you see. (M)

It's so annoying/why can't they have something that will calm their hormones and their sperms for a while/mm/and, you know, go on with the business, like you

actually have to calm your, er ... okay, why can't that go with men too, let their sperm, like, lay at peace for a while. (A)

Another framework was more psychosocial, which saw men as needing to boost their self-esteem by numbers of sexual conquests:

I heard a few say: I'll never ever use that thing because I don't want to destroy my manhood/ja/exactly. (A)

There's lots of males also don't open themselves up to these things. I mean: Where am I going to use a condom, I'm a man (laughs), you know, that kind of attitude ... I mean, it's, it's part of the ego also. (E)

I mean, if Maria is going to approach him with this thing of AIDS, then men usually think now she's bursting my bubble or attacking my ego and all this type of thing/ja/because when you question men sexually they usually think: Now, um, you're undermining me as a man or something like that. (J)

What is this guy, is he a real man?/mm and you feel like My God, it is a big blow to your ego. (F*)

Some also understood gender roles as being the result of a socialisation process which both men and women experienced:

Men generally has this attitude towards this sex, negative attitude I mean, it's been built into society and also AIDS, AIDS also challenges people's, um, relation to sex. (J)

But the whole, maybe the whole problem of, of, of the male being the problem and so on, um, maybe it's, it's because the way that they were brought up. I mean, basically in society we don't find parents sitting down with their child .. and discussing the whole thing of sex. (J*)

We are, I mean, we are being brought up to be tolerant of, er, men's behaviour, because you find that in most cases what our men are doing, we don't like them/mm/ but we accept them and we, we, we just, um, make excuses, you know ... ja, we all know our socialisation. (M)

From a cultural/traditional perspective, this behaviour could be understood as having been sanctioned by society in the past, often as a form of birth control:

And you must also bear in mind that in our, in our culture, so-called culture it has been accepted for years that a man has to have many women/mm/I meah, er, just to prove his manhood. I mean, a man sitting, um, with one woman, I mean, he is a laughing stock, stock amongst other men. So, I mean, all along we, er, we, it was an accepted thing, but now with, um, things changing gradually it has been discovered, I don't know how, that a man should stick to one woman and you know. So you know, there was no AIDS before, there was nothing, people were happy, and women, at that time, accepted the fact that: if my husband is not with me, he is over there, I know where he is, you know. In, in fact they even became

friends, and they knew they were sharing the same man, so there was nothing. But I don't know where we lost contact, I don't know, but today we couldn't accept, er, er, your, I mean, to share your boyfriend or your husband with anybody else. (M)

And another thing, I don't want to sound as if I am responding to other people's comments, but in the olden days when the men had many women, I think it was a form of contraception then. (M)

And finally one could understand men's behaviour as a result of political and economic oppression which allowed black South African men few opportunities to assert their manhood other than in the sexual domain:

I mean, you will find a man who is not, er, er, an unemployed man, the only thing that he can do is to prove his manhood, is just through sex, producing more children, that is all, that is the only thing that he can do, you know, he can't do anything, he can't prove his manhood, because he has got nothing to do, he just sleeps the whole day and the whole night because they are not bothered. (M)

From the above it is apparent that women assumed a number of positions in relation to this strongly-held conception of male dominance. On the one hand they seemed to accept the status quo without question; while on the other, they tried to justify it in ways which suggested that they found it problematic. Here they reflected notions either of men and women as victims of outside forces, or which tended to blame men for their behaviour, or which saw women as responsible for the situation, by allowing themselves to be dominated. (This theme of women's responsibility will be explored later).

These views of male power to determine the nature of sexual relations are reflected in feminist theory generally, as well as in writings about psychosocial aspects of AIDS (dos Santos & Arthur, 1991). For example, Holland *et al.* (1990a), in their work with young British women, commented on the tendency for women to define their sexuality in terms of men's needs and drives. More specifically, this seemed to reflect a '*male sex drive*' discourse as identified by Hollway (1984b) and other subsequent studies (Gavey, 1989; Kippax *et al.*, 1990; Miles, 1991), and as captured in the words of a (male) AIDS researcher: '*men are naturally attracted to women, and cultural practices, including dress, dance and music ... may weaken men's power to control their sexual desire*' (Mhalu, 1991, p. 2). Within the context of this perspective, AIDS education

strategies which require mutual responsibility and decision-making are not realistic options for many women. As discussed in Chapter One, feminist writers have pointed out that it is far-reaching transformation of gendered power relations which is needed to bring about effective AIDS prevention, and not calls for the use of condoms or abstinence by women, which can be understood as attempts to re-assert control over women's sexuality. From this perspective, AIDS could in fact provide an opportunity to refocus attention on gender inequalities and the need for women-centred notions of sexuality and desire (Ardill & O'Sullivan, 1987, Hollis, 1992). For AIDS workers dealing with alarming escalations of infection, there are perhaps hard choices to be made between such ideologically sound long-term goals and short-term options like female condoms or appeals to men on the basis of threats to the welfare of children (Bassett & Mhloyi, 1991; Valdiserri, 1989).

It was significant that there was so little said on the issue of sexual abuse and its implications for HIV infection, despite its reportedly widespread occurrence in South African society presently (Cape Times, 9/6/93). It has been argued that such a silencing of women's experience of sexual abuse involves a process of control of female sexuality (Levett, 1988). It is also reflected in a more general absence of 'voice' among South African women regarding issues of sexuality and experiences of gender oppression. In this regard, it would be important to speculate on the possible links with an earlier theme of AIDS as silent and invisible and the need for people with AIDS to keep their condition hidden.

Also noteworthy was the limited use of notions of culture, except to justify male sexual practices. And as was mentioned in the comparison of groups, it was mainly men who drew on a discourse of traditional culture. A number of writers have elaborated on the ways in which culture is always linked to power and how men invoke culture to legitimate oppressive practices toward women (Campbell, 1991; Seidel, 1990; Stamp, 1989). In South Africa, where the concept has historically been misappropriated to entrench racial discrimination, the issue cannot be avoided in AIDS work. The challenge is to explore ways to mobilise and reframe the role of culture to promote

safe sex, bearing in mind that women and men will probably position themselves differently in relation to these representations.

Women are not without Power

The meanings of sex are multiple, but all the meanings are not equally dominant in patriarchal cultures. The meanings which confer power on men and project weakness, need and vulnerability into women are the product of the dominant sexist discourses (Hollway, 1984a, p. 68)

An alternative view was that gender relations were not an all or nothing matter. Women were not without power in sexual relationships: they had some control over affairs and might themselves have multiple partners:

The girl could be having other partners and not say anything. (J*)

But it could happen that she has had affairs (unclear) and now AIDS will spread further. (P)

I mean it, it, it can so easily happen, the same with guys, I mean/even in marriage/ guys aren't even assured about women. (E)

And at the same time you find that it is not only guys who always are prepared or who are, who are always anxious to make love to women/mm/because there are some women/yes/mm/if we become realistic. (F)

Dawn could have an affair without telling, er, without talking about this thing, do you understand/mm/have an affair. (D)

This alternative discourse of women having the freedom to select partners, the '*permissive*' discourse as referred to by Hollway (1984b), seems to suggest that women are not limited to positions as objects of male sex drive. As Standing & Kisekka (1989) have proposed, depictions of female sexuality appear to be more varied than those of men. This stance also implies more equal power relations between men and women. However, it runs the risk of implying promiscuity among black women, as has appeared in some of the literature explaining the high rates of HIV infection among African and minority women. This depiction then serves to locate the problem among blameworthy others, women (Juhasz, 1990; Smart & Smart, 1978; Vaughan, 1990).

A further aspect of this perspective on gender relations was that women were able to be assertive in some contexts and so they ought to be able to be more challenging towards their partners regarding AIDS-related behaviour:

Now with us we, we are feminists, we want to stand up, we want to be equal, equal with men (laughter). (A)

We've got very chauvinistic men/phew/ja, very/(unclear) women have always stood up for their rights in other issues, work-related issues, the home, domestic issues. I think they should stand up for AIDS exactly/the same way/at the same level they have for other issues/other issues. (A)

Because it's your life, and it's your body, so you must decide what is good for your body. This is good for my body, ne? (pointing to cigarette) (laughter) (unclear) decide for yourself. (E)

Ja, we all know our socialisation, kind of all from that date, but it is about time that I think we should have to challenge these things and not to accept that men are stubborn, to try/mm/to discuss these things with men, try, and though it will be difficult because our men are so conservative, but try to be involved in the process of changing, to show them that, I mean, we are equal. (M)

But we're also too submissive/personally I don't have any problems taking the responsibility for, for/contracep-/contraception, because I have my own goals in life, so that if I don't take care of my, er,/ja/having babies and stuff like that, then I'm shattering my own goals. (A)

The implication was that gender dynamics were not static: the status quo could be challenged and power relations could be more equal. In other words, male power was not necessarily unified and coherent, women were not only passive objects. They could not only show resistance to male-centred sexual discourses but actively participated in the construction of alternative positions (Holland *et al.*, 1990a; Hollway, 1984a; Schoepf, 1988; Thomson & Scott, 1991). However, in this context these exhortations to confront gender power relations seemed to reflect a potential space for action rather than one which many women actually inhabited. It also appeared to be a rather fragile space. Women pointed out the many obstacles to challenging dominant power inequalities: any fundamental change in gender relations was going to be a long-term process; within the context of political struggle, it was not acceptable for women to challenge male hegemony; and more broadly, women's issues were not yet clearly on the national agenda:

But I think also man, if you talk about education and that, we are basically talking about changing the way people relate to each other/and that is a lo-o-ong term thing/ja/you know. For outsiders to suddenly say listen here, the way you people,

having a relationship between a man and a woman, whatever, must change, that's gonna take a lo-o-ong time... because if you're gonna have this general approach about, um, your, at your sexual attitude within a relationship, um, how you talk to each other in the relationship, the, how you bring about sex is going to be a lo-ong thing, you know, because we're talking about ye-a-a-ars of, of, of people's attitudes that has to be changed now all of a sudden. (J)

When you look at things like AIDS and whatever, you expect that the easiest guys to convince would be people who are politically involved, political leaders/mm/who, because they're supposed to be open-minded, but I'm telling you, even them, they won't accept condoms, so what I'm trying to say is that even in those circles like (name organisation) or political organisations or liberal organisations or whatever, you'll find that the men are very difficult to convince/mm/... Even, the, the issue of women's emancipation it's still, it's a burning issue still today/mm/and if we can also introduce this as women you know, it will be some kind of an attack on from the women's side on the menfolk you know, it's gonna cause other problems of men being very stubborn to actually consider using such things you know. (A)

I just think, for me, I just think there needs to come, to be some constitutional changes as well (laughter) ... AIDS needs to be put high on the agenda ... because, I think, if you look at other countries, like for example Australia, I mean, like, I think, women have much more, a much more sort of, I mean, they are protected in a greater sense. (J*)

These perceptions reflect reasonably closely more widely-held beliefs about gender relations in South Africa and elsewhere in the developing world (Ramphele & Boonzaier, 1988; van der Velden, 1992). Issues around the relevance of 'western-style' feminism for black women have also been hotly and at times acrimoniously debated locally (Hassim & Walker, 1992; Women & Gender Research Group, 1991) and have implications for the ways in which such a feminist project might be approached in AIDS work. This line of reasoning also links back into earlier discourses of male dominance and their hegemony in present society, and helps locate some of women's silence regarding these issues.

WHOSE RESPONSIBILITY IS IT?

The paradox is this: heterosexual identity can only be reconstructed as truly 'safe sex' when heterosexual men are just **queer enough** to wear a condom (Patton, 1993, p. 181).

Another key dimension of the gender focus in the groups centred around the issue of taking responsibility for preventing further spread of AIDS. Different depictions of the

problem have given rise to a diversity of responses to the AIDS epidemic, including mandatory testing and isolation of carriers of the virus. However, there is general agreement that individual behaviour changes can protect people from the virus. In the realm of sexual relations this usually means sexual abstinence, use of condoms and limiting of sexual partners. Given what we know of the disease at present, these sound like sensible and reasonable guidelines. In this regard, Kutkzo (1988, p. 173) has claimed that *'women who have the facts can assess their own risk and make decisions regarding their sexual lives'*. Yet they suggest that this is an unproblematic matter of individual/joint responsibility for both men and women, which seems to ignore the broader social context within which infection occurs (Critical Health, 1988; Jochelson *et al.*, 1991). Interestingly, for gay men there is often in fact such an idea of equality between partners and shared responsibility for implementing safe sex (Patton, 1990a).

A number of different positions regarding gender and preventative action emerged, which were accompanied by complex and often contradictory implications.

Everyone must Practise Safe Sex

In keeping with the dominant medical discourse on the need for health education to bring about personal behaviour change, women in the study emphasised the need for safe sexual practices. And they were generally familiar with what this entailed: open communication, partners talking to one another and negotiating about altering sexual behaviour:

Yes, if you have an open relationship, like if I'm going out with a guy and I've been seeing him for ten months, I should at least have the decent relationship with him and be able to discuss anything with him, and if that's the type of relationship you have with a guy, I don't see what's the problem of discussing AIDS. (J)

Like I would say it's best to sit down with your partner and talk about it. (L)

That is why we should talk to each other and know that we have to use a condom. (P)

It depends on whether you have a good relationship/mm/and/yes, then it won't be difficult to talk about, like we are having a discussion here/mm/and then you can also discuss it and, and decide what they are going to do about it then. (B)

The moral of the story is the first thing Maria should do is talk to her boyfriend about the situation, get his ideas about this whole thing. (F*)

If they had an open relationship she'd also find it easy to communicate with him. (E)

Thus women often have the knowledge of what is required for safe sex, but this does not always fit their experience of relationships. As Kane (1990, p. 433) has pointed out: '*it is not necessarily a failure of reason or will that leads women to reject using condoms*', rather '*it is the result of multiple, contradictory conditions*'. While this version of shared responsibility was one which participants did not challenge directly, their discussions highlighted just how complex and problematic the options really were.

Women Do and Men Won't

The starting point in alternative notions of responsibility seemed to be that men did not and would not take responsibility for safe sex. This was confirmed by a range of male behaviours. They were stubborn/silly, they did not want to listen and denied that AIDS existed. They also would not say if they were infected, neither would they be prepared to use condoms:

It's now Maria who is sitting with this whole problem of AIDS, you know, um, (coughs) like also in society, men usually don't take this, um, the sexuality within the relationship as their, their responsibility, man, you know. (J)

Because men don't have all that responsibility on them, I mean, they can just walk away from whatever they want to (pause) and therefore they won't see it as, it be that serious to them, whereas women will take it much more serious. (E)

Usually men are stubborn, the, the, they don't easily take and understand something. (M)

But all the same, it's very difficult to tell your boyfriend that he must go to the clinic, you know, men are very stubborn ... men always think they are right/mm. (G)

You must know that the African man will not be at a loss for words in his own house, he will also tell you that there's no such thing as AIDS, that there is nothing wrong with him, that he hasn't got a sickness, he will not believe. (K)

Mine [partner] says that we are all going to die if that is the case (laughter), they say they do not believe you know, they say they do not believe about this AIDS thing. (D)

He will say: What sickness is that (laughs). (B)

He wants to infect you because you are telling him about this AIDS, he doesn't listen, instead he's busy pushing his own way. (G)

If he wants to spoil your life, he won't tell you about his girlfriends and about his disease. (G)

Because there are some guys who don't want to use condoms.
In fact most of the guys.

Ja, most of the guys they hate condoms. (A)

An African man will refuse to wear the plastic thing. (K)

They only say no to condoms/mm/without an explanation/if men don't want to use condoms, what can women do? (N)

There's lots of males don't open themselves up to these things, I mean: Where am I going to use a condom, I'm a man (laughs) you know, that kind of attitude, they must change (laughter). (E)

These beliefs seemed to reflect a combination of actual experiences that women had had and expectations based on dealing with contraception and STDs:

They said I should give my boyfriend the condom and put it on. My boyfriend just took the condom, looked at it and filled it with water (laughter). He said: Sorry I can't use this thing (laughter), because, because it doesn't feel nice, you see (laughter).

So you did try it?/Yho, you don't know her! /

Yes, my boyfriend said to me, he said it's no good (laughter) because it's not nice if it goes in a condom (laughter) ... Yho, mine threw these plastics at me! (D)

I tell you for one thing, I, I, I'm talking on my personal experience, you find that well, don't look at him with those eyes (laughter) he'll tell you: No, I'm not going to use a condom, I'll be through when it comes to time of spending [ejaculation]/mm/... but then with AIDS it's another issue, he can't withdraw, he can't say I'm going to withdraw. (A)

And really, what the major problem is with partners, okay/ja/because I've heard quite a few discussions with males, you know, it's a taboo, it's a subject which is never, I mean, they don't even want to discuss it, you know, not necessarily about them, implying that they have AIDS within themselves, just discussing the issue, you know, how about using safety measures, they just don't want to hear about it at all. (A)

Mine told me to let him sleep around, he took the condom and said, and said he was going to take them with when he sleeps around, when he comes back to me then he won't use the condoms. I told him tha-, that is not true, he probably throws them away once he gets out of my sight. (D)

Say for instance let's take two, two, two, the part-, the couple, ne, the female suffers from an infection, a vaginal infection which will need, which will need, then he attends, she goes to the doctor, doctor gives a treatment which the doctor instructs that both should take, the male will never want to take it. (M)

The other side of this view was that women were responsible generally: this was their nature, they exercised responsibility in a variety of domestic situations as well as more specifically regarding reproductive health:

It is usually men that's stuck on condoms and it's because we are receptive and we, we women are, er, take things, um, we don't usually take things for granted, take things a bit serious, learn and we study and we understand the use of the condoms. (M)

I think their reluctance to use condoms is much more than ours/mm/ja/because already we have accepted using contraceptives. (A)

I mean the whole issue of men, women always taking responsibility of contraception. (A)

So it's worse with AIDS, because they want to put the blame to women and I think that's why most of the time when the health people are talking about AIDS they always talk about women. (A)

So they were the ones who would take the initiative in prevention of HIV infection (Segal, 1987). For this reason, a device like the female condom, which would give women control over AIDS prevention, was urgently needed:

Even if he refuses, I will use it, nobody will infect me. So far there is nothing wrong with me, but I will use a condom just in case, because he is the one who sleep around, do you understand? (N)

A woman can control herself, if her man is sleeping around, she knows how to control herself (unclear) the important thing is that she should protect herself. (K)

If we as women at least be given something you know to prevent AIDS/I think we will use it more than men. (G)

If there was a device that we could use, condoms as used by men, then we could use it freely, so we really know how to protect ourselves. (N)

No she must drink pills that will protect her like condoms (laughter)/yho!
Do you know about the pills?/no/I should think they must invent such pills. (L)

How can Sophie protect herself? Because it's obvious that only Sophie can protect herself ... now it's better if she protects herself, if she had something to protect herself with. (H)

The role of a female condom in AIDS prevention has generated some controversy. On the one hand, it is an option which many women see as helping to give them control over reproduction and disease prevention (Brown, 1993; Carovano, 1991; Stein, 1990). However, it is also argued that this device does not provide a real alternative: it does not change fundamental power relations and still requires the permission of the male

partner (Patton, 1989). AIDS activists have argued that the absence of research into alternative modes of protection specifically for women, like the female condom and spermicides, indicates the sexist bias of research priorities (Actup, 1991; Hollis, 1992). However for women in this study, the desire for a female condom was an understandable response to the weight given to male condoms as preventative method.

A somewhat different emphasis was that women **should** be the ones who took responsibility. Given that men were not reliable in this regard while women were, it was up to women to take the initiative to protect themselves, for this was after all a life-threatening situation:

I mean the responsibility should fall, should fall onto the women as well. They're going to indulge in the same acts, so they might as well take the responsibility too, because, look, they're risking themselves. (E)

It's maybe undiplomatic (overtalk) but it might be your last chance, it may be your last chance in your life, so it's a gamble whether you want to be diplomatic with this person/or not/I mean it happens just like that. (F*)

You've got to look after yourself, maybe you must use a condom.

I say she must find out by herself if her boyfriend is seeing other women and she must prove it. She mustn't allow other people to interfere or influence her relationship. (L)

But I strongly think we should not start making it someone else's responsibility to do this and this, just make it your own. If the guy wants to make it his responsibility let him do that, but you must also know it is yours. (A)

But then you are very worried about your own safety, okay?/ja, ja/and I think in this situation it's, I mean, um, you have to consider your needs first. (A)

The implications here were again that women **could** actually exercise influence over their position. There were a number of options open to women in this regard. As was outlined above, the starting point was discussing the issue with your partner. Another option was for women to be assertive and insist on the use of condoms and limited partners. Otherwise they should refuse sex or leave the man:

Like if you can talk to your husband, you can suggest safe sex. That doesn't mean you suspect him of anything, you want to use condoms just to keep yourself safe. (L)

Okay, let's say you know that he is going out with 20 girlfriends and yet you still love him. Okay, you tell him: Look (name) whenever you want to have sex with me I will give you a condom, understand?

I agree with you. A lady who has a man with 5 girlfriends must go and get condoms from the local health clinic, so that whenever you sleep with him you use a condom. (L)

Even the married ones could use a condom until they get tested if they have AIDS or not. After that they can then stop using a condom, being confident that the man will not sleep around again, and me too as a woman, I won't have other affairs. (P)

Well we must speak with our men, tell them if they don't want to use condoms there is no sex. (G)

You get no piece [sex] if you don't use a condom! (laughter) (E)

Or otherwise use a condom/must use protection/or people should stick to one partner, I mean not sleep around. (E)

Not to have this partner, that partner and that other partner, to concentrate on one partner. (H)

But if he is against the whole thing then she can bring condoms. If he still refuses and she again catch him with girls, she must terminate the affair. (L)

So he can't sleep with you if he does not use a condom.

What?

He can't sleep with you if he doesn't use a condom.

He cant sleep with me?/yes. (H)

Well her husband must use the condom if he wants to sleep with (name), (pause) and without condoms she must refuse to have sex with her husband/yes/ (laughter). (K)

If he does not want to use a condom you must stay on your own, if he sleeps around/if he sleeps around/if the person sleeps around you must stay on your own. (D)

If he is stubborn there is nothing you can do, you just tell him you want to end the relationship. (G)

It must end/it must come to an end/I will terminate the affair/yes because he comes back to make you dirty and leave you with the disease/mos, if that's the way I will also end my affair. (G)

Only one woman raised the possibility of alternative sexual practices:

Men can still do it the old ways. In our tradition men were allowed to have sexual intercourse with their pregnant wives as long as he does not penetrate her ... he would not penetrate you, instead he put his penis between your thighs far from your vagina (laughter) or even if he does he would not ejaculate ... this was done to prevent pregnancy (unclear) our men can do the same/mm. (K)

This absence is significant in that non-penetrative sex falls in line with feminist alternatives to male definitions of what 'real' sex is (Kippax *et al.*, 1990; Segal, 1987).

It would be important for AIDS educators to explore in greater depth the meanings of these practices and potential spaces for their use, especially among youth.

The above suggestions for protecting women from infection seemed again to draw on notions of women having the power to make such demands. From their discussion we see that this is not a strongly-held belief. Seidel (1990) has warned that depictions of women as dynamic, responsible, speaking subjects, while appearing to provide a liberating option may on the contrary impose constraints.

Alternatively, subjects thought that women needed to devise effective strategies for 'getting' men to change their behaviour: they needed to adopt a reasonable or persuasive approach, which might include bringing in professionals (doctors/clinic staff) to lend weight to their cause:

Well that's difficult, especially if they've been active before, then suddenly in the middle of the relationship you must use condoms, it's not, I don't know if he's gonna take it very well. She's gonna have to be really tactful to be able to, and persuasive to change his mind, that suddenly after a whole year's relationship with no condoms, you know, just straight sex, then suddenly. (A)

I mean, I mean, I should try, try, try a time, even if it is during er, bed, even if, when you are watching TV, try and talk about this thing, this thing AIDS. They talk you know, so and so, try to place a ground. If you understand what kind of person your man is, you place ground and try an approach so that he can easily understand it ... so I think the approach goes a long way even with us women getting condoms for the men. (M)

So maybe if you can use men to/oh/ja/ja/use someone who has an influence over that person, like in the case, that guy, if his boss comes to him and tells him there's AIDS and he really must play it safe and he must go for a test, that guy obviously has strong influence. (A)

He should not be told by another woman, he will say not even his own wife tells him that. It should be a man who goes there and explains to them how are people are dying from this, and even when he puts it across, he can say it is the women who brought this thing, because the men don't do anything wrong/mm/it is women who bring bad things/mm/he must tell them that women bring them these diseases/mm/so he should urge them to use the condoms as the women are killing them/mm/they will follow easily, they will never like any criticism aimed at them/mm/mm. (K)

Don't actually tell him to go, to get some tests for AIDS but maybe tell him to get, they must go to a clinic if they want to have children, just to test their blood. (J)

The only way you can prevent AIDS is to tell your boyfriend to go to the clinic, don't say anything about condoms, in the clinic they will tell him, because guys do not want to use condoms. (L)

Sometimes you try a way and, ne, say I visit a doctor and he test me, and I'll tell my doctor the reason for the visit, that I'm here because my boyfriend wants to marry me, so I want to be checked, and I'll also ask him to write a letter to give to him. Maybe after receiving the letter he may do something/mm. (G)

She should ask that they should write him a letter at the clinic and she can take it to him. (H)

However, this strategy of resorting to indirect persuasion was recognised as a problematic, dependent alternative by some:

I think all this, all this going around the bushes trying to check Sam is totally unnecessary. Depending on what type of man he is, he is going to be very understanding ... if you trick him and say: Listen here you better go for this insurance cover (laughter) ... it's totally unnecessary, it's gonna come out eventually, it's useless beating about the bushes, like saying um, I'm not actually going for this ... it's stupid man. (J*)

There are interesting contradictions attached to the notion of women persuading men or getting them to change behaviour (Cohen *et al.*, 1989). There was a sense of powerlessness in women having to draw on others, authority figures, other men, to get their partners to use condoms or go for tests, which seemed to be more in line with the implications of the '*male power*' discourse. The importance of having a sense of actually being able to implement health education strategies has been highlighted in work around the notion of self-efficacy in AIDS prevention (Perkel, 1992). But on the other hand, there was a degree of powerfulness, a space which women have constructed within which to manoeuvre, in being able to '*manipulate*' men to do what they were reluctant to do. This approach is reflected in strategies adopted by women in single sex hostels in the Western Cape in order to survive, as described by Ramphela & Boonzaier (1988). These manoeuvres also were suggestive of the approach which adults might adopt in dealing with recalcitrant children, a position of indirect control.

Arguments for women to take responsibility for AIDS prevention and care, as outlined in this study, represent an increasing focus throughout Africa on the ways in which women have responded to the epidemic and depictions of them as strong and resourceful educators and care-givers (Kaleeba *et al.*, 1991). Yet it has also been argued that women's strength in the household does not necessarily translate into

power in relation to their men (Campbell, 1991; Valdiserri, 1989). Some further problematic implications of such a position have already been discussed in Chapter Two.

Dilemmas of Responsibility

The injunction to practise safe sex and the acceptance that this was '*women's work*' generated grave difficulties and contradictions for women. An elaboration of the intricacy of these dilemmas goes a long way towards understanding why women cannot easily protect themselves from HIV infection.

'It's a difficult business'

Firstly, they recognised that for women, being assertive or even persuasive was not easy. Much depended on the quality of the relationship: generally it was not easy/common to talk about matters sexual, so an open trusting bond was needed:

Because I, because some women don't feel free to talk about sex/ja/and some men don't feel free/mm. (E)

AIDS also challenges peoples', um, relationship to sex, man, I mean, I don't think it's only men that, that, um, that is not able to talk about sex maturely. I think generally people is not able to talk about sex in a mature way. It's always been something dirty, um, and now all of a sudden we have to get AIDS and have to talk about sex in a mature way. (J)

The other thing is that we don't even discuss, er, sex that much, even among peers/even among the girlfriend and boyfriend/so then it becomes much more difficult when then there's even condoms involved. (A)

Some of us are very interested to learn a little bit about her, okay, sexual history, okay, and when you come to this issue of condoms, that's a very difficult part to talk about: Who have you been with before? Most people do lie/mm/but you ask her anyway, okay. So, but the thing is that, and you always choose a very comfortable place for this, for this thing, because it's going to be a little bit/soft?/ja. (F*)

Relationships were also invested with different meanings at different stages. From this perspective it would be easier in a new relationship to suggest the use of condoms, while the partner was still '*starry-eyed*':

So I think it is wise to introduce it during the first outing. It is then that the two of you will decide whether okay, I am going on with this relationship or no I can't ... because maybe, or maybe you might build up a relationship for, for, for let's say

three weeks and then you find out really I'm satisfied about this guy, his character and everything, and the minute that you start raising the question, the whole thing is spoiled; when you could have discussed it the very first day before any/oh ja/ attachments were made. (F)

It usually goes like this; if he is really serious and he wants you, when the affair is still new and the boyfriend proposes a marriage, he will never say no, he will go to the doctor, he will listen because he doesn't want to lose you/yes ... because as a girlfriend sometimes the affair is still fresh, he will listen to you. (G)

Can we turn this around the whole concept of AIDS, I mean of condoms. I think the best time to attack is when you, you start the relationship because if you are very firm then he is going to consider using a contraceptive, but if you let him get used to you it is going to be very difficult for you to convince him otherwise/mm/okay, some people are already in a relationship, that I appreciate, but I think if you are not in a relationship and this guy is still head-over-heels or whatever/mm/force him to use that bladdy condom, he's gonna use it/ja/mm/he's gonna use it. (A)

Alternatively, it could be more difficult because the relationship was not yet well-established:

But all the same it is very difficult to tell your boyfriend that he must go to the clinic, you know men are stubborn, it is better to tell him when he proposes a marriage/when you are married, when he think about marrying you/mm. (G)

No, it's fine if your relationship is 10 years old, it's fine, you don't have to, maybe you also want to have kids at that stage, so it's fine, you won't have to be on any prevention. (A)

I don't think there is any normal human being, male or female, who would talk about condoms the very first day they meet. (F*)

One night stands were a reality and needed to be tackled as well:

If you are going to have a one-night stand, whether you introduce the subject or not, it is okay if she says: Bigger it, I'm not doing it. You would say: Bigger it, I'm not going to bed with you, it is no break in the future relationship. (F*)

Those who were involved in marriage/long-term partnerships could less-easily take the risk:

Let me tell you one more thing: in the first place we are married, he is no longer the boyfriend, I'm no more the girlfriend, he'll tell you: Why should I use a condom? (A)

But when married it is not easy to divorce, he won't listen because he knows that you won't leave because of such things, but as a girlfriend you can tell him that you may end the affair. I think he will listen if you threaten to end the affair. (G)

I know of somebody who worked in (AIDS education organisation) and this person was very adamant, she said, she told us there's no ways, but then she didn't have

a steady relationship, and now every guy she met, of course she would insist and the guy would use a condom, it was either that or nothing. But now she's being having this steady relationship, okay. At first when she met this guy she insisted on condoms, but now because she's getting used, she's beginning to feel uncomfortable about actually forcing this guy to use condoms ... but what I'm saying is that much as she was such a strong, like, um, supporter of the whole condom story before she had a steady relationship, now that she's in a steady relationship she's considering letting go of the condom story. (A)

Notions of romantic love also meant that it was difficult to raise the issue of safe sex:

Maybe it's because she does not understand AIDS, that is why she won't be warned and also the fact that she loves this man/mm.

I also see she is in a difficult situation because when you love somebody, you love that person and you don't like to be told things about someone that you love.

Another thing is that we do not know this AIDS thing. A person tells me about AIDS I have not yet seen, and because I love my partner it would be difficult for me to end the relationship. (H)

One thing we know Sophie loves her boyfriend, she doesn't imagine leaving him. (L)

Okay, then I dismissed the issue [symptoms of STD] because I love him. (N)

Another important aspect was that of fidelity: if you wanted your man to use condoms, it meant you did not trust him or that you had been unfaithful and were thus probably infected. Raising the issue of condoms also might confront one with the possibility of a partner's infidelity:

It is not easy because the problem is, you may be honest but he will think you have other men. Also he will think you do not trust him, so it is difficult to raise the subject. (N)

I mean there is this couple that have shared everything, they trust each other, you know, they think that this one is living only for me, and now when this AIDS education comes up then the man brings up the subject of condoms, it might also create problems because it will sow that, er, seed of mistrust because they will think that why must, I mean, we have been faithful to each other for years, why this sudden thing about condoms, you know. (M)

When you trust him so much you don't think about condoms. (L)

Okay, even if you produce a condom, because I've got them in my room, your boyfriend changes and turns against you, and you actually, since that he suspects you of having other affairs, that you go around issuing condoms to other men, so the condoms do lead to misunderstandings with our boyfriends. (D)

Because you will ask him/mm/why is he using the condom, and he will say he just uses it. Why do you use a condom when you have sex with me?

That means he had sex with somebody else (unclear).

That will be because you think he has other affairs.

So that is why he does not want to use it (H)

Some, some people don't want to know that he sleeps around. (H)

There were also fears that requesting the use of condoms implied that promiscuity was being encouraged:

The reason I am saying that is because we send our children to Family Planning and when she comes back, she sleeps with all the men in the world, because she knows she won't fall pregnant ... and if I allow her to use condoms she'll always carry them inside her school bag and seems to encourage her to sleep around. (K)

You know, even if we women use condoms our boyfriends will find out and they will think there is something you do during the day during his absence. (L)

Another woman's marriage came to an end because the husband told her to leave when she advised him to use a condom in order to protect themselves from diseases. He took it as if she is also using it with other men, he told her to pack her things and leave the house. (K)

By allowing him to use a condom, it means you say it's right for him to see other women. (L)

Underlying all these nuances was the fact that the stakes were high for women. The man could turn to other women, which would increase your chances of infection. Or he might physically abuse you. There was also the likelihood that he might desert you, with the serious economic implications which that carried:

Maybe she, she fears that he'll, um, find another girl and she desperately wants him. (E)

Or he would just hit you with a stick, he hits you. (P)

But it's difficult for those who don't know anything about the old ways because if you refuse he will beat you, that's what you'll get from him. (K)

If you use it your man will hit you. (L)

But you can't tell your boyfriend that you have AIDS/but you must be honest with your boyfriend, tell him you have AIDS.

No, he will run away from you. (G)

She was very thin/mm/she was very thin, she was normally a big person/mm.

AR: Where was her husband?

She was not married.

AR: Didn't she have a boyfriend?

Yes she had a boyfriend.

AR: Where is he now?

He ran away when he found out that she had AIDS. (K)

PR: What sort of advice would you give her?

Not to have sex with him (laughs).

PR: To stay away from sex, is that a possibility?

One solution, yes.

AR: Is it practical if you are married?

No it is going to be a problem, it can wreck the whole marriage. (B)

But even in those other issues, the only women who can afford to stand up for their rights are people who are self-sufficient/ja/to some extent and can fend for themselves/ja/'cause if I don't want to use the condom, I can just refuse because I don't depend on no man to support me or anything. But take a typical township or even/mm/some white females, they do some of them depend/mm/on their men for support, but take an average housewife who is not earning an income, for survival she is dependent on this guy, it is very difficult to be assertive and to stand up. (A)

Sophie cannot tell him to use a condom because she hasn't got a job... Sophie is dependent, she has to think about her life. (H)

She cannot leave him just like that, remember she has a financial problem. (L)

Thus, assuming responsibility for safe sex was fraught with difficulties. Firstly, effective AIDS prevention depended on the quality of the relationship and the ability to communicate openly (Fullilove, *et al.*, 1990). However, in South Africa at present, political instability and violence create an unlikely climate for the type of openness and trust required. The possibility of implementing safe sex also depended on the stage of the relationship, and it seemed that no phase of a relationship was without difficulties, so that quality became that much more important. Finally, the ability to practise safe sex depended on the meaning invested in the relationship, with notions of fidelity, trust and promiscuity playing a role (Ehrhardt, 1988; Thompson & Scott, 1990). Yet research in Africa has found that high levels of antagonism and lack of trust often exist between partners (Standing & Kisekka, 1989; Seeley *et al.*, 1991). In other words, current depictions of relationships which these women drew on, did not seem to provide real opportunities for negotiating safe sexual behaviour.

The risks as outlined by subjects were also high. The prospect of economic abandonment here, as in the rest of Africa, is particularly stark (Krieger & Margo, 1991; Schoepf, 1988). Ongoing drought and increased levels of poverty have made women more likely to depend on a regular partner, or to resort to multiple partners for financial survival. Nyamathi & Vasquez (1989), in a study among latina women, found that the overwhelming focus that directed their lives was dealing with threats to their role as

provider. However, the critical role of economic factors in AIDS spread is a complex one. For example, in many areas it is not only poor women who are becoming infected (Gwede & McDermott, 1992). So there is the danger of setting up a false dichotomy which encourages some women not to recognise their risk of infection. It was also argued earlier that the common phenomenon of female headed households (Cooper *et al.*, 1991) may either increase or reduce power to influence sexual behaviour. It is likely too that the depiction of women paralysed by poverty generates a measure of helplessness in the face of these structural forces, which is counterproductive for AIDS work. Moreover, while improved economic conditions would undoubtedly change dramatically the face of the epidemic in developing countries, to suggest that such measures would remove the kind of gender inequalities outlined above substantially oversimplifies the issues at stake.

The fear of interpersonal violence expressed by participants too is realistic (dos Santos & Arthur, 1991; Strebel, 1992), and underlines the fact that for many women sex has always been associated with danger anyway (Segal, 1987). Together with politically-motivated violence, South Africa has also recently seen sharp increases in criminal and domestic violence. Therefore, suggesting to women that they undertake behaviour which may increase the likelihood of such violence may be irresponsible on the part of AIDS educators.

Taking/taking away responsibility

Another problem which women identified about the issue of responsibility was the paradox that by assuming for themselves the responsibility for AIDS prevention, in addition to their many other responsibilities, AIDS became women's problem. This let men off the hook; they were relieved of the necessity of recognising their own role in the spread of the virus and in the need for behaviour change. The irony was that it was men who engaged more in unsafe sex and who had the power to implement changes:

What is so sad about it is that women has a lot of responsibilities, a lot of responsibilities land on their shoulders with everything, with the, the different options. I mean, she wants a family but she can't because on the other hand she has to think of she might have AIDS, she can't get a child, the contraception, all those things. I mean, even if you come back to the education and all that, the responsibility still lies with women. (E)

Because it's a lot of responsibility on women: you take the pill, you gain weight, there's so many side effects/mm/... all he does is go bang, and he's gone, bang and he's gone ... I think it should be a shared thing. (A)

So this whole thing of AIDS is becoming Maria's problem and it's not Sam's problem and she has to bring it up with him. And it's not as if Sam hasn't heard of AIDS before, um, so, so that is the other problem in their relationship, that the whole responsibility of bringing up AIDS and addressing it is, is Maria's responsibility solely. (J)

I mean, wearing a condom every, taking a contraceptive pill, you know, delivering a baby, I mean it's too much ... (laughter) They're doing nothing, you've got to do the cooking (laughter), do the washing (laughter), do everything for them (laughter), I mean/sometimes he doesn't even bring money home/you are an extension of their mothers, I mean, when are they going to grow up and take responsibility ... so why should we suffer for them, I mean, it's about time (unclear) shared the responsibility. (M)

Because if he doesn't agree, you can't use a condom, because he is the one that must put it on. (P)

Furthermore, the discourse of women's responsibility also implied that their responsibility extended to the cause of the problem:

He can say it is the women who brought this thing because the men don't do anything wrong/mm/it is women who bring bad things/mm/he must tell them that women bring them these diseases/mm/so he should urge them to use the condoms as the women are killing them/mm. (K)

This perspective again absolved men from the need to take action and was in line with the notion of women as reservoirs of the virus, as evident in much AIDS writing (Gilman, 1988; Ingstad, 1990).

Thus the contradiction of both taking and simultaneously taking away responsibility is clearly difficult and has implications for AIDS interventions. For example, the use of a female condom reflects this dilemma. It was also articulated by South African women in response to attempts to establish a national SWAA branch in 1991 (Strebel, 1993a). There is growing recognition that an appropriate response to AIDS as a problem for women must involve men and their responsibility to practise safe sex (de Zaluondo *et al.*, 1989; Kurth & Hutchinson, 1990; Reid, 1992; Tapping, 1991); as is taken up in the following section.

Sharing blame and responsibility

There was also a voice which recognised that the positions were not that unambiguous. On the one hand, women were not only impotent victims of male irresponsibility: they also were reluctant to take responsibility and to use condoms (McCombie *et al.*, 1991), and did not take warnings seriously:

I mean the responsibility should fall, should fall onto the women as well, they're gonna indulge in the same acts, so they might as well take the responsibility too, because look, they're risking themselves/mm/and they're risking somebody else if they might have the disease. (E)

But it's not so easy ... I mean, you're taking the risk so you must be responsible for what you did. If, if she gets AIDS or if she has it, if she goes through with the thing, then it's her fault entirely because maybe the community has come out and tried to educate her on the whole thing, but still she's decided to do something else. (E)

We are also the problem, because I know, I've got a very negative attitude towards condoms. I don't know whether, maybe I also need more education, but I tried a condom for the first time. I told myself: no, I just had a attitude, er, towards this thing, now I'm going to enjoy using a condom, but I never did. (A)

The condom is the right thing, but, but we still don't want it, nurse (laughter). (H)

So even women can also be affected by this AIDS thing, I mean by this condom use and mainly with the teenagers/mm/at school, you come across them and um, their boyfriends are complaining that it's these girls that don't want to use condoms, they say they want flesh on flesh, they say wearing a condom, and another one just said (chuckles): I mean having sex with a condom on is like having, I'm having a shower with a raincoat on (laughter). (M)

It was interesting that this position was not expressed by women in the two mixed groups, although men raised it in both sessions in which they participated (See earlier discussion of single sex versus mixed groups in Chapter Three, and Strebel, 1993a).

On the other hand, not all men were the same: some were worried about AIDS, took the problem seriously and could be trusted, while some even were prepared to use condoms:

I think they are just as scared. (E)

A wise boyfriend will understand and allow you to go for a check-up ... most men are really scared of AIDS, when you hear them talk about AIDS you can hear they are scared. (N)

Because it might also have happened that even the husband was faithful to the wife, to Dawn during marriage. (M)

Because for instance we [nurses at a clinic] are dishing out condoms and a lot of people are coming to fetch those condoms, a lot, believe me.

Is it men mostly?

Men, most of them, and even some you would never think they would, a lot of them and they're not even ashamed of that/mm/so maybe they're moving/ja/very slowly. (A)

But then there are men who do actually want to take responsibility/ mm/and actually take the weight on their side and ... and make sure that you are on contraceptive, otherwise it's like: Let's use the condom and make sure, and those are men who actually are taking responsibility for their lives, you see, and share it, and I think they should be given the chance to be able to make the decision.

(A)

It also depends on how he feels about her (pause) if he really cares about her, then he will stand by her. (C)

They say they will control themselves because they have heard about this thing/ mm/and you can see he is serious.

Some guys, when they come to propose to you, they mention the condom issues, they say you must not be offended because there is a disease and that they use a condom, understand/mm. (N)

I think I think we shouldn't assume men don't want to wear condoms. I mean, they, condoms are not used as a method of contraception as much as all that, but the few people who come are mostly men. (M)

This quite strongly-supported stance seemed to suggest that the situation was not all that bleak. While the notion of male power and dominance was compelling, it was nevertheless not impenetrable. For example, many black women demonstrate substantial power and assertiveness in other contexts. So rather than needing to start from scratch, we need to explore ways in which this power might be extended to other contexts. Also, if men and women share some common understandings of gender dynamics, there is ground for mutual problem-solving (Airhihenbuwa *et al.*, 1992; Merson, 1991). Reid (1992, p. 2) has expressed this strongly:

Women alone cannot stop this epidemic nor care for its sick and its survivors. Women alone cannot bear the burden of its psychological, social and economic impact. Nor should this be expected of them. To do so would be to build in the certainty of failure, not because of any failing in women but because the nature of HIV transmission requires a conjoint, shared responsibility.

Therefore interventions require a nuanced approach; which recognises possible spaces and resistances, and which enhances those which seemed to be helpful for AIDS work, while not raising unrealistic expectations.

CONSEQUENCES

The need to practise safe sex confronts women with a fundamental contradiction: on the one hand, they are faced with a construction of gender relations in which men have freedom and power to determine the nature of the sexual interaction; while on the other they may accept that it is women's responsibility to take action to prevent spread of HIV infection. Women responded to this dilemma in a variety of ways. Many blamed men for the situation, describing them as irresponsible, uncaring and recalcitrant:

Then you can blame your boyfriend about it, you tell him it's because of him, that you are sick, it's his fault, so he is forced to look after you and care for you, because you got the disease from him. (L)

But I think personally that if the man was never honest, he did all the sorts of things, went from one lady trying affairs, I think he deserves to get AIDS, and even deserving the disease, the fact that Dawn should tell him that these are the results of what you have been doing, so you have got to pay for what you have been doing, I can't go on with you like this. (M)

Because even if he, he, he should a, a, that one has got AIDS, you are going to look after him and say: No, it's my husband, I made a vow that, through thick and thin I'd be with him, (unclear, overtalk), but when, when it's your turn, say if you got the virus, then the whole family, the whole family will be against you, I mean there won't be any, you know/support/no, no, there will be no support for you because it's a disgrace, you shouldn't have done that ... but if it's a man, I mean, they, they make all kind of excuses for you. (M)

Others felt guilty, that they were to blame for not being strong enough to take the necessary action, as described earlier. Another reaction was one of fatalism and helplessness:

I think if he doesn't want to go and get the condoms, don't beg, and just stay there and say nothing, if he doesn't want to prevent, just stay at home. (L)

I was going to say it's useless for Sophie to leave this guy because she will go on looking for a man that will satisfy her, sleeping with this one and leave all the time, this does not help her solve her problem. (L)

(Sighs) No, there's no other way, but at the same time it's difficult to leave your man over a condom (laughter). (L)

You will also pass it to somebody else, there isn't much you can do here, you will hear that he has it already and leave him, this will not help because you can leave him for somebody else and this person will get it from you. (D)

But if he does not want to use it then that means there is no way for you to protect yourself/if you are not prepared to lose him/if he does not want to/if he does not want to use a condom, you decide that rather than leave him, I rather sleep with him and die with him. (D)

It's a threat, it's a real threat/(unclear)/I mean if you are in a relationship and you are sexually involved, you're not exactly going to say: Okay! bye-bye, tu-tu, next one (laughter)/ you know, it's the real thing (unclear) it's not as if you are still young, you know. (A)

For me, if my boyfriend does not want to use condoms then I will have to accept it. If I don't, then he will leave me and I will get one who also will object to the use of the condom, then you will end up changing men, which is wrong. (N)

In the end, for those women who were economically dependent there seemed to be no solution, while for those who could, the only option was to leave the relationship, probably all relationships - a bleak and unfulfilling prospect:

Sophie seems to be in a difficult situation because her friends are warning her, and at the same time she loves this man, now she has a problem ending this relationship as she can see that he helps her a lot. Right enough, she hears what they say, that he might bring her AIDS, but she does not understand this because she loves this man since he gives her gifts/mm/I see Sophie in a difficult situation in the sense that she is not working and this man is helping her out/mm/and while her friends are warning her she does not even fully understand AIDS/mm/hence she does not heed the warning/mm not heeding the warning. (H)

I, I, I, I'm just thinking of another scenario/mm/for example Maria could just, um, distance herself completely from, from relationships ... the woman could completely um, see the situation as useless, um, feel that she can't handle it and, and just, um, back out, back out of relationships. I think it could have that adverse affect as well on, on, on say women's confidence. (J*)

It's better to be on your own, stay on your own (pause) the doctors, until the doctors find out that you also have the disease. (D)

My younger sister, sister used to ask me: But sisi, what is AIDS, I would like to be a doctor because I don't want to have AIDS. And when it comes to the issue of having boyfriends, she's 12 years old and she says: I wouldn't like to have a boyfriend because I understand people who've got boyfriends they've got AIDS. (A)

I chased my boyfriend away, because I am frightened for the AIDS (laughter) or he'll bring AIDS from outside. (D)

What about the woman, er, the woman who perhaps, who likes sex and she can't do without it, what is she going to use? (C)

An almost inaudible voice was the one which identified women as having some united power, to work together to identify problems and possible solutions, and to make demands as they have in other spheres:

I was thinking for example let's say there is an organisation that helps people at clinics or hospitals, that if we as women in these organisations at least be given something, you know, to prevent AIDS, I think we will use it more than men. (G)

And then women from their own side perhaps come together and discuss it. (M)

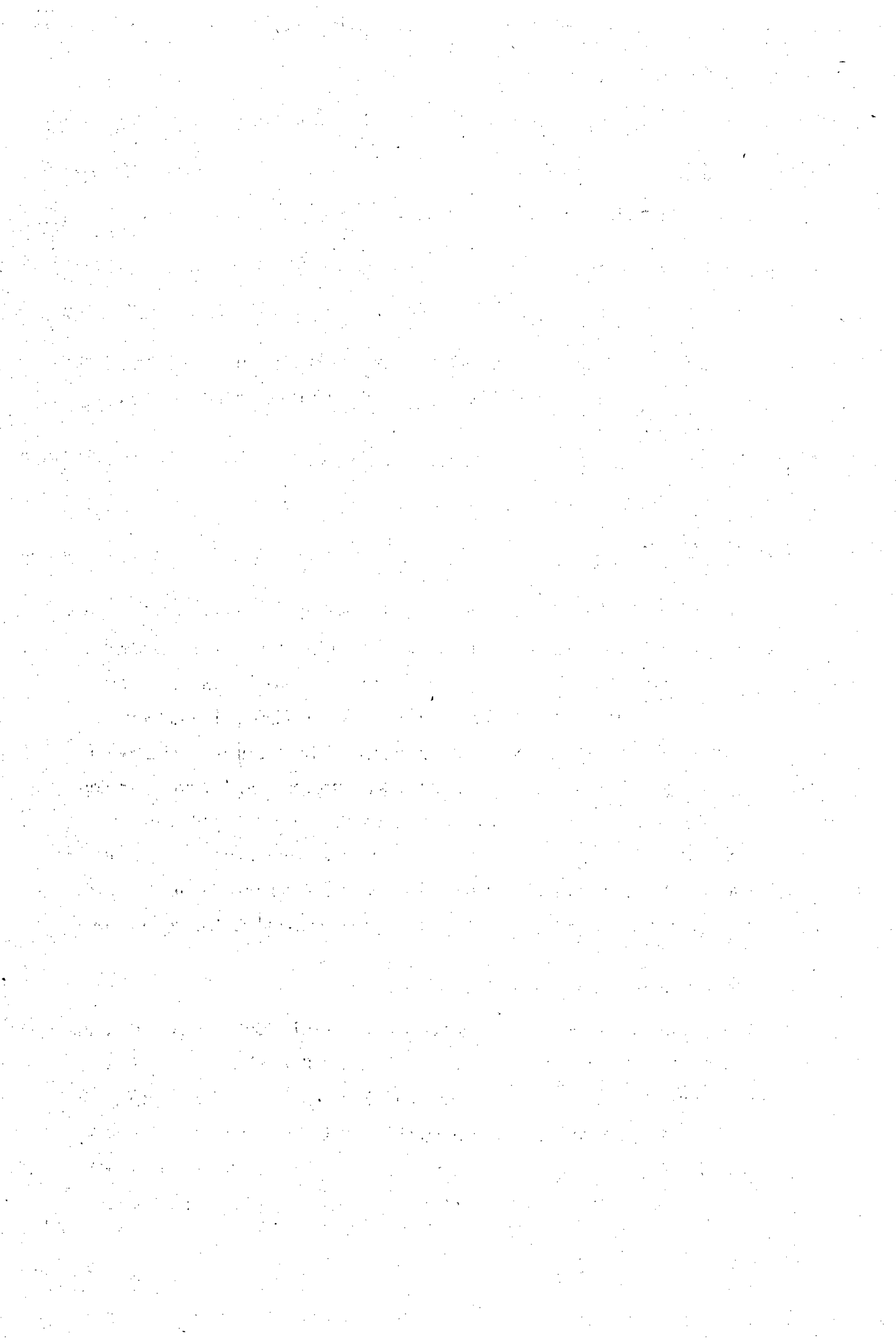
We've got very chauvinistic men, whew!/ja/very/(unclear) women have always stood up for their rights in other issues, work-related issues, the home, domestic issues. I think they should stand up for AIDS exactly/the same way/at the same level they have for other issues/other issues. (A)

This problem requires that we should hold meetings as women and we gradually involve the men and the youth as well, also gradually, we should not be in a hurry. (K)

This range of responses requires serious consideration. Reactions of blame and guilt, while temporarily relieving of anxiety are not very constructive. Fatalism and helplessness are substantial obstacles to the adoption of preventative strategies, and a major task of any interventions would be to recognise these positions as legitimate and develop empowering alternatives. In connection with such feelings of hopelessness and depression, Profumo (1991) has described an innovative psychoanalytic model of community AIDS education, in which he approached the whole community as an extremely depressed patient which was unable to channel its rage.

An important route to this goal would seem to involve the strengthening of the voice of united action, as has already proved to be an effective strategy for AIDS work among gay activists (Wachter, 1992b). However, it is recognised that such strategies are difficult for women, faced with depictions of an epidemic requiring individual behaviour change and often isolated in the domestic realm (Patton, 1989). Given the political awareness of many of the subjects and the strong history in South Africa of women's struggle, it is interesting to speculate on the relative silence of this voice in the present study. While women have played an important role within broader political struggles, they have not yet won substantial gains on women's issues generally, nor felt confident to tackle issues of sexuality (Charman, de Swardt & Simons, 1990; Walters, 1991). Also, AIDS has not yet featured prominently in national democratic campaigns, which is understandable given the flurry of issues needing immediate attention, but needs urgent redressing (Gevisser, 1992).

It seems therefore that, while women articulated some resistances to dominant depictions of AIDS and recognise some alternative spaces for intervention, the epidemic generally invokes strong negative reactions. Unless AIDS work with women takes account of these meanings and implications, it will continue to magnify dilemmas rather than generate viable options. The following chapter will attempt to outline possible approaches to this task.



CHAPTER FIVE

PULLING IT ALL TOGETHER - CONCLUDING SCENARIOS

This chapter aims to integrate much of what has gone before, to explore the implications of this for HIV/AIDS prevention, and to offer some comments on the value of the approach for both research and intervention.

THE BIG PICTURE

An initial challenge to the contribution of this study is its ability to respond to what appears to be a rather obvious and fundamental paradox in the findings. Thus, a crucial question which the analysis needs to address is the following: if women generally seem to have reasonable knowledge/awareness of AIDS and what they need to do to avoid infection, together with a strong sense of the negative implications of becoming HIV-infected, why then are they not taking preventative action, changing their behaviour, practising safe sex? This section will strive to pull together the many strands which contribute to an understanding of this issue. It will do so by highlighting some of the central depictions which women drew on in their accounts of the problem and by speculating on the possible implications for prevention of HIV infection of these stances.

A first stage is to locate the present findings within their specific historical context, and thus to understand the phenomenon of AIDS as evolving through and reflective of a dynamic interaction with particular social constellations. As was outlined in Chapter One, the present stage of the epidemic in South Africa is characterised by relatively few identified AIDS cases, estimations of a much larger number of those already HIV-infected and more or less dire predictions of what the future holds. Given this situation,

AIDS is readily depicted currently as a silent and invisible disease. This occurs in a number of ways. For many people AIDS is not a lived reality, part of their everyday experience, it is not yet much talked about. Also, one is not able to 'see' the disease, since those who are infected might show no symptoms. Moreover, it has not yet touched them directly, as most people do not personally know anyone infected. Such a range of constructions was repeatedly offered throughout the project: by people working in the field of AIDS (Study One), as well as by the HIV+ women of Study Two and the women in the Main Study.

A further dimension to this version of the problem, was the belief that the HIV-infected person should keep silent about her/his condition. This was necessary because of the consequences of such infection, as outlined by HIV+ women in Study Two and women generally in the Main Study. '*Having AIDS*' would lead to isolation within the family and community, desertion by partner/s and family, and neglect from the medical profession. This was considered to be the result of the sexual stigma attached to the disease which lead to blame of the victim, rather than sympathy; and because of the epidemic's associations with deviance and death. So the prudent strategy was to keep the condition hidden, thus compounding the otherness and invisibility of the problem.

These reactions need to be considered alongside much of the professional response to AIDS, which has often emphasised the need for testing, identification and control of those infected; all of which reinforce perceptions of the need to avoid disclosure of HIV status. The media have also perpetuated this '*shroud of secrecy*' through their handling of those infected. Another interesting parallel of this response is its resonance with the silence and guilt surrounding the sexual exploitation of women in South Africa.

Thus, we have the emergence of a strong discourse of silence/need for silence. The likely concomitant of this position is the encouraging of a sense of denial: AIDS is not a '*real*', tangible problem, there is **no need to do anything**. However, this response does not go unchallenged and does not necessarily provide an uncomplicated solution. The very silence and invisibility of the epidemic carries its own threats, as was evident in the expressions of fear and uncertainty of HIV+ women and those in the Main Study.

Secondly, we need to consider how the prevailing dominant **AIDS discourses** contribute to the dilemma. In this regard, the pervasiveness of the medical paradigm, as evident in the accounts of women in the Main Study, is significant. While positioning within this discourse might offer some reassurances in the promise of scientific solutions, it also engenders feelings of powerlessness and dependence on professionals to identify and deal with the problem. In other words it suggests that the individual **can't do anything**. Furthermore, even the benefits of medical technology, in the form of treatment and vaccines will not be available to the majority of black working class women. Hence the sense of fatalism of many of the women in both Study Two and the Main Study.

At the same time, discourses of AIDS stigma, created through associations with promiscuous sexuality, the deviant behaviour of '*the other*', and, paradoxically; racist views of '*African AIDS*', were readily adopted by women in the Main Study. Investment in such positions would only increase the sense that personal risk was not great, that AIDS was not of immediate concern to these women, through the process of denial. As a result, the perception that the individual/groups **don't need to do anything**, as also identified through the discourse of silence, is reinforced. Once again however, the potential escape from discomfort which this route promises is challenged by the implications of alternative discourses, which evoke strong fear and the previously mentioned helplessness, both of which women in the Main Study demonstrated.

And finally, for women the complexity of the situation is compounded through **discourses of gender**. Here, the central paradox was clearly demonstrated in all three studies. On the one hand women are positioned and position themselves as responsible for prevention of infection: for themselves, their children and their partners. They are also then by implication responsible for spread of the virus. As a result, they **should do something**, it is incumbent on them to take action to curb spread of the virus and to care for those infected. This stance is manifest in the burgeoning research focus on women and the multitude of AIDS initiatives being undertaken by women worldwide and especially in Africa.

However, on the other hand, through the discourse of gendered power relations, they are seen as dependent on men, lacking control over their lives, and so unable to insist on condom use, abstinence or monogamy of male partners: in other words they **can't do anything**. This is frequently compounded by their economic need. As a result of these conflicting stances, they land up feeling both guilty and helpless, as voiced by women in the Main Study.

In summary therefore, we are confronted by a complex web of contradictory representations/alternatives in which the specific historical context of the AIDS epidemic, in South Africa at present, plus dominant AIDS discourses, together with discourses of gendered power relations, both of which are mediated by economic forces, make effective AIDS prevention unlikely at present and especially difficult for women (See Figure 1).

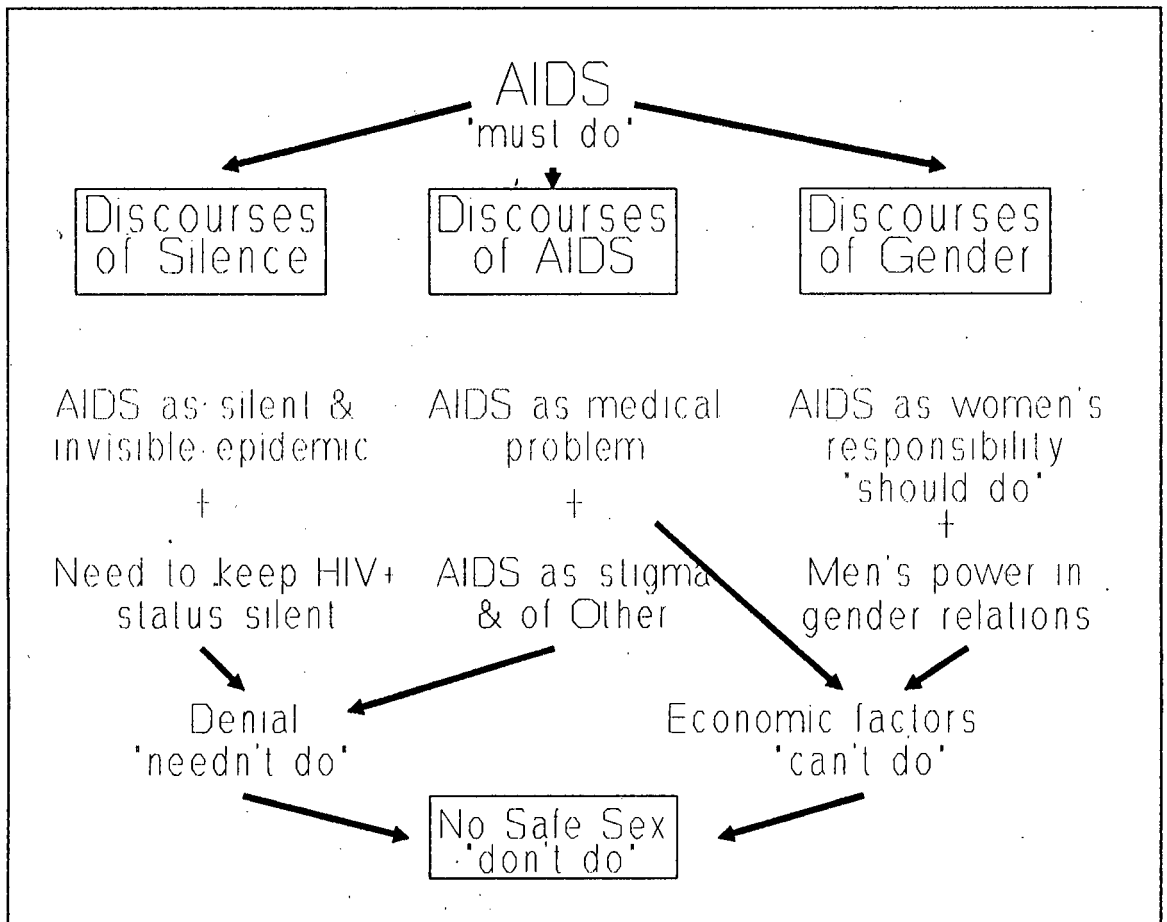


Figure 1: The Big Picture

THE WAY FORWARD

The need for change is urgent, but clearly change in this area will be slow partial and contested (Holland et al., 1990a, p. 24).

The above synthesis, while it provides a possible framework for understanding why AIDS-related behaviour change might not be regarded as a priority by many South Africans, nor in fact a viable option for those women who might wish to protect themselves, seems to paint a rather bleak picture, which identifies tensions, constraints and complexity. Yet it is in fact the very multiplicity of discourses, the softly-stated alternatives and contestations, the detail and nuance, which offer spaces for change and suggest the key to a more positive response. There are a number of intersecting dimensions along which such shifts are possible.

THE CHANGING CONTEXT

In the first place, the current context, with its accompanying climate of silence, is not unchanging. There are a variety of changes in material conditions which can be predicted. For example, as more people unfortunately become identified as infected, manifest symptoms, present for treatment and die, the epidemic will of necessity become more visible and less silent. This will reduce the possibility of effective denial and increase the likelihood of recognition of personal risk. Also, as medical advances are made, treatment options and the possibility of access to them will increase, although this will remain somewhat of a distant consolation for many developing countries, South Africa included. Political changes in the country too will have an impact on depictions of and responses to the problem.

ALTERNATIVE DISCOURSES

Another important source of change is within the domain of discourses themselves. Reservations about the capacity for the field of discourse analysis to produce transformation or incite to action were identified in an earlier chapter, as were some assertions about possibilities for practical resistances and interventions. In this regard,

it was argued that dominant discourses are neither static nor unchallenged. They are contrasted to alternative positions, to less-dominant ones and to silences, and they are modified in interaction with discursive positioning. Thus, the reflexive process of identifying the range of available repertoires and the investments associated with positioning in relation to them allows for movement, changes in response to and management of the problem (Burman, 1990; Butchart *et al.*, 1991). However as Hollway (1984b) has argued, this is not simply a process of replacing old discourses with new ones: all relations and practices are imbued with the capacity for both change and stasis.

There is also the possibility of direct intervention. Juhasz (1990, p. 43) has proposed that what is needed is a challenge to the process of attempts to control women through depictions of AIDS, an active engagement to '*muster our representational forces to attempt to contribute to the social construction of women and AIDS*'. In similar vein, Watney (1989, p. 71) has suggested that there must be resistance to the dominant cultural agenda of AIDS, that the '*rhetoric of AIDS can be forced to speak new meanings*', as has happened among gays. In another way, Fortin (1987, p. 918) has argued that:

The language of AIDS in Africa is one derived from the West. It is a transplanted language that is dependent on the West for its meaning and continued development. It speaks in Western symbols and with a voice that was born from that cultural cosmology ... Given the richness of the cultural diversity of the African continent, the language of AIDS should be a polyphony of voices, aware of the many dimensions and problems that this epidemic presents.

Such conceptualisations of discourse and agency encourage the identification of shifts in depictions of the problem, spaces for alternative responses, and the enhancing of previously silenced narratives. In the present study it is possible to highlight some examples of this in relation to the discourses outlined in the previous chapters. Firstly, regarding medical depictions of AIDS, we could expect an alternative, more positive discourse of dealing with AIDS, in which HIV infection is not a disgrace and those infected need acceptance and care. McGrath *et al.*, (1991) in fact point to an increasing trend in Uganda towards acceptance by family of HIV+ members, as more families become affected directly by the problem and they recognise the common

bond of illness. Such a shift would need to include careful unwrapping of the relatively silent homophobic and moralistic discourses evident in the study. Another modification within the medical paradigm might include an alternative view of hopefulness for those infected, a sense of living with rather than dying from AIDS. As more becomes known and a better understanding is developed about what retards and what facilitates progression of the disease, more options will emerge and a sense that there is something you can do to reduce the agony of being HIV+, so it is worth knowing your HIV status (although remedies remain out of reach for the poor). This would allow the holistic health option to be made visible.

Secondly, in the area of the stigmatising of AIDS, there are a number of possibilities. A weakening of the discourses of the other is likely as AIDS statistics grow and the virus is represented more strongly as everyone's problem (as in the rest of Africa). Moreover, racist discourses might require less investment as political changes in South Africa better represent the interests of the majority of the people. Also, we could expect the development of an indigenous language of AIDS, as the problem gets constructed more in terms of people's own experience, on the basis of increased experience with the disease and its ramifications. Such a process may be facilitated by accentuating the intersection of traditional health practices with the disease, and by engaging with notions of traditional culture. However, the strength of the discourse of sexual stigma might not be easily tempered, especially if it is black women and men who are mainly infected, although challenges to the concept of high-risk groups may help.

With relation to discourses of gender there are also potential spaces. Notions of male power may be countered by reinforcing perceptions of potential for more power for women (as articulated in this study), and drawing on the strength of women's collective action; although the entrenchedness of patriarchy and economic dependence makes this difficult. Also, depictions of women's responsibility for AIDS can be shifted to those of shared responsibility with men for a community and family problem. And importantly, spaces need to be opened around notions of sexuality: to expand the realm of desire and sexual options, to include alternatives to penetrative intercourse, to challenge

views of prevention as control of women's (or limitation of men's) sexuality, and to tackle issues of sexual abuse.

While the above options offer some hope for creating a more conducive climate for tackling the problem of HIV infection, they are not shifts which will automatically or necessarily occur. Even with active commitment of AIDS workers and policy-makers to such a task, unintended or unexpected constructions and investments are likely. Nevertheless, this level of analysis of the issues generates valuable conceptual frameworks and provides strategies for both broad-ranging and small-scale, focused interventions.

MORE IMMEDIATE ACTION

While changes in the AIDS epidemic and in material conditions in South Africa, together with shifting possibilities in discursive positioning, suggest some options for increasing effective AIDS preventative behaviour; some might justifiably claim that the realm of discourses is an abstract and obtuse one, and that the above-mentioned alternatives are long-term, slow-impact contributions to what is after all an urgent crisis. However, the process of mapping the present discursive positions and practices serves an additional purpose, in allowing for a clearer recognition of realistic and effective intervention possibilities. In this way, more immediate and direct strategies can also be initiated. The findings described in previous chapters suggest two complementary paths for action: one which approaches women directly, and the other which involves women and men together.

A logical and appropriate starting point must be the mobilisation of women through existing and new structures. However, such rhetoric flows more easily off the computer than it is implemented in the daily reality of women's lives. Unlike the gay groupings in the USA, who had a history of activism and the necessary resources to back their initiatives, women are often isolated in the domestic sphere, economically vulnerable and represent anyway a diversity of interests. Moreover, as discussed earlier, the immediacy of the political process and economic crisis in South Africa at present

allows AIDS to be relegated easily to a back-burner of priorities. Nevertheless, women in South Africa have a strong tradition of motherist movements, and a long history of involvement in church groups and political organisations. They have also begun to focus increasingly on women's health issues (Miles *et al.*, 1992). And in this study they expressed their strong concern about AIDS as an urgent problem for themselves and their families. This energy needs to be harnessed for the development of collective responses from women. In this regard Reid (1992) has stressed that women need to increase their influence in AIDS policy making, programme development and implementation. She outlines four steps in this process: consciousness-raising, organisation, strategy planning and coalition building.

At this stage there are a number of possible issues around which women could lobby in order to reduce their risk of exposure to HIV and to enhance the quality of care for those infected. Firstly, they need to ensure that men are brought into the AIDS picture wherever possible, for example around issues of mutual concern like their children. Equally important is the need to work for improved economic conditions of women, to reduce dependence on men and increase access to health care and education. More specifically, they should insist on the development of female methods of AIDS protection, which offer somewhat more control to women. Together with this is the need for improved access of women to AIDS research and drug trials, so that they gain appropriate benefits from technological advances. Of related concern should be efforts to redress some of the imbalance of women as the targets of education (the soft option), while men are the focus of biomedical research. It would also be in the interest of women to ensure adequate training, support and resources for those involved formally or informally in care of those infected, sick and dying.

The second important route of intervention should involve bringing men directly into AIDS work at all levels. This would require the reframing of the issues in a way which emphasises AIDS as a problem for all members of society, so as to develop a model

of collaborative action. To do this is to increase the likelihood of effective strategies for women, as Airhihenbuwa *et al.* (1992, p. 270) have argued:

HIV prevention efforts that utilize social organization as a means of educating and mobilizing the community should focus on both male and female in order to maximize its impact. This reknitting of individual and community connections can strengthen the power base that women must have in order to build equitable, protective relationships with men.

Together men and women need to make clear the links between private experience and collective interests (Frankenberg, 1984), so that they can embark on joint undertakings which are not limited to AIDS issues but rather to a broad political vision of social change. In this regard, it would make sense to begin with shared concerns of immediate relevance to peoples' everyday lives. A key part of such a project would involve highlighting the central role of economic factors in the epidemic, and therefore to campaign for improved living conditions for all and more specifically for increased access to AIDS education, treatment and future vaccines.

A further commitment in collaborative efforts between women and men should focus on making gender relations a priority. In order to succeed, such a project would need to develop a nuanced understanding of power relations and the needs or investments involved in different discursive positioning for women and men, and so avoid simplistic blaming and stereotyping. Hollway (1990, p. 60) has interestingly suggested that '*the positions that people took up in gender-differentiated discourses made sense in terms of their interest in gaining themselves enough power in relation to the other to protect their vulnerable selves*'. There is also an urgent need to bring male experience back into our understanding of gender. As argued throughout this study, the exclusive focus on women in gender issues is not always in the interests of either women or gender equality. This has been clearly demonstrated in approaches to AIDS prevention for women. Male sexuality and power need to come under the spotlight if our analysis is to reflect the complexity of positioning in gendered power relations and AIDS-related behaviour. Without this, the solutions generated will involve unrealistic and unachievable options for the vast majority of women, as well as sparking counterproductive emotional responses.

CONCLUSIONS

The approach to the problem of AIDS developed in the preceding sections of this chapter has produced a model for understanding and analysing the issues as they relate to women at this particular phase of the disease in South Africa. On the one hand, it highlights how difficult effective AIDS prevention for women is at present. However, it has also identified some positive aspects: the context is continually in flux, so that changing social conditions will influence ways in which the problem is represented; discourses are not immutable, which allows for resistances and alternatives to be expanded/strengthened, and previously-silenced positions to become audible; such variations illuminate possible routes of more immediate action.

Thus, the model makes a number of valuable contributions to the field of study. In the first place, it provides better understanding of the complexity of the problem generally. Moreover, it provides insight into the ways in which available discourses hinder effective understanding of the problem and behaviour change. It also enhances our understanding of how women are placed with regard to the problem and why it is particularly difficult for them to take protective action. Secondly, it ensures consideration of specific contextual factors, and identifies how and which discourses might more or less easily change as shifts occur. At the same time it identifies alternatives to dominant discourses, where spaces can be emphasised, facilitating behaviour change. And it highlights how discourses might interact with broader forces in shifting the network of factors. Thirdly, it provides a framework for devising more realistic and effective AIDS interventions.

However, there are also drawbacks to opting for such a '*big picture*' approach. Inevitably, attempts to provide an integrating model run the risk of oversimplifying the issues at stake. Any privileging of particular discourses must be subjective and selective, and necessarily silences alternative depictions. Yet, without this process of '*reductionism*', any stance which is identified can be juxtapositioned to multiple alternatives; each discourse folds back on itself or splinters into a maze of contradictions. In the end though, the methods used require that both these versions

are entertained simultaneously and deemed valid, and the task is to find a workable balance of these tensions, recognising that the result is but one possible configuration. This makes for an approach which offers the researcher much of the abyss and little of the stepping stone. While this counterposing of synthesis and fragmentation is especially provocative for the impatient practitioner, it does provide an essential counter to impulsive and eventually frustrating interventions.

Moreover, there is a further challenging aspect of this approach to research, which involves the use of the method as action, the potential for utilising research as intervention. As mentioned earlier, a significant subtext to the whole process was exploring the feasibility of combining data gathering sessions with raising awareness, enhancing understanding, and motivating for action. Although such an enterprise carries possible drawbacks, for example of posing conflicting goals and roles for researchers, there are also compelling arguments in favour of the attempt. There has been a growing challenge to the legitimacy of conceptualisations of research as a process whereby expert researchers are entitled to '*parachute*' into communities and obtain data by whatever means, in the interests of '*science and progress*'. While this is undoubtedly a multifaceted issue (Seeley, Kengeya-Kayondo & Mulder, 1992), there is some consensus on the ethical need to strive for more equitable give-and-take between researchers and the researched. In the area of AIDS research this is especially telling, where the issues are often literally life-and-death ones, and where time is a crucial variable. A further consideration is to what extent the two enterprises can in fact be regarded as separate processes. Does not all research involve intervention, only some methods of data-gathering are more likely to lead to emotional engagement and investment on the part of participants than others? In short then, there are strong reasons for conducting AIDS research which also consciously aims to intervene, to provide a service, and this was then also an intention in the present study.

Over and above the more explicit educational component of the project described earlier, the research process was designed to maximise AIDS education opportunities. This seemed to involve a twofold process. Through the task of identifying the

discursive repertoires which women utilised, there was the opportunity for joint reflection on this process between researcher and subjects, and so increased awareness. Also, the particular group format of data-gathering drew on group therapeutic principles in a way which would enhance interactive development of insight on the part of participants. Some aspects of these opportunities for transformation were evident in the study. Firstly, through my trying to understand how subjects saw the problem, positions were mapped out in the public arena which allowed for greater reflection, clarity and insight for participants too. Then, in generating repertoires of meaning, subjects were also exposed to alternative positions, and so challenged to reflect on their own investments. Thus, the group context allowed for a wider and possibly contrasting range of representations for consideration by participants than an individual interview might have produced. This process of constructing accounts and meanings has tantalising resonances with the process of developing understanding and insights in psychotherapy. I was continually struck by this overlap of process between these data-gathering sessions and previous group psychotherapy contexts. The place of post-modernism and discourse in therapy has been explored in recent work of Michael White and colleagues in Adelaide (Epston & White, 1992; Lowe, 1991).

It was moreover, the group format of the sessions which appeared to facilitate the process in a variety of ways. As mentioned above, the group context encouraged debate, negotiation and challenge and so required participants to reflect on their own process. It thus provided a context for peer learning, and importantly, support and encouragement from others in similar circumstances. Finally, and perhaps most significantly for effective AIDS work, the group also created a collaborative context: both for a social rather than strictly individual understanding of the issues, as well as for considering the possibilities for joint rather than individual action.

While conclusions about the effects of this combining of research and intervention are preliminary and perhaps premature, they were an exciting and not entirely expected, although indeed hoped for, aspect of the whole research process. Subsequently, I have used the combination more explicitly in a number of feed-back and education sessions, with promising results, and intend to carry forward this exploration.

RESERVATIONS

If this concluding section has created a rather too tidy and optimistic tone, it is perhaps useful to end by referring to some of the more pertinent loose threads. In the first place I was aware of rather too easily gliding over issues of language and translation in a method which is so centrally concerned with text and constitution of meaning. While it is obvious that many of the possible problems could be avoided by researchers who '*speak the language*', I would also suggest that the nature of the research question, the level/depth of investigation will determine the extent of precision of detail required in the text to be analysed. However, much more finely-tuned and focused research would be needed to elucidate these considerations.

I was also conscious of not having dealt satisfactorily with issues of culture. Here again, the topic is an intricate one and calls for specific research. My sense is that in the present study, both researcher and participants contributed to a degree of '*consensual silence*' around the topic. On the one hand, given the history of conflation of culture with race in South African politics, I was perhaps reluctant to pursue the question too rigorously. On the other hand, subjects were perhaps somewhat reticent to offer insights in a realm which some would regard as indicative of conservative or unmodern beliefs.

Moreover, by positioning myself within a '*research must deliver action*' discourse, I have opted for rather broad sweeps and given less attention to theoretical detail. What has not yet been analysed adequately is the interplay between the macro- and micro-process of shifting investment in particular stances: what contributes to positioning and repositioning, how to understand differences between and within individuals, the interface of structure and agency. Some rather more sophisticated exploration is still needed to respond to these questions.

Furthermore, by choosing to work with women from a somewhat different background to my own, I have been guilty of perpetuating notions of the '*other*'; AIDS as something which happens to other women. While there were legitimate reasons for focusing as

I did, the task remains to turn the analytic lens more specifically on myself and women in similar positions in South African society.

Another bit of unfinished business relates to the responsibility of researcher to subjects. Although aspects of this issue were tackled directly by the research process, as described earlier in this chapter, another consideration has sometimes been the feeding back of results to participants. However, good intentions in this regard often founder, for a variety of reasons. In this study, attempts to discuss results were not always successful. Creative ways of getting research findings to connect with participants' more immediate needs are required.

And on a rather different level, as I write this section, the political climate in South Africa is starkly pessimistic, with the daily news dominated by harrowing accounts of violence, so that the issue of AIDS seems more silenced than ever. While at the time of conducting the fieldwork, the atmosphere seemed ripe for dynamic AIDS interventions, this is not the current mood. Although available figures confirm that infection continues to spread, the spaces for AIDS-related initiatives appear especially constrained at present.



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APPENDIX A

LIST OF PARTICIPANTS INTERVIEWED FOR STUDY ONE

CAPE TOWN

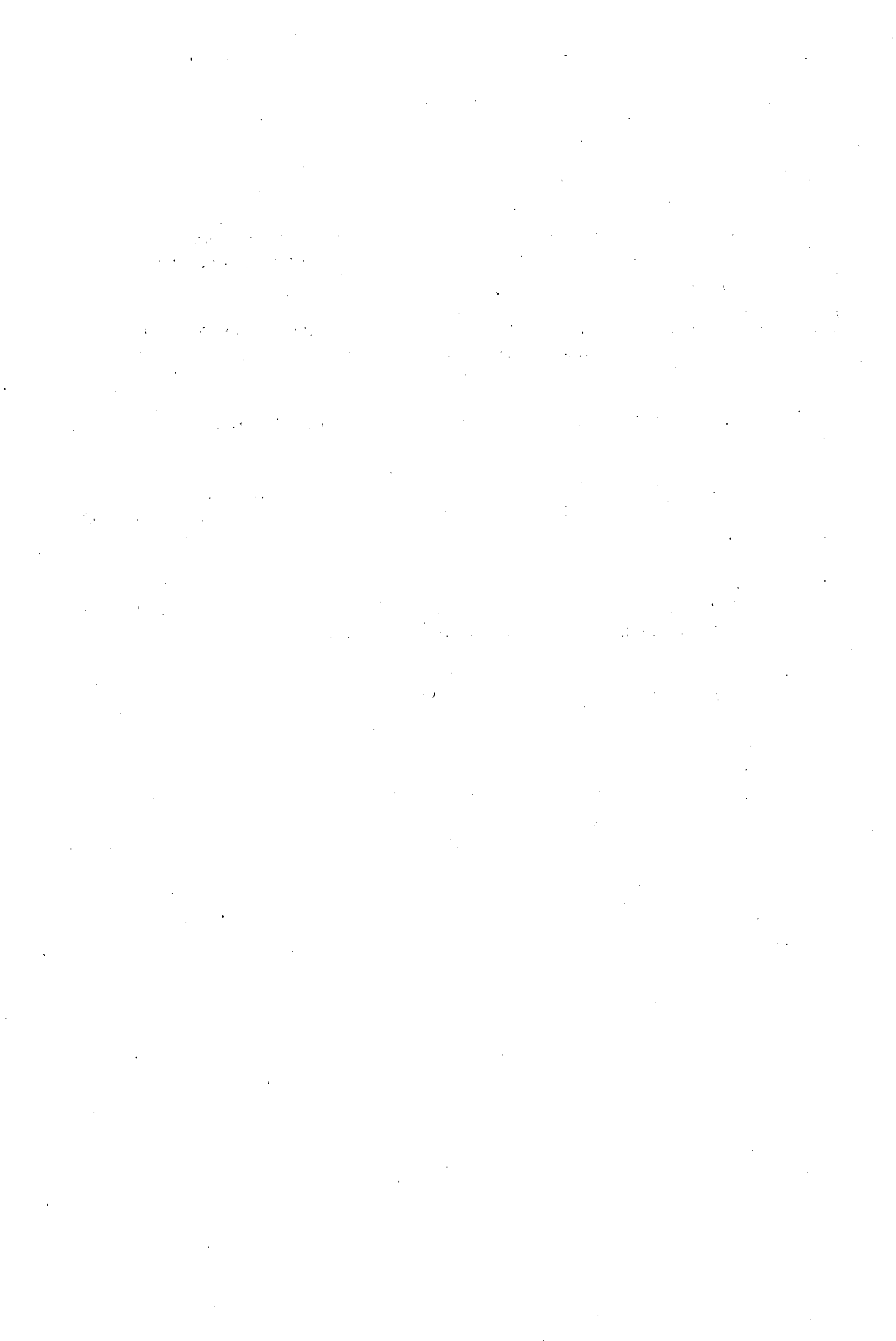
ATICC - AIDS Training, Information and Counselling Centre
CERSA - Centre for Epidemiological Research in South Africa
Groote Schuur Hospital Out-Patient Department
IHRG - Industrial Health Research Group
PPA - Planned Parenthood Association
Rape Crisis
Red Cross Hospital

DURBAN

Alan Whiteside - University of Natal (UN)
ATICC
Dory Posel - UN
Eleanor Preston-Whyte - UN
King Edward Hospital, Paediatric Department
MRC - Medical Research Council
Nqwelezane Hospital, Infectious Disease Control Sister
PPHC - Progressive Primary Health Care Network
SAHWCO - South African Health Workers Congress
Women's League of the African National Congress

JOHANNESBURG

ATICC
Baragwanath Hospital Virology Department
City Health/Community AIDS Information and Support Centre
Gill Eagle - Wits University
Outreach Project
PPA
SABSWA - South African Black Social Workers Association
SAIMR - South African Institute of Medical Research
Soweto Clinics
TAP - Township AIDS Project
Tammy Shefer - Organisation of Appropriate Social Services in South Africa
Winterveld AIDS Project



APPENDIX B

DESCRIPTION OF PARTICIPANTS IN STUDY TWO

A - twenty-five year old woman, living in a male hostel with her common-law partner of 12 years, both of whom are HIV+. She has one child, limited primary education and is unemployed.

B - fifty-five year old woman, living on a farm with her partner of ten years. They both have TB and she has two children with whom she has no contact. She has primary education and is too ill to work on the farm any longer.

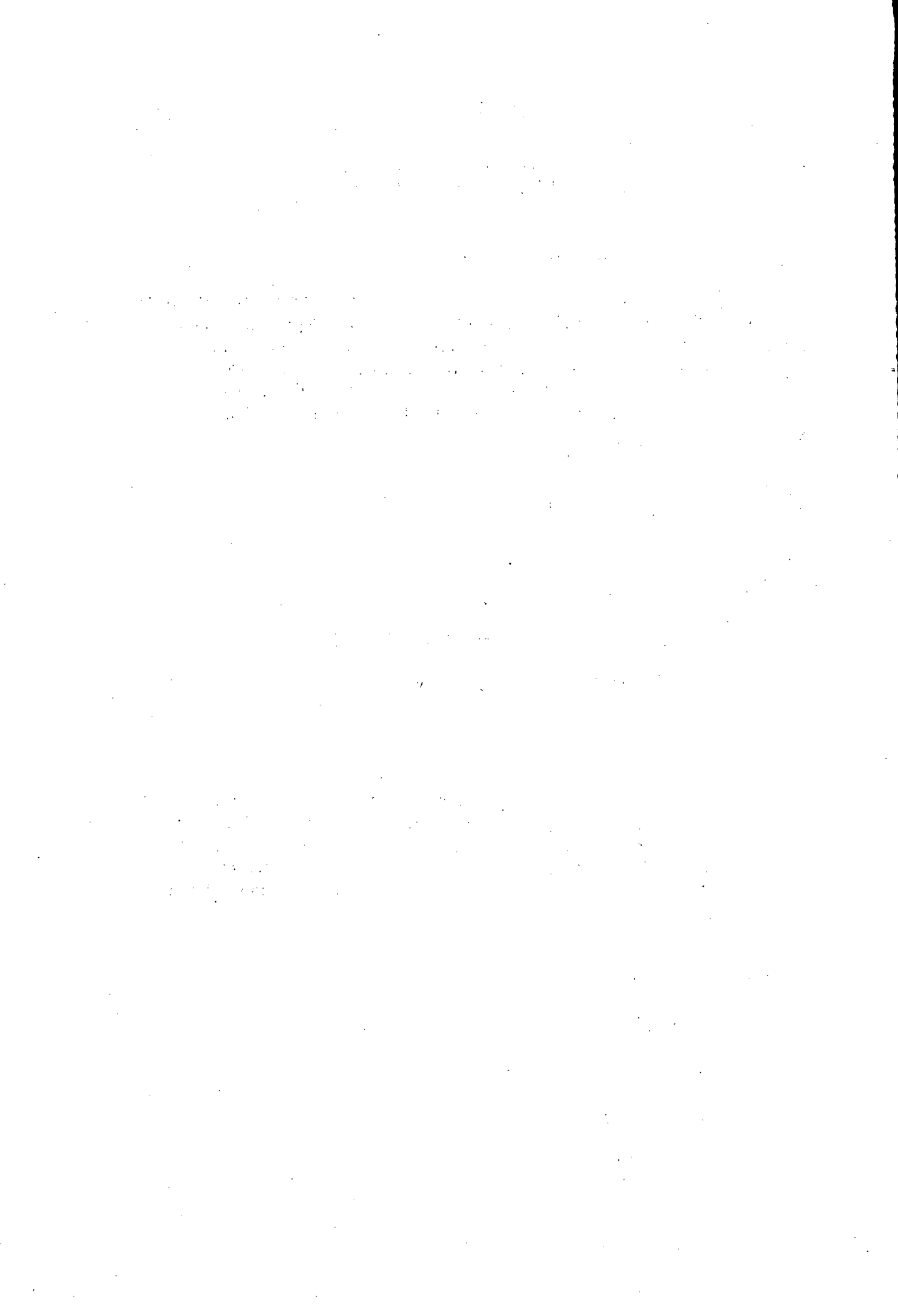
C - thirty-two year woman, with tertiary education, who is still teaching. She and her second husband are both HIV+ and she has no children.

D - thirty-five year old woman, living with her brother, and has no partner since her casual partner died of AIDS. She has one child, but despite some secondary education is unemployed. She has family in a rural area.

E - thirty-seven year old woman with TB, living in a night shelter. Two children both died at birth and her steady partner recently died of AIDS. With some primary education she is unemployed. Her family are in a rural area.

CODING CONVENTIONS FOR STUDY TWO

- ... section omitted
- [] explanatory information
- (A) letters A to E in brackets to identify interviewees
- a pause
- () information changed to preserve anonymity



APPENDIX C

VIGNETTES IN ENGLISH

VIGNETTE A: Sophie and Jakes

Eighteen year old Sophie came to Cape Town about a year ago from up-country. She is staying with her uncle and his family while she looks for a job. Last month at the taxi-rank she met a very attractive guy, who takes her out and buys her things. She hasn't found a job yet, but her boyfriend helps her out when she needs money. Her friends warn her to be careful of Jakes, because he has lots of girlfriends and a girl can catch AIDS from such a guy. Now Sophie is worried that he might be infected and pass the virus on to her.

What do you think of Sophie's situation?

How could she become infected with HIV?

What should she do about it?

How can she make sure that she doesn't get infected?

What about the future?

VIGNETTE B:

Maria, who is 23 years old, has been working in a clothes factory since she left school after Std 8. She is very popular, enjoys going partying and has lots of friends. However, for the past year now she has been with the same boyfriend and the relationship is getting serious: he wants them to get married and have a baby. But the other day at work there was a health talk about AIDS and now she is worried that she may be infected, because this is not her first boyfriend.

What do you think of Maria's situation?

How would she know if she had the virus?

How could she have got infected?

What should she do about having a baby?

How should she approach this with her boyfriend?

What about the future?

VIGNETTE C:

Dawn, who is 28 years old, has three young children and lives with her husband John, and his family. He is the only breadwinner of the household but has been ill with TB. He has just finished treatment for the TB and feels well enough to go back to work. However, yesterday Dawn and John were called back to the clinic where they were told that he has the virus which causes AIDS.

What do you think of Dawn's situation?

What do you think it means to have the AIDS virus/be HIV-positive?

How do you think he was infected with the virus?

What do you think is Dawn's risk of getting infected?

What can she do to prevent getting infected?

Are their children at risk?

Should they tell anyone about this?

How would other people react if they found out?

What will happen to them in the future?

APPENDIX D

BIOGRAPHICAL QUESTIONNAIRE IN ENGLISH

PLEASE FILL IN THIS FORM AS ACCURATELY AS POSSIBLE. ALL INFORMATION WILL BE TREATED AS CONFIDENTIAL. YOUR NAME IS NOT NEEDED. PLEASE ASK IF YOU ARE NOT CLEAR ABOUT ANY PART OF THE FORM. THANK-YOU FOR YOUR CO-OPERATION

1. How old are you?

2. Are you married divorced/separated widowed single?

3. If single, do you have a regular partner?

how long have you been together with this partner?

4. How many children do you have?

5. How much schooling have you had? None
 Primary
 Secondary
 Further qualifications

6. Where were you born?

7. Where do you live now?

8. Where do your family of origin live now?

9. How long have you lived in Cape Town?

10. How many people are in your household?

11. Are you employed?

 If yes, what is your present job?

 If no, have you ever had a job?

 What did you do?

12. How many others in the household are employed?

13. When you are not working, who supports you?

14. Who would you go to for help if you had a problem?

THANK YOU AGAIN FOR ANSWERING THESE QUESTIONS

