

# Engulfing Darkness: The Impact of HIV/AIDS on the Family

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## Abstract

A qualitative study undertaken in Mumbai, India, explored the family experience of HIV/AIDS. Seven nuclear households (4 with concordant couples in which both spouses in the marriage were seropositive, and 3 with discordant couples in which only one spouse was seropositive) included in the study reported devastating impacts in various spheres of family life, following the onset and the progress of HIV-related illness, and the knowledge of the seropositive diagnosis. Complex changes were observed in family composition, spousal relationships, family formation, family roles and responsibilities, family economy, quality of life, and family aspirations. The findings have direct implications for policy formulation, program planning, and service delivery in the field of HIV/AIDS.

THE HIV/AIDS EPIDEMIC CONTINUES to grow despite worldwide efforts to contain and control its spread. More than 34 million people are living with the virus worldwide, and the incidence is increasing (Joint United Nations Programme for HIV/AIDS [UNAIDS], 2000). Southeast Asia is considered to be the epicenter of the pandemic, with the majority of new infections expected to occur here (UNAIDS, 2000). Within this region, trends in incidence and prevalence rates in India present a disturbing picture (UNAIDS, 2000). Though the presence of HIV in India was detected much later than it was in other parts of the world, its steady rise has made it a public health problem with enormous social and economic implications (Basu, Gupta, & Krishna, 1997; Bharat, 1996, 1999; Bloom & Mahal, 1997; Godwin, 1997, 1998; Mane & Maitra, 1992; Narain, Jha, Lal, & Salunke, 1994; Ramasubban, 1998). From the first HIV case reported in a female commercial sex worker (CSW: nondiscriminatory term for prostitute) in 1986, the official Indian estimate puts the number of infections in the country up to the year 2000 at 3.86 million ("HIV/AIDS Indian Scenario," 2000). Moreover, there are numerous predisposing and precipitating risk factors

that either directly or indirectly facilitate HIV transmission in India. These are intricately linked with social and cultural aspects of life including migratory patterns, increasing urbanization, poverty, illiteracy, patriarchal values, subordinate status of women, high rates of sexually transmitted diseases (STDs) and intravenous drug use, and widespread prevalence of unsafe sexual practices. Inadequate access to health information and services are found to affect the ability of the population, particularly those at risk including women, to protect themselves (Basu, Gupta, & Krishna, 1997; Bharat, 1996; Bloom & Mahal, 1997; Godwin, 1997, 1998; Joshi & Rao, 1999; Mane & Maitra, 1992; National AIDS Control Organization, 1998; Nag, 1996; Narain, Jha, Lal, & Salunke, 1994; Ramasubban, 1998). Primary prevention activities, aimed at controlling the spread of HIV/AIDS, are totally inadequate in content, volume, and orientation, and leave much to be desired in terms of the effectiveness of the programs and policies. They therefore have done little to stymie the growth of the infection (Asthana, 1996; Ramasubban, 1998). The grossly inadequate development of secondary and tertiary health interventions has burdened populations with the responsibility of providing

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<sup>1</sup> Structural adjustment: The process of debt repayment by developing countries or the Third World to the First World or to multilateral agencies conducted in such a way that it involves cutbacks in social spending ("Structural adjustment," n.d.).

home-based health care for ill members. Moreover, in this age of structural adjustment,<sup>1</sup> community care has become the watchword for secondary and tertiary interventions (Duggal, 1998), even though it is a well-known fact that, in India, community care is a mere euphemism for family care (McCann & Wadsworth, 1992). In HIV/AIDS, these policies are promoted by the adoption of the continuum-of-care model as the globally recognized and recommended ideal form of intervention to deal with the infection (See Global Program on AIDS, 1995). Families thus have to bear the bulk of the responsibility for the care and support needs of their sick members, experiencing, in the process, long-term implications of a social, economic, and psychological nature.

It is significant to note that the active promotion and implementation of community care and continuum-of-care measures in the management of HIV/AIDS has not translated into much research attention being paid to the family experience of HIV/AIDS (Bharat, Singhanetra-Renard, & Aggleton, 1998; Grunseit & Kippax, 1992; King, 1993; Poindexter & Linsk, 1998-1999). Undoubtedly, in many respects, the family experience of care and support in HIV/AIDS is similar to that of other chronic diseases. Yet there are other unique effects, specific to the distinguishing features of the infection. Bor, Elford, Hart, and Sherr (1993) list some of these effects, namely that (a) HIV challenges traditional definitions of the family and concepts of normative family functioning; (b) family is an important source of emotional and practical support and care for the seropositive individual, which makes relevant a study of the patterns of care and support and their consequences for the family; (c) the family experiences similar problems as seropositive individuals do, including stigma and isolation; (d) HIV infection in one family member is a signal of the possibility of HIV infection in another, while also putting other family members at risk, both of which have implications for care, support, and household environment; and (e) the relationship between family support and the occurrence of clinical and psychological symptoms in the person with HIV. Further, since the pandemic has struck mainly young adults, its presence in the family engenders role reversals that represent major upheavals for families. Yet, in terms of empirical investigations, it remains one of the least studied areas.

A review of literature on the family and HIV/AIDS

(D'Cruz, 1998) and a look at studies published after that (Bharat & Aggleton, 1999; Bharat et al. 1998; UNAIDS, 1999; Warwick, Bharat, Castro, Garcia, Leshabari, Singhanetra-Renard, & Aggleton, 1998) indicate that work in this area, in terms of both the number and scope of the studies, is limited. Many of the studies deal with individuals as members of families but lack a family perspective<sup>2</sup> per se. Moreover, though the studies cover various family forms, different stages of the illness, and a range of themes, seldom does a single study encompass all of these features. Methodologically too, the studies do not always comply with the requirements of family research (For details, see D'Cruz & Bharat, 2001). With a view to overcoming these lacunae, the present study, set in Mumbai, India, explored the experiences of HIV/AIDS in various spheres of family life. Its foci included the psychoemotional reaction to a stigmatizing and terminal illness; the impact of the infection on the family, care, and support for the infected family member; family coping; and the interface with the informal support system and the health care system. A family perspective was incorporated methodologically by including multiple units of inquiry per family and by focusing on three levels of conceptualization and analysis within the family, namely, the individual members, the marital dyad, and the family unit. This paper reports the impact of HIV/AIDS on the family.

## The Context

The study was conducted in Mumbai, the capital city of the western state of Maharashtra, which covers an area of 600 square kilometers and houses 9.9 million people (Census of India, 1991). Being a commercial and industrial center, Mumbai has always attracted people in search of livelihood and better economic prospects. Migration has made the island city congested and polluted, with increasing space demands on an area that has natural limitations to geographic expansion. Squatter settlements and slums, which are crowded, poorly ventilated, and lack sanitation, sewerage, and clean water, have proliferated to house those who cannot afford decent accommodation. Being a significant contributor to the Indian economy, Mumbai is a major partner in the global process of development. It is all these various features that have made the city a breeding ground for drug peddlers, traders of flesh, and people indulging in high-risk behavior, bearing serious consequences for the spread of the HIV epidemic (Bharat, 1996).

<sup>2</sup> Family perspective involves including not just individual family members as the unit of understanding but the entire family unit and the various subsystems such as the marital dyad, the parent-child subsystem, the sibling subsystem, and so on, as the units of conceptualization and analysis. The entire family unit or multiple family members serve as units of inquiry (See D'Cruz & Bharat, 2001, for details).

## The Participants

Respondents were selected through the purposive sampling technique (Morse, 1991). The specifications included

1. the index patient, either male or female, should be a married individual,
2. the marital partners should be living together in a nuclear household,
3. all the families should largely be from one income group, to reduce socioeconomic variability in the study,
4. the household should be in an early or relatively early stage of the family life cycle,
5. the index patient should have at least one opportunistic infection, and
6. the index patient should have shared his or her seropositive status with his or her spouse.

Two other variables of significance as suggested by the literature review were also included, (a) concordance or discordance of infection between the partners, and (b) presence or absence of children in the marriage. Concordance occurs when both spouses in the marriage are HIV seropositive, while discordance occurs when only one spouse is HIV-infected.

The final sample comprised 7 nuclear families (also referred to as households). The families were comparatively young, that is, 6 of the families had very young or adolescent children. One family was in the early stage of formation, as the couple was recently married. Three households belonged to the lower economic class, 3 were from the lower middle class, and 1 from the middle income group. In 6 households, the husbands were the main earners, while wives in 3 households were support-earners. The job profile of the husbands included temporary unskilled daily wage earners (2), a full-time permanent government employee (1), and self-employed individuals (3). The 7th household was female-headed, with the family relying mainly on the wife's earnings, since the husband had not been receiving his salary for a long period owing to company losses (See table 1 for details of the sample).

Among the 12 children of schoolgoing age and above in the study families, 2 had discontinued their education in favor of employment. In one case, this decision, made independently by the child, was related to the father's severe HIV-related illness.

In these 7 households, 3 couples were discordant (husbands were HIV-positive and wives were HIV-nega-

tive) and 4 were concordant (both the spouses were HIV seropositive). A history of risk behavior (i.e., sex with CSWs, unprotected sex, multi-partner sex either prior to and/or after marriage) was reported by 5 of the infected husbands. However, only 4 of these 5 husbands attributed their HIV status to this behavior. One denied the connection between his risky sexual behavior and HIV positivity, attributing it instead to his wife having contracted the infection during her delivery. Of the 4 concordant couples, 2 were not sure of the route of infection, nor as to which spouse had been infected first. Two couples were sure that the wives' infection was due to the husbands' seropositivity. In all of the 4 concordant families, the husbands were the index patients, that is, they were the ones to present themselves with HIV-related symptoms. The wives did not present any symptoms when data collection was in progress.

Diagnosis of HIV infection in the husbands was preceded by several episodes of illness, both mild and severe, ranging from fever and diarrhea to tuberculosis (TB) and Reiter's syndrome. The illness episodes in all the husbands persisted up to the time of the interview; 3 husbands were suffering from severe illness which had incapacitated them to a large extent, whereas 4 husbands showed milder symptoms. Wives were tested for HIV because of the positive serostatus of their husbands, but among the 4 concordant wives, none reported the presence of any illness up to the time of data collection.

Altogether, there were seven children in the families of the 4 concordant couples. Four children who had undergone testing for HIV, tested seronegative. Three were to be tested at an older age.

## Procedures

Broadly, the study aimed at understanding the changes occurring in the family following the onset of HIV/AIDS in one or more members of the family. Such an endeavor necessitated exploration of dynamics and functioning of the family both prior to, and after the serostatus diagnosis, in order to determine the nature of, and factors explaining, the impact. Moreover, the research problem was a sensitive one, covering many emotional and personal themes. Given all these factors, the qualitative approach was found to be suited to the study. Its characteristics of holism, contextualism, focus on process, detail and people's perception, flexibility, and relative lack of structure (See Bryman, 1988; Hudelson, 1994; Taylor & Bogdan, 1984; Padgett, 1998) complemented and supplemented the study objectives.

From the range of qualitative research methods available (See Bryman, 1988; Hudelson, 1994; Taylor & Bogdan, 1984), keeping in mind time and resource constraints, as well as the sensitive nature of the research problem, the in-depth interview method was thought to be the best suited option and was selected for the purpose of data collection. This involved nondirective, unstructured, nonstandardized, open-ended, face-to-face conversations between the me and the participants, aimed at understanding the latter's perspectives on their lives, experiences or situations, as expressed in their own words (Taylor & Bogdan, 1984).

An interview guide was developed, covering the key topics to be explored with the respondents (such as family structure and functioning prior to the HIV/AIDS diagnosis, family response to the HIV/AIDS diagnosis, the effects of the infection on the family, the provision of care, the family's experience of informal social support and coping following diagnosis, and the family's interaction with the health care system in the post-diagnosis phase). Observations were noted during the course of the interview.

Given the sensitive nature of the research problem, difficulty in identifying and retaining respondents was expected. Hence, I simultaneously contacted a number of organizations involved in HIV/AIDS-related work. In keeping with ethical guidelines in research on HIV/AIDS, I did not approach potential respondents directly. The staff of the agencies introduced the idea and explained the purpose of the research to the seropositive individuals accessing services from them, and I was introduced to them only after they had agreed and were comfortable enough. Following rapport building and soliciting their cooperation, respondents were required to sign a consent form, informing them of details about the study and their rights as respondents. The location of the interview was determined by the respondents, as well as the possibility of tape-recording the interviews.

The units of conceptualization and analysis were the family unit, marital dyad, and individual members. While the unit of inquiry was the marital dyad, only individual interviews of the spouses were conducted. Offspring were not interviewed because the families were in the early stages of the family life cycle and the children were still young, and particularly in the light of the sensitive nature of the research problem.

With some of the families desiring interviews in the agency rather than at home for reasons of confidentiality, and with the time and financial constraints faced by the families in coming to the agency, there were limits on the

number and duration of interview sessions with some families. Thus, for families who could spare the time, there were a greater number of interview sessions and hours of interviews, as compared to interviews for families pressed for time. Notwithstanding the limitation of time, the interviews proceeded as largely nondirective, unstructured, open-ended conversations, rather than formal question-answer sessions. Though they started at points that the respondents wished to discuss, theme and time linkages allowed for the coverage of the various areas of the interview guide through the flow of a natural conversation. Undoubtedly, in the midst of flexibility, some direction was given when the focus was lost, and probes were used as and when necessary.

Five couples were interviewed in Marathi, the regional language, and 2 couples in Hindi, the national language. None of the respondents objected to the use of the tape recorder after its purpose was explained to them. During interviews, the observations were made about the respondents (and about their homes, if the place of the interview was the residence). After the session ended, field notes based on these observations were written up.

Professional caregivers were also interviewed to provide an outsider perspective (For details, see D'Cruz & Bharat, 2001). Professional caregiver interviews, conducted during the data collection period, covered 6 of the 7 study households. The interview guide was used and data were recorded on cassettes. However, details on some themes could not be obtained from them because they had never discussed such issues with the respondents. Data from these interviews were limited and focused mainly on the post-HIV diagnosis period.

Detailed follow-up of the families proved to be very difficult because of time constraints. Therefore, this was done only through contact with the professional caregivers. There was follow-up of 3 families, chronicling major events in their lives for a period of 1 year. These data were recorded through handwritten field notes.

### **Data Analysis**

During the period of data collection, interviews were translated and transcribed. I then read these transcripts carefully and repeatedly, immersing myself in the data (Crabtree & Miller, 1992). This approach did not involve prefigured categories but allowed my intuitive and interpretive capacities to prevail (Crabtree & Miller, 1992). Immersion allowed identification of themes, categories, and patterns emerging from the data (Marshall & Rossman, 1999). This process was facilitated through the use of various tools such as charts, matrices, event lists, causal

networks, and memos (Miles & Huberman, 1994). These tools were also used to examine the linkages between themes, patterns, and categories, and thereby initiate interpretation (Patton, 1990). Proceeding in this manner, the I developed various understandings (such as concepts, causal linkages, processes, and so on) of the phenomena under study. These understandings were used to inform further data collection, through which they were tested and challenged. Based on newer data, they were further developed, thereby feeding back into the analysis (Marshall & Rossman, 1999). Iteration thus formed an integral part of the research process.

When all of the data were collected, I immersed myself further in the transcripts and the preliminary findings. Through the use of Miles and Huberman's tools and memoing, I not only identified more patterns, themes, and categories in the data and looked for interpretations at this level, but also subsumed under major themes, those themes, patterns, and categories and their linkages within and across respondents, that held together in a meaningful yet distinct way. Interpretations were made based on this level of analysis.

Wherever major themes dovetailed while simultaneously retaining their singularity (Guba, 1978), they were organized around core themes, which allowed for greater interpretation and deeper understanding. The present paper describes the core theme of the impact of HIV/AIDS on the family.

## Findings

That HIV/AIDS is an illness of the family—and not that of the individual alone—is brought out strongly through the findings. Its impact is varied and increasingly pronounced with illness progression. Within all of the 7 households, illness episodes of various kinds predated the HIV diagnosis. Due to this, as well as because of the progressive and incapacitating nature of their health problem, the impact of the infection in some families was felt long before the medical diagnosis of HIV infection was made. But it was the knowledge of their HIV serostatus that markedly altered couples' perception of their or their partner's health and their response to it. That is, they were extremely disturbed to realize that their situation would increasingly deteriorate. Concordant couples also realized that wives would one day be in the same predicament as the husbands. As time progressed and AIDS-related complications set in, the impact on the household worsened. The major themes and themes discussed in this section therefore describe the experiences of the house-

hold over time, using retrospective data in combination with data pertaining to current experience, in order to highlight changes in the family due to HIV/AIDS. The temporal dimension has been incorporated in two ways. Three time periods related to specific events in the experience of HIV infection were identified in the couples' experience of the virus: T1—the pre-illness phase, that is, where there was no health problem; T2—the pre-HIV diagnosis phase where illness bearing relation to the positive HIV serostatus was present but not diagnosed as such; and T3—the post-diagnosis phase, that is the period following diagnosis of HIV infection. However, the dynamics of only some major themes and subthemes were found to be linked to this conceptualization. They are therefore discussed as such. For other major themes and subthemes, the progression of the infection was found to be a more significant indicator of changes over time, and so these are discussed in relation to the severity of HIV-related illness.

### *Spousal Relationships*

Good spousal relationships were reported by couples in 4 families in the pre-illness phase (T1). "Good relationship" was explained as an overall smooth and satisfying relationship. Among the other 3 couples, alternating phases of good and poor relationships were reported by one; an initial good phase followed by a long drawn period of strain was reported by another; while the couple in a third household spoke of a largely tenuous relationship.

Aspects of the lifestyle of the husband, involving drinking and/or gambling or a sexual relationship outside the marriage and the impact this had on the household, were crucial factors determining spousal relations. The 3 households with strained spousal relations were those where the husbands indulged in a risky lifestyle, squandered money, and neglected the family, whereas the 4 families with good spousal relations did not have such experiences.

In the pre-HIV diagnosis phase (T2), the illness of the husband affected spousal relationships only in the case of 2 couples. Irritability in the husband, because of recurrent and severe illness as well as his perception of insufficient care, occasionally sparked off conflict for 1 couple. In the household with a tenuous marital relationship, however, caregiving on the part of the wife brought about a positive effect on the spousal relationship.

Following diagnosis of each husband's HIV-positive status (T3), changes in spousal relationships were reported in all 7 families. In 3 cases where the progress of the husband's infection was not yet severe enough to affect family well-being and where past spousal relations had

been good, HIV and its implications led to greater bonding between the spouses. There was, for example, a greater sense of support and of protectiveness between the spouses. However, more complicated changes were reported in the case of the other 4 couples where the husband's health was declining rapidly due to the severe state of HIV infection and had begun to affect the family's economic condition and/or where spousal relations had been poor in the past. Concern, support, compassion, and protectiveness coexisted with anger and resentment on the part of wives.

*I feel that he is responsible [for our problems]. He should have listened to me when I told him not to waste money drinking, going to women, but he did what he wanted and now we are suffering.... If I don't get angry then what ... it is such a tension for me.... I feel compassion also—he is suffering so much. (Wife, 31, HIV-negative)*

Out of 5 wives who knew or suspected the etiology of the infection as being related to the lifestyle of the husbands' either before and/or during the marriage, and where the wives considered their husbands responsible for the infection, 4 wives were angry and hurt, even when spousal relationships in the past had been good. The anger was not so much about the fact that husbands had visited CSWs or had had premarital or extramarital relationships as much as for causing problems for the entire family. Three wives had earlier known and tolerated the husbands' lifestyle, but the later upheaval it caused for the household, either through the acquisition of HIV and/or through its effects on the family economy, made all the wives bitter toward their husbands. This was despite the bonding in some couples. The wives were convinced that the problems were invited problems and could have been avoided. As economic hardships grew and resources dwindled, there was more frustration and bitterness. Wives perceived their husbands as directly responsible for their suffering. Among these women, there was also the case of a wife being angry with her husband for infecting her. Yet, only 1 of these wives communicated her anger directly to her husband.

*I am not angry that he went to another woman. I don't mind what he does. Let him do anything. But I am concerned about myself and my children. I don't want my children to be deprived of anything. I told him this when I heard that he had this illness and how he got it. I got angry and fought with him. I told him*

*that there was no point in my saying anything, because the damage had already been done. I was angry and expressed it to him. I told him that if you had done this, why did you want to destroy anyone else. He said, "I hardly knew that this would happen. My friends were so forceful that I could not put them off. So that's why I left their friendship. After that I never went out nor did I keep any friends." I was very angry at that time. Now there is no benefit in being angry—it does not change anything. But if he becomes irritable, I tell him that if he had not done that, we would not have to face such days now. (Wife, 24, HIV-positive)*

The other wives did not express their anger to their husbands primarily because they felt that the husband was suffering enough on account of the infection and its implications. When HIV-related illness was severe, the husbands' pain and suffering was considered sufficient punishment for their past behavior. "What to say to him? He is suffering enough—imminent death, hospitalization ... no improvement in his health ... so ill for so long" (Wife, 31, HIV-negative).

Anger, resentment, and bitterness did not appear to be related to concordance and discordance. Seropositive and seronegative wives seemed to be equally angry. Despite anger, the wives were largely supportive towards their husbands and provided as much care as was possible and/or required. Moreover, all of them maintained that there was no change in their "respect" for their husbands, despite the experience. This is indicative of the extent to which the Indian value about the revered position of the husband in the life of a woman was ingrained in the respondents.

*Everyone, even the children, knows that he is responsible for the illness. He is repenting now. But we respect him as much as before ... after all, he is the father. No matter what the father or husband is, one respects him. (Wife, 31, HIV-negative)*

The terminal nature of HIV infection deeply affected spousal relations in all families, tempering wives' anger toward their husbands for being responsible for the present problems and misfortune of the household. It stimulated in them a desire to do whatever was possible to preserve the life and health of the husband, thereby influencing their caregiving behavior in a positive way. To some extent, wives wished the husband to survive for their own sake, widowhood being an undesirable social status that they wished to avoid in a patriarchal society.

*Even if he cannot work and is just at home, it is fine with me ... but I would be happy if he survives. If there is no man, a woman is afraid. People talk about single women—they take advantage of them. (Wife, 31, HIV-negative)*

The narratives highlighted that the wives did their best to provide care to their husbands, in spite of the negative feelings in some cases. Caregiving by the wives was appreciated by the husbands, and promoted good spousal relationships, even in households with poor past relationships. This was true for all but 1 household. In this case, the husband perceived care to be insufficient, which led to conflicts and tensions. The husband complained,

*She hardly does anything for me—comes to the hospital, brings food and goes. I have to ask her to put oil [on his body—this is a part of an Ayurvedic treatment regimen that the respondent was following] to bathe me, and only then she does it. On her own, she does nothing. I have to ask her. She only comes to see me of her own accord. (Husband, 36, HIV-positive)*

The wife, on the other hand, reported,

*He makes demands on me that I cannot fulfill. I have so little money to run the house, and yet he will ask for food that he likes, and if I don't give it to him, he gets very angry and starts shouting. (Wife, 31, HIV-negative)*

### **Sexual Relationship Between the Spouses**

Onset of HIV-related illness (T2) did not create any major disturbances in the sexual relationship of 5 couples. In 2 families, however, an impact on the couples' sexual functioning was reported. One of these was a newly married couple for whom sexual activity ceased during illness episodes.

In the case of another couple, the husband's physical condition precluded sexual activity. The husband complained of severe joint pains because of which he was unable to perform sexually, and all sexual activity had stopped.

The major impact on sexual functioning of the couples, however, was felt following diagnosis of the husbands' serostatus (T3). Even though sexual activity of the couples was reported to be low in most households, knowledge of the HIV infection in the husband brought in further effects. Two couples opted for sexual abstinence, though the reasons given were different in each

case. In the case of 1 discordant couple, the wife's decision to abstain came as a precautionary measure.

*He is now in hospital, so no sex. Even when he comes home, I will not indulge in it. I cannot afford to get infected. I don't care how he feels. Feelings are not important. I also feel bad but what to do? (Wife, 31, HIV-negative)*

But for the husband, abstinence was mainly due to his poor physical condition. The possibility of HIV transmission to the wife was a secondary reason.

*I will abstain from sex because I have no energy. I don't know what [wife] will feel ... If she wants to have sex ... still I will not have it. I will tell her that I can't manage it, that it is beyond me ... And plus, she will get infected. (Husband, 36, HIV-positive)*

For 1 concordant couple, sex seemed to have lost all charm following the knowledge of HIV infection and its effects on the family. "We are so depressed, who can think about sex?" (Husband, 36, HIV-positive).

Reducing the frequency of sexual activity and the adoption of safer sex methods like using condoms were the responses from the 5 other couples. Two discordant couples said that they continued with sexual activity, though its frequency was reportedly lower than earlier times, and condoms were used during intercourse. Knowledge about the sexual route of HIV transmission did not seem to make these discordant couples give up sex altogether. In one case, the couple was young and did not wish to give up. In another, the husband wished to continue sexual activity. Post-test counseling advising the use of condoms served to reassure them of protection for wives. "We have been having sex. The doctor at [the AIDS research center] told us to use condoms during sex" (Husband, 39, HIV-positive).

Sexual impact of HIV/AIDS was felt differently by husbands and wives. Wives in general seemed less affected than the husbands. Many of them considered sex unimportant and easily dispensed with. Thus, curtailing or giving up sex following husbands' HIV infection did not affect them. "I would not mind if he stopped [sex] completely but men want it. They cannot stop" (Wife, 33, HIV-positive).

It was mainly their husband's sexual drives that were adversely affected by the HIV infection. However, most of them accepted these changes as means of adapting to and living and coping with the virus.

### Family Roles and Responsibilities

Prior to the onset of HIV-related illness, the distribution of family roles and responsibilities in most households was largely on traditional, gender-based lines, with men mainly in the earner role and women in the homemaker role. The husbands reported assisting with a few household and child care tasks, but it was the wives who performed the bulk of household and child care tasks in all the families. In 4 households, wives shared the earner role too, with 1 of these households becoming female-headed for some time prior to the onset of illness. Once HIV-related illness had set in, the husband's ability to perform his roles was affected. The extent of the impact depended on the severity of the illness and on the incidence of hospitalization episodes. In the early onset period, when illness was mild, physical condition interfered with role performance only during episodes of illness. However, once the husband's health improved, he could carry out all of his tasks. Thus, there were alternating periods of husbands being active and inactive.

As infection progressed into AIDS-related complications, the husbands were increasingly unable to perform their roles, including the earner role. This was evident in the case of 2 husbands in whom severe illness precluded role performance, and for a while, only the earner role could be managed with interruptions. Over time, the physical condition of 3 husbands deteriorated to such a degree of debilitation that it resulted in incapacitation and inactivity. As a result, 2 of them had to give up their jobs, while in a third household, the husband was able to perform only the earner role during the spells when he felt better and stronger. This was facilitated mainly by the proximity of his workplace to the residence, the sedentary nature of his job, and the cooperation of his department colleagues.

Since the wives were the only other adult member in these 3 families, they had no choice but to take on the husband's role and responsibilities. With regard to the earner role, since men were the main earners in these households, their health status had a direct impact on the family economy, necessitating wives to take on this role, fully or partially, if they were not already doing so. Wives who were not earning earlier or who were working on a part-time basis had to consider full-time jobs. Moreover, wives also had to assume the caregiver role for their ill husbands. The impact was felt in terms of concentration of all the roles solely in their hands, instead of being shared with the husband. For some wives who had older children or who had external supports, the burden was alleviated to some extent. In these households, therefore, a

movement toward female-headedness was discernible. Despite this development, the internalization of patriarchal values came out strongly when spouses in 2 such households insisted that the husbands were heads of the family with the decisionmaking role power as before. In only 1 household, the husband, being totally demoralized with severity of his physical condition and prolonged hospitalization, had washed his hands of all household-related responsibilities and left them in the wife's hands.

*He tells me what's on his mind. He says, "You see to the children, educate them, see to the house. Don't expect me to live." I tell him my anxieties, but what can he do? He is not earning or anything. He can't help me face them. He usually does not respond to what I say, he keeps quiet.... I feel he is unsupportive because he never gives me courage.... He says, "Do what you want, I will die." I feel bad about it. (Wife, 31, HIV-negative)*

Wives in these families evidenced a high degree of burden, but faced their predicaments in adaptive ways. Nonetheless, the experiences of these women are a matter of concern, particularly where the woman is also seropositive and therefore in need of physical and emotional care even in the asymptomatic phase.

In 4 families where husbands were experiencing HIV-related illness but where the infection had not yet developed into serious ill-health conditions, there were fewer changes in the distribution of family roles and responsibilities that occurred only during illness episodes.

### Children

Four households illustrated the impact of HIV/AIDS on children. As HIV infection in the father progressed to a greater degree of severity and/or engendered numerous changes in the family, it affected the children negatively, especially the young children, as they were economically and emotionally dependent on their parents. Children's education and well-being were affected most quickly and adversely. With the drop in the standard of living, children were deprived of whatever lifestyle they had been used to earlier.

*Children are deprived and they express it. They want to go out here and there... [they want to go for] tuitions at school—which I can't give them. The children feel upset when they see others getting food, clothes, toys, outings, and they cannot get. The younger two [children] do not realize my circumstances because they are small [and] so they go on harassing me for what they want.*

*The elder two are more sensible and do not do so—only once in a while. If I explain to them [the elder two], they keep quiet but the younger two do not ... they get angry with me.” (Wife, 31, HIV-negative)*

In one household where economic impact was severe, the eldest child (a girl of 14) withdrew from school of her own volition to start earning. In contrast to direct major impacts described earlier, there were some subtle changes reported too. For example, in one household, the disturbance in a child’s cherished routine of an evening walk with the father, affected the child emotionally.

Changes in the quality of life, tension at home, and frequent and sometimes prolonged absence of the father due to hospitalization, affected children’s psychoemotional state.

*The children are much subdued now—not like before, because the atmosphere [in the household] is such that one feels something is wrong. They cry a lot too. They don’t say much but I can sense their feeling of sadness. (Wife, 31, HIV-negative)*

Although children could sense the changed atmosphere in the family, especially when change and loss were of greater severity and affected them directly, not all of them could comprehend the enormity of their parents’ problems. Younger children felt only their own losses, but older children who understood the situation better became more responsible. For example, in one household, the mother reported that the older children had stopped quarrelling because they realized that it upset her. They also began to help with the housework. Moreover, once the elder child came to know what illness the father had, she decided to leave school and start earning in order to help the mother out. According to the mother,

*because she [the daughter] knows that he [the father] has this illness, she says, “I will work and earn something and help you; otherwise, how will you manage? You will die of worry and what will become of us?” (Wife, 31, HIV-negative)*

### **Family Formation**

Before the seropositive diagnosis was known (T2), HIV-related illness episodes did not affect decisionmaking regarding family formation for 4 couples yet to complete their family size. Only 1 couple aborted a pregnancy during the husband’s TB episode for fear of infection in the new-born. However, once HIV serostatus was confirmed (T3), it made a major difference in decisions re-

garding additions to families yet to complete their formation process. For the 3 couples, (1 of whom had been recently married), HIV infection meant an end to their desire of having any or any more children.

*No more children now that we know that we have this disease. If we did not, then I would not have minded. The doctors have advised us against it and I agree with them because why to create more problems for ourselves. (Husband, 38, HIV-positive, with one child)*

Undoubtedly, all the 3 couples were disturbed at having their plans thwarted. This feeling was particularly acute in the case of the couple that had not even started the process of family formation. Moreover, this couple had earlier aborted a pregnancy and they now deeply regretted doing so, realizing that HIV/AIDS had put a stop to their dreams.

*We both feel bad about not having a child and we tell each other this. We both regret the [earlier] abortion. She still says that she wants a child, even after knowing my diagnosis ... I explain to her the risks involved for herself and for the child, and how it is wrong, sinful to go ahead knowingly. Then she keeps quiet. She does not cry or get angry about it. I feel bad about it—both about not having a child and about hurting her. I tell her that we will adopt a child ... I told her this about 1–2 months ago. She was happy about it. (Husband, 30, HIV-positive)*

Infection with the virus reportedly interfered with the couples’ decision to expand the family size, but this did not always result in regular use of contraception to avoid pregnancy. While 2 couples reported using oral contraceptives or condoms on a regular basis, 1 continued sexual activity without any precautions.

### **Family Economy**

The baseline economic condition of the family was found to significantly influence the resource drain that HIV/AIDS brings with it. The middle-class household did not report any substantial economic impact of HIV, possibly because their relatively more stable economic condition was able to absorb the costs, at least till the time of data collection. However, the 6 other families reported deterioration in their economic conditions. The impact was more pronounced in 3 households with severe illness of the husbands, and in 1 household where the husband had lost his job.

The source of treatment was the starting point of the economic effect that HIV-related illness had on the family, from the time of onset of the symptomatic stage. Most families in India prefer to seek treatment from the private health sector, as this is viewed as more efficient and effective than the public sector. People therefore do not mind incurring expenditures for this purpose. Most couples (6) in this study reported seeking treatment for initial HIV-related health problems in the private health sector, when their seropositive status was not known. Multiple and recurrent episodes of sickness resulted in mounting medical expenditures in terms of consultation fees, treatment fees (for injections, medicines, etc.), and cost of medicines. This constituted a significant drain on family resources. However, the indirect costs (e.g., travel costs, traveling time, and waiting time) incurred were minimal when seeking treatment from the private sector. For the 7th family, which was accessing health care from a public sector hospital, direct costs were incurred only on a few occasions when medicines were unavailable in the hospital dispensary and had to be purchased privately. In this case, since the husband was employed in the hospital, indirect costs were absent.

All of the families experienced considerable reductions in the direct costs of treatment (i.e., consultation fees, treatment fees, and medicines) in the post-diagnosis phase, when they shifted treatment to the public sector. But indirect costs skyrocketed. It is pertinent to note that for most families, the transfer of treatment to the public health sector was because of the private sector's refusal to treat HIV-infected individuals, rather than because of family financial considerations. Only 1 household shifted treatment voluntarily for economic considerations, and 1 was recommended to the public sector by a private sector doctor on economic grounds. Because there are very few organizations/hospitals providing HIV/AIDS-related services in Mumbai, many patients and their caregivers had to travel considerable distance, incurring heavy expenditures, indirect costs and undergoing physical exertion. These expenses worked out to be very steep for families given their baseline economic condition and deteriorating financial status because of HIV/AIDS.

Absence from work was not uncommon during episodes of illness, especially severe illness. During the initial phase of HIV-related illness, such occurrences were fewer for the husbands in the sample, but with the growing severity of the infection, not only did the frequency and length of absence increase, but 3 husbands were physically incapacitated and hence could not continue in their jobs. Two of them were completely unable to work,

whereas the 3rd husband could manage work only during the spells when he felt better and stronger, since the job requirements and environment were both conducive to such a development. The effects of missing work and inability to earn were largely contingent on the nature of employment. Husbands who were self-employed (2) or who worked as temporary daily wage earners (3) were the most affected, as they suffered loss of income. Interruptions in earning implied reduced pay packets for the family, and the inability to work resulted in a drastic fall in family resources. The husband in permanent employment (1) was in a better position, because of the fringe benefits the job entailed. Medical and personal leave benefits allowed him to miss work without facing cuts in income, at least up to a given length of time.

The loss of a job because of the husband's HIV status, despite the absence of any major health problem, was a significant cause of 1 family's economic setbacks. In order to subsist, the husband, previously a temporary daily wage earner, began to sell liquor. In comparison to the earlier employment, the present means of livelihood brought in lower returns and did not assure a fixed and regular income. Thus, discrimination faced by the husband at his work setting was instrumental in plunging the household into economic despair.

Inability of the husband to work made the wives in single-earner households (3) consider entering the workforce. The wife working on a part-time basis (1) considered full-time employment, while in another household, the eldest child, a 14-year old girl, entered the workforce in order to ease the burden on the mother.

Disturbances in the work life of the wives (2) were also reported, particularly as the severity of HIV-linked infections increased and with it, the need to provide care. When the household was female-headed, wives gave their earner role top priority as family survival depended on it. Other wives had to take leave from their jobs till the illness abated, and this sometimes led to reduced income, depending on the nature of employment.

With expenditures outweighing income, families coped through their savings, if they had any (4); through loans, if they had no savings, or once their savings were depleted (6); and/or through the support of their informal support networks (4).

Most families, being from the lower or lower-middle classes, had limited savings (if any), which saw the family through the initial illness phase only. Households without any savings and those whose savings were depleted, relied on loans from the informal support system and in some cases, from more formal sources, to whom repayment had

to be made with interest. In some families, these loans added on to earlier loans.

Given the economic condition of the family and the likelihood of it deteriorating with the progress of the infection, couples, especially the wives, reported great anxiety about the repayment of loans. One wife, who had the largest amount to repay, and a major part of whose marital life had been spent repaying loans, said,

*I am very tense—sometimes I can't sleep and my head aches. This happens when I actually start thinking about the situation—What will happen? How will we manage? How will we repay the loans? How can we go on coping with this illness? (Wife, 33, HIV-positive)*

Another wife whose family was undergoing severe economic impact, said, "I am extremely anxious because of money problems—I have to return so many debts to people, to the company [where she works]. I don't know how to do this—I keep thinking about this." (Wife, 31, HIV-negative).

A drastic change in the quality of life was reported by 3 households, and a worsening of the existing quality of life in another 3 households was observed. A husband from a household in the first set said,

*There is nothing in the house. The children are totally deprived. We get very little money from her family and have to manage with that. We have not been able to pay for [the elder child's] education expenses this academic year [his fees, dress, books], so he has not resumed school yet. Food is scarce for us. The children seem to be weaker physically. Everything is scarce at home. We have to be very frugal and sparing. The kids do not really know what is happening but they do feel the pinch. They were used to getting a lot and so now they keep asking for things that we can't give. So we tell them that they will get it when I am better. I used to take them out once a week. That has stopped completely. Due to lack of money, there is a great change in our lifestyle. There is a lot of deprivation. Both of us feel very bad about it. (Husband, 36, HIV-positive)*

Changes in quality of life were observable in relation to clothing, education of children, leisure, recreation, and social activities. In 1 household, the nutritional levels of the family were also affected, whereas in other households, wives ensured that the nutritional level did not suffer because they were aware of the significance of good nutrition in stalling the progress of the infection. Yet food

and snacks brought from outside, which were once frequent pleasures, were totally stopped. Social activities were stopped in all the households. In one household, the children's outings comprised visits to the hospital where the father was admitted, but these too were infrequent because of the expense involved. Children's education was affected. One household reported that while the eldest child had voluntarily terminated her education in order to assist the family monetarily, for the other three children, payment of fees, provision of extra tuitions and purchasing of uniforms and books were serious problems. Another household reported that while they could presently manage money only for the eldest child's private school and tuitions (though it was difficult at 500 Rupees [Indian currency] per month), sending the two younger children to the same school was out of the question—they would have to go to a government-run school. All couples feared that the children would not complete their education in this changed economic condition. Spouses were very tense about the situation, especially about the education of the children. The future plans of the family were thus destroyed.

Couples, especially the wives, put their best foot forward to make ends meet and shield the children from deprivation. Intra-household allocation of resources favored children and the husband over the wife. However, despite all such efforts, children were unable to escape the effects of economic deprivation.

The provision of material and financial support from both informal and formal sources cushioned the intensity of the economic impact to some extent. Four families got some support from relatives, while 4 families were in receipt of formal support through a nongovernmental organization providing services to seropositive people and their families, specifically to children of HIV-infected parent(s). Though it did not take care of all problems and needs, this support was of great benefit to the families. Formal support, in particular, provided some stability to the family's quality of life, putting an end to their need to borrow. Some nutritional requirements, children's education and medical expenses were taken care of. Yet, in spite of support, families were unable to save and loans were still to be repaid.

Economic deterioration due to HIV/AIDS brought about psychoemotional distress in all the couples. This became acute once the diagnosis of HIV seropositivity was known, because couples anticipated further downsliding. Wives in families experiencing greater degrees of economic distress (4) evinced intense anger toward their husbands for bringing such economic hardship to the family.

*All this [the problems the family is facing] is of this husband—if he had some sense, this would not have happened. Things would have been fine. He never listened to me about squandering money drinking, going to women ... that is why things are so bad today. I do not know why he did not listen to me. I cannot understand his mind. He should have some sense in his head, is it not? I used to always tell him to save—that we needed money for the children, for their education and for their marriage. But he would not listen. He would say, "We will save. Now they are young, so there is no need." And he used to spend away. (Wife, 31, HIV-negative)*

### **Aspirations and Future Plans**

Diagnosis of HIV positivity spelled the end of whatever aspirations and plans couples had for themselves and their children. When the exact nature of the illness was not known (T2), couples continued to dream of a better future, despite strained spousal relations and poor economic conditions in some families, which were seen as part and parcel of family life. But knowledge of the husband's HIV diagnosis (T3) marked the beginning of despair and uncertainty for all the spouses, as expressed in these words, "Every thing has been destroyed" (Husband, 36, HIV-positive).

Even though some spouses (2) at times denied the loss of their aspirations and their feelings about the same, depression over shattered dreams was common in all the affected families. Some husbands expressed guilt over their responsibility in creating such a disastrous situation for the family.

*I wanted my family to come up, to do well, to become "big," to be rich, but that will not happen. How will it happen? When I could have done it, I did not do it. When I had money, I squandered it—drinking, having a good time. I never listened to anyone, not even my parents. They used to warn me, correct me, but I did not listen and now this is the result. (Husband, 38, HIV-positive)*

Couples now had to look at the future in a different light and consider alternatives for the survival of the family. Anxiety, uncertainty, and insecurity about the future of the family, in particular the children, were palpable in all the couples. Women were worried about how they would manage after the deaths of their husbands. Additionally, shelter for those with no home of their own, widowhood, and in the case of seropositive women, their future health status were pressing concerns.

Three couples made some plans for the future whereas the other 4 could only explore their options. A man from the first group said,

*I have the land in the village. We want to go and put it in the children's names. Then if I am well, we will return to Bombay where I will work. If not, we will settle in the village and do farming. Once I die, [my wife] will settle in the village and work on the farm. That way, she will have something of her own, no rent, no obligations. (Husband, 36, HIV-positive)*

In contrast, a woman from the second group said,

*We have not made any arrangements. We have no money for anything. I am afraid about it. What will happen to us? So far, my brother has helped me a lot and what brother will desert his sister? I can stay with him if I want, if I don't get this place. I know my in-laws will do nothing. Up to now, they have never bothered about [our child], so why will they do so later. I feel that only my brother will see to her, but so far I have not told them anything or asked them. I have only that hope. (Wife, 33, HIV-positive)*

Comparing couples that planned versus those who only explored their options, the deciding factor was the material and financial resources available to the families. Families with such resources were in a position to make plans, whereas those who lacked these resources only examined alternatives available to them. "No preparations for the future after my death—we do not have enough money for the present, how can we think about the future?" (Husband, 38, HIV-positive).

From the data, it appeared that concordant couples with children worried about the future of their children after their deaths, and for them, regardless of the availability of material/financial resources, social resources, like support from relatives, were of utmost importance. Some dependence on others was unavoidable for the future of the children in these households. Those with good support systems had no reason to doubt that they would provide such help, but for others with a reluctant support system or none, and/or who had not thought beyond the husband's death, spouses worried about the future.

Discordant couples did not appear to consider social resources to be of such critical significance, since the surviving spouse would be present to manage the family either through available resources and/or earning capacity. Yet there were differences in spousal percep-

tion. For the husbands in discordant households, the knowledge that the wife would be around after their deaths to see to the family relieved some of the tension. "I have no thoughts for the family's future. [my wife] is there and she will see to the children" (Husband, 36, HIV-positive).

For the wives, however, there was a great deal of anxiety and to some extent, diffidence, as to how they would manage single-handedly, even though these families also happened to be female-headed and had been so for some time in the past. "I don't know how I will manage alone. Where will I get money from? How will I bring up the children? How will I meet expenses and satisfy needs?" (Wife, 31, HIV-negative).

There were also periods of hope. During these times, the spouses felt that the husbands would improve or a cure would come, allowing them to do something for their families.

### Limitations of the Study

The study generated considerable data on a private and sensitive topic, giving insights into various dimensions of the family experience of a stigmatizing, debilitating, and terminal health condition. The adoption of qualitative research methodology allowed for an in-depth, contextualized understanding of people's experiences of HIV/AIDS, from their own point of view. At the same time, the inclusion of a clinical sample brought in biases in representativeness and sample features.

The use of a retrospective design can be faulted for poor recall due to memory loss. Moreover, time constraints precluded follow-up with families after data collection and so this was undertaken only with the professional caregivers, covered only 3 households, and included only major events in their lives.

Reliance primarily on in-depth interviews as the method of data collection could be criticized in terms of employing highly subjective data. At the same time, given the intimate nature of family life, the sensitivity of the topic, ethical guidelines, and time and resource constraints, interviewing was judged to be more feasible than observation.

The attempt to incorporate an outsider perspective was hindered by the limited data that professional caregivers could provide, and by the secondary position accorded to observation as a means of data collection in the study. Thus, largely, it is the insider viewpoint that the study is able to represent.

### Implications for Practice

The findings of the study have direct implications for program planning, policy formulation, and service delivery.

The intense stress that seropositive individuals and their families undergo in coping with the virus, its impact and implications, underscores their need for emotional support to help them adjust to the situation. Counseling facilities and emotional support services that go beyond mere pre-test and post-test counseling need to be incorporated into the repertoire of services provided by HIV-testing and HIV/AIDS-treatment centers. These should include both individual and group-level interventions.

The paucity of secondary and tertiary HIV/AIDS-related services in the city of Mumbai has come out clearly in the study. Most interventions in HIV/AIDS focus on primary prevention activities, namely, education and awareness programs. While the efficiency and effectiveness of these programs certainly need to be stepped up, providers of care need to widen their focus and initiate treatment centers, hospices, and other such institutions. Within these institutions, free and subsidized treatment and sliding scales should be formulated in order to reduce the costs of care for the lower socioeconomic groups.

The findings of this research has documented the devastating economic impact of HIV/AIDS on the family that creates needs for material and financial support, especially for poor families. The data go on to show that the response to these needs has largely been by the voluntary sector. However, since such organizations cater to specific needs and specific types of families, as the data have shown, a greater number of organizations, catering to more needs and more families is called for. Other areas needing intervention are respite care for caregivers, assistance with planning for the future, and support with the direct and indirect costs of treatment. Support to maintain health of the seropositive person and the caregiver is also very important. Institutional care for seropositive people and/or for the children in affected households is required if wives are unable to provide care because of their earner roles.

The economic impact of HIV/AIDS on the family arises in part due to its affects on employment. HIV/AIDS-related discrimination at the workplace resulted in the loss of a job for 1 respondent in the present study. For others, the growing severity of the infection initially resulted in interruptions in work attendance, and later forced dropping out from the workforce. Both sets of events plunged the household into economic despair. Three sets of interventions would be instrumental

in maintaining better economic conditions. First, awareness about the epidemic throughout the workforce to dispel myths and develop sensitivity toward HIV-positive individuals. HIV-positive people would then feel less threatened about disclosing their serostatus with others, and knowledge of seropositivity would evoke sentiments of support and empathy, rather than acts of discrimination. Second, policies against dismissal from employment on the grounds of HIV/AIDS need to be formulated. Third, the possibility of providing a part of the salary and/or some benefits during periods of severe illness and/or incapacitation, particularly within the unorganized sector, needs to be explored. This would buffer against the downfall in quality of life, conserve savings to some extent, and procrastinate the taking of loans till as long as possible.

The experiences of women reported by the present study underscore the relevance of gender-sensitive intervention programs. Women are not only burdened by their caregiving and support roles, but they also experience acute distress. Moreover, seropositive women need care and support for their physical and emotional conditions. Women's needs, therefore, require immediate, adequate, and comprehensive attention. The provision of emotional support; respite care; material and financial support; support with regard to treatment and shelter and planning for the future; employment; training; assistance with caregiving, especially if earning is an unavoidable role of the wife; and attention to health needs, especially those of seropositive women, are all of utility. This should not solely be the responsibility of the voluntary sector, but of the community and of the informal support network as well.

No child in an HIV/AIDS-affected family remains untouched by the infection. Material deprivation, psychoemotional distress, disruption of the individual life cycle, and a "parentification" process are the most common outcomes. Services and programs to arrest these processes need to be developed, so that children may lead as normal a life as possible. Sometimes, children may need to be institutionalized since the family environment proves to be even more damaging, and institutionalization is a better option to ensure a more normal life for the children than the one they are being exposed to in the HIV-affected household. Institutional facilities to provide a home to orphaned children are also of importance. This is so because for children with concordant parents, the future is a pressing concern. Parents may not always have the resources to provide for the children's future and even if they do, after their deaths, children may still be in need of guardians because the extended family

may not wish to deal with the illness whether the children are HIV-infected or not, and/or because economically, they are not in a position to do so. If the children do have guardians to look after them after their parents' deaths, it is important to check that they are not being exploited or abused in any way.

One discordant couple in this research, forced to curtail family formation on account of HIV/AIDS infection, spoke of adoption as an alternative to gratifying their needs for parenthood. A review of adoption and foster care policies is therefore inevitable. Whether seropositive parents should be allowed to adopt, whether the serostatus of such parents should be disclosed prior to the adoption procedure, and so on, are issues of concern. With regard to children, whether HIV-positive children can be adopted, whether children of HIV-positive parents can be adopted, whether serostatus of the child to be given in adoption should be revealed, what procedure should be followed if the child's serostatus is discovered after adoption, are issues that call for exploration.

The study documented the cases of 2 discordant couples who continued sexual activity, though the frequency was reportedly lower than earlier times and condoms were used during intercourse. This is because post-test counseling advising the use of condoms served to reassure them of protection for wives. In reality, condoms are not 100% safe and put wives at great risk of infection. There is, therefore, a need for a critical re-examination of advice on safer sex measures for HIV-infected people.

In addition to measures specific to the problem, developmental policies, especially those pertaining to overall socioeconomic development and women's empowerment, would go a long way to create environments conducive to better coping with the experience of HIV/AIDS within families.

## References

- Asthana, S. (1996). AIDS-related policies, legislation and program implementation in India. *Health Policy and Planning, 11*, 184-197.
- Basu, A. M., Gupta, D. B., & Krishna, G. (1997). The household impact of adult morbidity and mortality: Some implications of the potential epidemic of AIDS in India. In D. Bloom & P. Godwin (Eds.), *The economics of HIV and AIDS* (pp. 102-154). New Delhi: Oxford.
- Bharat, S. (1996). *Facing the challenge: Household and community responses to HIV/AIDS in Mumbai, India*. Unpublished project report. Mumbai: Tata Institute of Social Sciences.
- Bharat, S. (1999). *HIV/AIDS related discrimination, stigmatization and denial in India* (A study in Mumbai and Bangalore). Unpublished project report. Mumbai: Tata Institute of Social Sciences.

- Bharat, S., & Aggleton, P. (1999). Facing the challenge: Household responses to HIV/AIDS in Mumbai, India. *AIDS Care, 11*, 31-44.
- Bharat, S., Singhanetra-Renard, A., & Aggleton, P. (1998). Household and community responses to HIV/AIDS in Asia: The case of Thailand and India. *AIDS, 12*(Suppl B), S117-S122.
- Bloom, D. E., & Mahal, A. S. (1997). AIDS, flu and black death: Impacts on economic growth and well being. In D. Bloom & P. Godwin (Eds.), *The economics of HIV and AIDS* (pp. 22-52). New Delhi: Oxford.
- Bor, R., Elford, J., Hart, G., & Sherr, L. (1993). The family and HIV disease. *AIDS Care, 5*, 3-4.
- Bryman, A. (1988). *Quality and quantity in social research*. London: Unwin Hyman.
- Crabtree, B. F., & Miller, W. L. (1992). *Doing qualitative research: Multiple strategies*. Thousand Oaks, CA: Sage.
- Census of India. (1991). *Series 14. Maharashtra—Provision Population Totals* (Paper 1 of 1991). New Delhi: Government of India.
- D'Cruz, P. (1998). *The family context of a terminal illness: The case of HIV/AIDS*. Unpublished dissertation. Mumbai: Tata Institute of Social Sciences.
- D'Cruz, P., & Bharat, S. (2001). Towards methodological rigor in the study of the family: Problem and prospects. *Psychology and Developing Societies, 13*, 71-91.
- Duggal, R. (1998). Health care as human right. *Radical Journal of Health, 13*, 141-142.
- Global Program on AIDS. (1995). *1992-93 Progress report: Global program on AIDS*. Geneva: World Health Organization.
- Godwin, P. (1997). *Socio-economic implications of the epidemic*. New Delhi: United Nations Development Program.
- Godwin, P. (1998). *The looming epidemic*. New Delhi: Mosaic.
- Grunseit, A., & Kippax, S. (1992). *Response to HIV/AIDS at the individual, household, community and society levels*. Australia: National Center for HIV Social Research.
- Guba, E. (1978). Toward a methodology of naturalistic inquiry in educational evaluation. Los Angeles: UCLA Center for the Study of Evaluation.
- National AIDS Control Organization. (2000). *HIV/AIDS Indian Scenario: Estimation of HIV infection among adult population*. New Delhi: Author. Retrieved September 28, 2001, from <http://naco.nic.in/vsnaco/indianscene/update.htm>
- Hudelson, P. M. (1994). *Qualitative research for health programs*. Geneva: World Health Organization.
- Joshi, P. L., & Rao, J. V. R. P. (1999). Changing epidemiology of HIV/AIDS in India. *AIDS Research and Review, 2*, 7-9.
- King, M. B. (1993). *AIDS, HIV and mental health*. Cambridge: Cambridge University Press.
- Mane, P., & Maitra, S. A. (1992). *AIDS prevention: The sociocultural context in India*. Mumbai: Tata Institute of Social Sciences.
- Marshall, C., & Rossman, G. B. (1999). *Designing qualitative research*. Thousand Oaks, CA: Sage.
- McCann, K., & Wadsworth, E. (1992). The role of informal carers in supporting gay men who have HIV-related illness: What do they do and what are their needs? *AIDS Care, 4*, 25-34.
- Miles, M. S., & Huberman, A. M. (1994). *Qualitative data analysis: A sourcebook of new methods*. Thousand Oaks, CA: Sage.
- Morse, J. M. (1991). Strategies for sampling. In J. M. Morse (Ed.), *Qualitative nursing research* (pp. 127-145). Thousand Oaks, CA: Sage.
- National AIDS Control Organization. (1998). *Country scenario 1997-98*. New Delhi: Author.
- Nag, M. (1996). *Sexual behavior and AIDS in India*. New Delhi: Vikas.
- Narain, J. P., Jha, A., Lal, S., & Salunke, S. (1994). Risk factors for HIV transmission in India. *AIDS, 8*(Suppl 2), S77-S82.
- Padgett, D. K. (1998). *Qualitative methods in social work research*. Newbury Park, CA: Sage.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Thousand Oaks, CA: Sage.
- Poindexter, C. C., & Linsk, N. L. (1998). Sources of support in a sample of HIV-affected older minority caregivers. *Families in Society, 79*, 491-503.
- Poindexter, C. C., & Linsk, N. L. (1999). HIV-related stigma in a sample of HIV-affected older female African-American caregivers. *Social Work, 44*, 46-61.
- Ramasubban, R. (1998). HIV/AIDS in India: Gulf between rhetoric and reality. *Economic and Political Weekly, 33*, 2865-2872.
- Structural adjustment: A major cause of poverty*. (1998-2001). Created July 20, 1998 and periodically updated. Retrieved September 28, 2001, from <http://www.globalissues.com/TradeRelated/SAP.asp>
- Taylor, S. J., & Bogdan, R. (1984). *Introduction to qualitative research methods*. New York: John Wiley.
- Joint United Nations Programme on HIV/AIDS. (1999). A review of household and community responses to the HIV/AIDS epidemic in rural areas of sub-Saharan Africa. Geneva: Author.
- Joint United Nations Programme on HIV/AIDS. (2000, June). *Report on the global HIV/AIDS epidemic*. Geneva: Author. Retrieved September 28, 2001, from [http://www.unaids.org/epidemic\\_update/report/Epi\\_report.htm](http://www.unaids.org/epidemic_update/report/Epi_report.htm)
- Warwick, I., Bharat, S., Castro, R., Garcia, R., Leshabari, M. T., Singhanetra-Renard, A., & Aggleton, P. (1998). Household and community responses to HIV and AIDS in developing countries. *Critical Public Health, 8*, 311-328.

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